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COMMENTARIES

The Necessity of Cultural Awareness in Healthcare Providers to Reduce Diagnostic Delays in Reproductive Health for West Asian Immigrant Women

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Women’s health is one of the most underfunded and under-researched areas of medicine, with minority health being an even smaller subsection receiving little funding and research. Polycystic ovarian syndrome (PCOS) affects more than 10% of women globally; however, 70% of women with PCOS remain undiagnosed. Even more concerning is that for many girls and women across the globe, access to women’s healthcare remains a privilege and is inaccessible to many. This article explores how diagnostic delays occur for West Asian immigrant women in the United States who have endometriosis and/or PCOS. In studies about women’s health experiences across Western Asia, the reality is even worse for women living there. We discuss how fear of stigma often impacts women’s ability to seek healthcare in the United States. However, healthcare providers can adopt a more empathetic lens to acknowledge patients’ fear of stigma and provide reassurance and support (instead of bias and projections of their own beliefs) by adopting a shift in mindset to include cultural awareness to address a wider and diverse patient population. By prioritizing cultural awareness, healthcare providers must acknowledge the societal reasons for diagnostic delays for this patient population and work toward reducing that risk. This ensures not only that immigrant health is taken seriously and adequately addressed but also that patients with reproductive conditions like PCOS and endometriosis feel safe enough to seek a diagnosis for conditions that worsen when diagnosis is delayed.

Introduction

Cultural awareness enhances healthcare outcomes and also promotes inclusive healthcare for West Asian women living in the United States. For this commentary, we defined West Asian immigrants as women from Iraq, Turkey, Syria, Lebanon, Iran, Egypt, Yemen, and Pakistan. Also, the term *healthcare provider* refers solely to physicians when referring to healthcare providers outside of the United States; when referring to healthcare providers within the United States, the term can be used to refer to physicians, physician’s assistants, or nurse practitioners.

Polycystic Ovarian Syndrome and Endometriosis

Women's health is one of the most under-researched fields of medicine.[1] Two common reproductive conditions continue to impact and destroy the lives of women and girls globally: polycystic ovarian syndrome (PCOS) and endometriosis. PCOS is a condition that causes abnormal and painful periods, elevated testosterone, accumulations of follicles on the ovaries, acne, excess hair growth, and weight gain.[2] Endometriosis is the invasion of the endometrial tissue, which typically only lines the inside of the uterus, into the exterior of the endometrium.[3] It is a painful condition that can cause abnormal pain, heavy menstruation, inflammation, and scarring of tissue.[3] According to the World Health Organization (WHO), approximately 6% to 13% of women of reproductive age are affected by PCOS around the world, yet up to 70% of them will go undiagnosed.[2] Endometriosis is another commonly undiagnosed reproductive condition, and it is estimated to impact over 190 million women and girls around the world according to the WHO.[3] While we know there is no cure to eliminate either condition, the role of early diagnosis and symptomatic relief for both PCOS[2] and endometriosis[3] are life-changing for patients who have these conditions. Of the $47.7-billion-dollar research budget the National Institutes of Health (NIH) received in 2023,[4] across the entirety of research conducted at different NIH research institutes, only $3.7 billion (8%) went to women's health.[5] Of the $3.7 billion, approximately $700 million (19%) went to breast cancer research[6]; meanwhile, $30 million or less (0.8%) went to PCOS and endometriosis research, each.[6] This reveals a major gap in funding and lack of awareness of the need for increased prioritization of women's reproductive conditions, especially when both PCOS[2] and endometriosis[3] have no cure.[6] Just because the NIH received funding for women's health does not mean it is shared equally: endometriosis is not at the top of the list, especially when compared with the amount of funding breast cancer receives.[5]

Oral birth control is used as way of symptom relief for many women diagnosed with PCOS[2] and/or endometriosis.[3] However, limitations in access to birth control options for West Asian women and girls is still an obstacle,[7] especially owing to cultural and social stigmas[8] that restrict or scare away unmarried patients from using birth control in Western Asia. Between reproductive conditions that are underfunded and a minority population that is underserved, the opportunity for delays in care for endometriosis and PCOS is evident. This commentary aims to shed light on the reasons behind these diagnostic delays and the impact cultural awareness can have on reducing the risk for delays in diagnosis and treatment, especially once West Asian women immigrate and seek care in the United States.

The Consequences of Diagnostic Delays in PCOS and Endometriosis

According to the WHO, approximately 6% to 13% of women of reproductive age are affected by PCOS around the world, yet up to 70% of cases go undiagnosed.[2] Endometriosis, another commonly undiagnosed reproductive condition, is estimated to affect over 190 million women and girls around the world, according to the WHO.[3] Most importantly, the underlying threat these two conditions share is that they are both the leading causes of infertility in undiagnosed women. One study looked at how intervention with glucagon-like peptide-1 receptor agonists (GLP-1RAs) in women with PCOS reduced inflammation, reduced insulin resistance, helped lower weight, brought about more regular menstrual cycles, produced cardiovascular benefits, relieved some symptoms of PCOS, and helped with ovulation, as obesity and insulin resistance were often two barriers affecting fertility.[9] This is significant because, as reported in one study,[10] PCOS has been found to have variations in how it presents physiologically depending on race/ethnicity. The study looked at patients of different disparities and ethnicities in the United States and cited global studies that found different phenotypic expression of classic PCOS symptoms in different ethnic and racial groups.[10] The difference was noted to be based on the expression level of the 5-alpha reductase enzyme, which is responsible for turning testosterone into dihydrotestosterone (DHT).[10] Specifically, higher levels of 5-alpha reductase enzyme were associated with more DHT and, therefore, worse severity of hirsutism.[11] This means that PCOS symptoms can look different for two patients with the same condition. For example, the study reported that hirsutism was more apparent in West Asian and Indian patients than in Norwegian and Finnish patients.[10] The takeaway is that PCOS diagnosis and treatment is not a one-size-fits-all approach; any physician suspecting PCOS should not rule it out solely based on clinical comparison to another patient who has PCOS.

One case report[12] documented a patient's 10-year journey to an endometriosis diagnosis, detailing the physical and psychological distress experienced by the patient, who navigated everything from medical gaslighting to frustrating symptoms with no explanation. Currently, in the United States and within the general US population, it is reported to take 7 to 10 years to get a diagnosis of endometriosis, after consulting with multiple healthcare providers.[13] We sought to address how much longer the delay is for West Asian women in the diagnosis and treatment of symptoms, especially immigrant women in the United States. Clinical consensus suggests that timely diagnosis of PCOS and endometriosis is a critical factor in lowering the long-term risks[2] of infertility.[3] Therefore, any obstacles or health disparities that result in diagnostic delays have the risk of impacting fertility and are worth being mitigated. Additionally, delays in diagnosis also mean delays in medical intervention to address PCOS and endometriosis symptoms.

PCOS causes abnormal and painful periods, elevated testosterone, accumulations of follicles on ovaries, acne, excess hair growth, and weight gain.[2] Endometriosis is a painful condition that causes heavy menstruation and abnormal pelvic pain (often meaning pain that disrupts daily life, which can occur before, during, and/or after menstruation).[3] Both conditions have symptoms that can be alleviated by the use of birth control. In addition, leaving these conditions untreated has been correlated[2] with a considerable mental burden from the difficulty of the symptoms, including excess weight gain, facial hair (hirsutism), and acne.[3] The consequences of diagnostic delays are devastating, but this is an area in medicine that has drastic potential for improvement.

Understanding the Societal and Cultural History Behind Diagnostic Delays

West Asian women have historically needed to have resilience against gender-based violence, gender disparities, the stigmas associated with mental healthcare, and having a lack of autonomy, which affects whether a young woman would be able to seek healthcare for their specific healthcare needs. For example, one study[14] looked at Syrian women and the consequences endured over the course of conflicts and long-term forced displacement, often into Lebanon, opening up a world view to the mental health and sexual health conditions post-conflict that Syrian women may suffer from silently. The outcomes of the study emphasized that these women endured violence, trauma, posttraumatic stress disorder, and food insecurity.[14] Conflict and displacement often goes hand-in-hand with extreme poverty and low access to healthcare, leaving these women highly vulnerable to poor sexual health outcomes, especially when seeking treatment for sexually transmitted infections.[14] One of the most important points from this study, which aimed to evaluate the sexual health of 350 female patients, is that only 250 women actually participated, while the rest were either too busy with other responsibilities or restricted by their husbands from being allowed into a study that would examine their sexual health, giving a glimpse into the lack of autonomy some of these women have.[14] When women and girls are affected in conflict, their worries often shift and magnify into concerns over shelter, safety, whether they have to leave their homes, and making sure they have enough food to eat, while actively avoiding violence and risk of death from war. Hence, from the active threat against their lives and from fear of violence (via death or rape), these women and girls are forced to prioritize things like physical safety and refuge over things like painful periods and hormonal acne, therefore deferring medical care. The current reality is that these women and girls are impacted by gender-based violence, sexual exploitation, abuse, and worse when war and displacement is destroying their lives and actively disrupting them from seeking healthcare.[15]

Every woman deserves access to healthcare, and that includes nondiscriminatory reproductive care, but according to the WHO, this fundamental human right is imperiled for West Asian women.[16] Throughout Western Asia, women's bodily autonomy, especially unmarried women, is often threatened through restrictive families, societal thinking, discrimination, judgement, and shame regarding seeking reproductive healthcare unless they are married.[17] One report[17] shared a midwife's thoughts about working in Iran, stating, "It has been established in our country that infections and gynecological problems occur after marriage. That is, unmarried women cannot have such issues." The unfortunate reality is that the use of birth control in Western Asia is often correlated with the sole thought that the woman is engaging in sexual activity, ignoring the reality that birth control can also be used to alleviate painful symptoms of PCOS and endometriosis.[7] One study found that the attitudes and beliefs of physicians in Western Asia against unmarried women seeking access to sexual reproductive healthcare created barriers to quality of care because of physicians' resistance to inform patients about birth control and, as a result, they acted on their beliefs instead of following the science and their medical training to treat patients ethically.[7] These physicians had been found to ridicule and judge both married and unmarried women for seeking sexual reproductive health counseling, especially when patients asked them questions.[7] They also gave poor counseling on contraception options, often misinforming patients and aiming to avoid offering conversations on family counseling.[7] These physicians as well as other staff were especially rude and judgmental toward unmarried women who were seeking sexual reproductive healthcare, as it was seen as opposing their beliefs for an unmarried woman to seek contraception and counseling from them.[7]

Another study looked at Turkish college students and the social stigmas and shame surrounding birth control that are felt so strongly[8] that to even suggest birth control use for medical conditions seems impossible. The study results focused on four main themes that display the perspectives surrounding contraceptive use in that setting: individual views, sociocultural pressures, knowledge and awareness levels, and education and information needs.[8] The outcomes highlighted how in the university setting, internal views and beliefs about contraception being a "personal and practical" option contradict or collide with societal, cultural, and/or familial pressures to hide or avoid contraceptive use.[8] The overarching opinion of the students was that they had outgrown the sociocultural norms, attitudes, judgments, and stigma that serve as barriers to accessing contraception, especially for unmarried participants.[8] Nothing about this situation would make a woman feel safe in seeking reproductive healthcare and would more likely lead her to feel that her concerns are not worthy of seeking healthcare.

The social constructs and stigmas connected with the use of birth control in unmarried women in the Western Asia region is just one example leading to diagnostic delays, and this creates another barrier to medical intervention for PCOS and endometriosis symptoms.

The Necessity of Cultural Awareness in Combatting Healthcare Provider Bias

With so much historical context, it is prudent to examine the healthcare setting for immigrants in the United States and the healthcare provider's role in immigrant healthcare outcomes. Healthcare provider bias, stemming from age, religion, race, marital status, and other factors, is heavily intertwined in this issue.[18] The results from one research study[19] found that when West Asian women, especially Muslim West Asian women, were seeking healthcare in the United States, they specifically avoided healthcare providers of their same religion or cultural background because they wanted to avoid negative judgements, dismissiveness, neglect, and mistreatment. The study also found that physicians who shared the same religion as West Asian women were withholding information, ignoring reproductive and sexual health conversations, and not providing contraception options, displaying a clear threat to the ethical basis of informed consent and autonomy.[20] This showed an obvious example of physicians' prioritization of their own religious beliefs and a protective cultural paternalism taking the lead over the health of the patient, combined with the physician's fear of judgement, as well as the patient's fear of judgement.

Additionally, beneficence, which refers to protecting the best interest of the patient, was threatened during women's healthcare visits when these patients were not offered cancer screenings by their primary care providers, despite being of the same faith background.[21] It is alarming that healthcare provider bias can carry such weight in the delivery of healthcare to women, yet this bias is not always acknowledged. Many of these women were treated unfairly by a healthcare provider prior to immigrating to the United States, so they already had mistrust,[19] but how a healthcare provider handles and acknowledges awareness of those struggles is where a difference can be made in the quality of care she receives.

Cultural awareness is critical for healthcare providers in order to provide healthcare that is inclusive of the patient and their background and to work together with the patient to choose their route of care. Cultural competency training for healthcare providers and their staff is a great way to introduce this in clinics, especially in locations that see higher rates of immigrant patients. Healthcare providers can also consult with social workers on how to navigate culturally sensitive healthcare and provide trauma-informed care. This effort hopefully enables a safe environment for patients to trust their healthcare provider and receive the care they need, especially reproductive care for endometriosis and/or PCOS. A patient's social determinants of health should not cause healthcare providers to form a bias against them, so it remains essential for physicians to know how to provide equitable and inclusive care, free from biases.

Conclusion

Future suggestions for healthcare providers caring for immigrant West Asian women in the United States include expanding both the cultural perspective and their lens of empathy for these patients, in hopes of reducing diagnostic delays. Endometriosis and PCOS are conditions that often disrupt a woman's life for 7 to 10 years before a diagnosis is properly made. For immigrant women this delay may be even longer, yet it does not have to be this way. When healthcare providers have cultural awareness, diagnostic and treatment delays can be drastically shortened. To achieve this, cultural competency training can be implemented for healthcare providers and staff, especially in locations that have higher rates of immigrant patients. In addition, healthcare providers can consult with social workers on how to navigate culturally sensitive healthcare issues, such as contraception for West Asian women. Physicians are some of the most trusted individuals with direct access to these patients, often some of the most marginalized patient populations in the United States. Hence, it matters that healthcare providers are fully trained to provide care that encompasses cultural awareness, empathy, and understanding.

There is great opportunity for improved healthcare outcomes when healthcare providers are fully informed and aware of the hidden fears and concerns that immigrant West Asian women in the United States may face. When a healthcare provider is culturally informed and aware of the social determinants of health and the numerous obstacles that these patients face, then that is one step toward enhancing the quality and inclusivity of healthcare that these marginalized patients receive in the United States.

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