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Policy Commentary

Addressing Cultural Stigma: Endometriosis Diagnosis in the Arab World

معالجة الوصمة الثقافية: تشخيص التهاب بطانة الرحم في العالم العربي

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Abstract

Endometriosis, a challenging chronic disease, has often been shrouded in delayed diagnosis. Efforts to enhance the quality of life for affected women by facilitating earlier diagnoses is crucial. Early diagnosis in the teenage years can impact not only the individual but also her family.

In conservative cultures such as those found in the Arab world, including the Arab Peninsula, North Africa, and East Asia, reproductive capacity stands as a defining feature in a woman's life. Endometriosis, viewed as both a stigma and a threat to reproductive capabilities, can significantly influence a girl's marriage prospects, especially as within these cultural contexts, marriage is perceived as a protective shield, guarding against potential future hardships.

The stigma associated with endometriosis intensifies the anxieties of both the affected girl and her parents about the future. This policy commentary dives into the intricacies of reproductive stigma, offering thoughtful suggestions to systematically address it on both policy and societal levels. The proposed interventions involve active engagement with adolescent girls, their families, partners, schools, healthcare institutions, specialized professionals, workplaces, and the broader communities. Comprehensively addressing these aspects can foster a supportive environment that empowers individuals to navigate the challenges posed by endometriosis in conservative cultures.

الملخص

غالبًا ما يُكتشف تشخيص التهاب بطانة الرحم، وهو مرض مزمن صعب، متأخرا . إن الجهود المبذولة لتحسين نوعية حياة النساء المصابات من خلال تسهيل التشخيص المبكر أمر بالغ الأهمية. التشخيص المبكر في سنوات المراهقة يمكن أن يؤثر ليس فقط على المرأة ولكن على عائلتها ايضا. في الثقافات المحافظة مثل تلك الموجودة في العالم العربي، بما في ذلك شبه الجزيرة العربية وشمال أفريقيا وشرق آسيا، تقف القدرة الإنجابية كسمة محددة في حياة المرأة. يمكن أن يؤثر التهاب بطانة الرحم، الذي يُنظر إليه على أنه وصمة عار وتهديد للقدرات الإنجابية، بشكل كبير على فرص زواج الفتاة، خاصة أنه في هذه السياقات الثقافية، يُنظر إلى الزواج على أنه درع وقائي يحمي من الصعوبات المستقبلية المحتملة.

إن وصمة العار المرتبطة بانتباذ بطانة الرحم تزيد من مخاوف الفتاة المصابة ووالديها بشأن المستقبل. يتعمق تقييم السياسات هذا في تعقيدات الوصمة الإنجابية، ويقدم اقتراحات مدروسة لمعالجتها بشكل منهجي على المستويين السياسي والمجتمعي. تتضمن التدخلات المقترحة المشاركة النشطة مع الفتيات المراهقات وأسرهن وشركائهن والمدارس ومؤسسات الرعاية الصحية والمهنيين المتخصصين وأماكن العمل والمجتمعات الأوسع. إن معالجة هذه الجوانب بشكل شامل يمكن أن تعزز بيئة داعمة تُمكن الأفراد من التغلب على التحديات التي يفرضها التهاب بطانة الرحم في الثقافات المحافظة.

Keywords: *Endometriosis, Quality of life, Adolescence, Social Stigma, Policy*

الكلمات المفتاحية: بطانة الرحم، نوعية الحياة، المراهقة، الوصمة الاجتماعية، السياسة

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1. Introduction

Endometriosis is a complex and often debilitating medical condition characterized by the abnormal growth of endometrial-like tissue outside the uterus. This condition primarily affects women of reproductive age, with estimates suggesting that it afflicts approximately 10% of women worldwide. A discernible trend in current practice involves the increasing levels of stress and anxiety that teenagers and their families undergo when confronted with a diagnosis of endometriosis. Their concerns revolve around the condition's impact on health, the necessity for long-term care, and potential repercussions on future reproductive capabilities. The imposition of such a diagnosis at a tender age places a substantial psychological burden on both the girl and her family, particularly within the conservative landscapes of the Arab peninsula and North Africa. In these societies, where teenage girls have limited agency in decision-making and where reproductive capacity is regarded as a crucial aspect of the female identity, the weight of this diagnosis can be difficult for patients to handle (Hatzenbuehler et al., 2013). As the scientific community and experts strive toward early diagnosis and the development of suitable, effective, acceptable, and cost-effective long-term treatments for endometriosis, there is a growing awareness of the social and psychological implications that accompany this progress. One significant aspect is the reproductive and social stigma associated with the condition (Sims et al., 2021). Notably, teenagers make up approximately 9% of women diagnosed with endometriosis (Shukri et al., 2022). This demographic underscores the importance of addressing this issue comprehensively.

1.1. Endometriosis and stigma

Stigma, as defined by the *Cambridge Dictionary*, is the prevailing disapproval felt by a society toward something, especially when this judgment is unjust (Cambridge Dictionary, 2023). Hatzenbuehler et al. characterize it as a complex, context-dependent social process that assigns a label to an individual based on a trait that deviates from societal norms. They underscore its importance in determining health outcomes, exerting significant influence on both the individual and the broader social structure, thus playing a central role in population health (Hatzenbuehler et al., 2013). Stigma has a profound impact on access to vital resources like knowledge, financial means, health services, and societal power dynamics. Furthermore, it directly affects individuals by causing stress, influencing psychosocial and behavioral responses, and shaping interpersonal relationships. Stigma not only hampers access to crucial resources such as education, finances, healthcare, and influence, but also exerts a profound influence on the individual, manifesting in heightened stress levels, alterations in psychosocial and behavioral responses, and shifts in interpersonal relationships (Hatzenbuehler et al., 2013).

The precise etiology of endometriosis remains a subject of ongoing research, with several theories posited. One prevailing hypothesis suggests retrograde menstruation, wherein menstrual blood containing endometrial cells flows backward through the fallopian tubes into the pelvic cavity. These displaced cells then adhere to various pelvic organs and surfaces, leading to the formation of endometriotic lesions.

However, retrograde menstruation alone does not account for all instances of endometriosis. Genetic predispositions, hormonal imbalances, immune system dysregulation, and environmental factors are all believed to contribute to its development. Recent studies have also highlighted the potential role of epigenetic modifications in influencing susceptibility to endometriosis. The clinical presentation of endometriosis is highly variable, ranging from asymptomatic cases to severe, chronic pelvic pain, dysmenorrhea, and fertility issues. Additionally, endometriosis can give rise to a spectrum of associated conditions, further complicating diagnosis and management.

Endometriosis significantly impacts various aspects of women's quality of life (Bourdelid et al., 2019; El-Kader et al., 2019). The diagnosis of endometriosis has posed a notable challenge, resulting in a substantial body of literature dedicated to addressing this issue and mitigating its long-term effects on women's well-being (Ballard et al., 2006; Hudelist et al., 2012; Mousa et al., 2021; Shukri et al., 2022). It is widely acknowledged that rectifying the diagnostic delay in endometriosis yields benefits not only for women but also extends to their families, communities, and the broader healthcare system. This includes a reduction in suffering and a decrease in healthcare costs (Surrey et al., 2020).

Hall et al. conducted a study investigating the factors associated with reproductive health stigma in Ghana (Hall et al., 2018). While endometriosis was not specifically addressed in their survey, we can extrapolate from the similar type of stigma examined and apply it to endometriosis (Hall et al., 2018). The Adolescent Sexual and Reproductive Health Stigma Scale, a validated instrument comprising 20 items, assesses three forms of environmental stigma. Internalized Stigma refers to society's perceptions of a teenager with endometriosis. Enacted Stigma encompasses the ways in which these perceptions manifest in actions toward the girl or her family, and Stigmatizing Attitudes pertain to the emotions and attitudes experienced by the girl and, in our context, her family in response to her diagnosis (Hall et al., 2018).

When delving deeper into the origins of these stigmas, Sophie Laws, in her book, *Issues of Blood: The Politics of Menstruation*, refers to cultural attitudes toward menstruation as the ”etiquette of menstruation” (Law, 1990). She explains that a fundamental aspect of this etiquette is concealment. While Laws' book is not specifically focused on Arabic culture, it serves to illustrate what could be considered a universal attitude toward menstruation. Many women are taught to discreetly purchase sanitary products. In stores, they are often placed in the farthest corner, usually the only area where you can readily find a black plastic bag to discreetly carry your purchases. Once home, they are stored away from the sight of male members of the family. The use of sanitary products is handled with utmost secrecy, and disposal is done without detection. When a girl faces challenges related to her period, euphemisms like “women's issues” are employed. As a result of this menstrual etiquette, girls endure their struggles in silence. Mothers and other women in the social circle encourage younger women to adopt this practice of concealment.

1.2. Endometriosis and its multifaceted impacts

Endometriosis comes with a package of exacerbating symptoms that would otherwise be manageable and concealable. Conditions like dysmenorrhea and dyspareunia can disrupt one's ability to carry out work responsibilities. They also impact intimate relationships in ways that are challenging to discuss or disclose, even to a partner. If they muster the courage to do so, they often face stigmatization, leading them to withdraw and avoid further disclosure or discussions. A study conducted in Egypt involved 654 schoolgirls, shedding light on the prevalence of endometriosis in this specific age group and detailing the array of symptoms they experience. Among the most commonly reported symptoms were painful bowel movements (48.2%), painful urination (26.8%), while nausea and vomiting affected 12.5% of the participants. Notably, an equal percentage of patients were asymptomatic [14]. These symptoms can be so debilitating that they lead to school absences and hinder the girls from engaging in certain activities. This, undoubtedly, has a profound impact on the emotional well-being of these teenagers, who simply yearn for a normal life.

Undiagnosed endometriosis can have significant, long-term ramifications for women. It is linked to the development of various associated conditions, including autoimmune diseases, cardiovascular disorders, and gynecologic cancers such as ovarian, endometrial, and cervical cancer (Ii et al., 2019). A meta-analysis underscored the elevated risk of these conditions, emphasizing the importance of regular check-ups for diagnosed endometriosis patients to mitigate potential risks of developing correlated ailments (Ii et al., 2019).

Furthermore, endometriosis can lead to alterations in key hormonal markers. Specifically, it is associated with an accelerated decline in Anti-Müllerian hormone (AMH) levels and an increase in follicle-stimulating hormone (FSH). These hormonal shifts result in prolonged reproductive timelines and heightened likelihood of encountering fertility issues (Freeman et al., 2012; Romanski et al., 2019).

Uterine fibroids are another condition that can co-occur with endometriosis. Although a patient may be diagnosed with both simultaneously, research indicates that they operate independently. Both conditions, however, contribute to a decline in the female fertility cycle (Uimari et al., 2011).

Rectovaginal endometriosis represents a deeper form of the condition, invading the vagina, rectum, and rectovaginal septum while causing damage to the pouch of Douglas (Moawad & Caplin, 2013). This variant, categorized as stage IV in Kirtner's classification, manifests as chronic pelvic pain, dysmenorrhea, deep dyspareunia, and dyschezia. Notably, infiltration of the intestinal lumen induced by rectovaginal endometriosis can lead to complications such as obstructive symptoms, rectal bleeding, hemorrhagic ascites, protein loss, intussusception, and edema (Moawad & Caplin, 2013). Although pain levels can vary among patients, this type is generally recognized as one of the most severe forms of endometriosis, often posing a challenge for accurate diagnosis (Moawad & Caplin, 2013).

Failure to diagnose endometriosis in a timely manner can result in its proliferation to different regions of the body, including the rectum. In some cases, it may even implant in the bladder, giving rise to Bladder Deep Endometriosis (Bladder DE), a rare form that induces notable discomfort and inflammation. Symptoms may encompass frequent urination, presence of blood in urine, and pelvic pain (Jenneh Rishe et al., n.d.).

The development of endometriosis in the pelvic region or other anatomical sites within the pelvis can lead to a range of distressing symptoms, including painful menstrual periods, discomfort during intercourse, irregular bleeding between periods, heavy menstrual flow, chronic fatigue, as well as episodes of nausea and diarrhea (Jenneh Rishe et al., n.d.).

The progression of this condition can culminate in anxiety and depression, which are among the most prevalent side effects. It is worth noting that endometriosis is classified as a debilitating condition, one that can substantially impact social connections, sexuality, and mental well-being (Laganà et al., 2017). Additionally, endometriosis has the potential to induce central sensitization syndrome, heightening patients' sensitivity to stimuli that typically do not elicit pain responses. The diverse manifestations and symptoms of endometriosis collectively impinge on the overall well-being of women, significantly disrupting their quality of life (Latremoliere & Woolf, 2009).

The diagnosis of endometriosis is heavily influenced by cultural stigma, particularly in the Arab world. There is a lack of knowledge and awareness among women due to cultural factors, coupled with apprehensions about seeking help and visiting a gynecologist. Anecdotal evidence suggest that when a teenage girl experiences stomach pain, often attributed to dysmenorrhea, she is typically advised by her mother to take remedies like “Panadol’ or consume “natural herbal drinks” to alleviate the discomfort. Unfortunately, mothers may not possess sufficient awareness of the underlying physiological issues. This pattern of dismissing stomachaches can eventually lead to the revelation that these were in fact symptoms of endometriosis.

It is crucial to note that women afflicted with endometriosis exhibit a range of symptoms, encompassing pelvic pain, psychological distress, and infertility (Shukri et al., 2023). These manifestations are frequently misconstrued as mere ”Period pain” or ”PMS” – the latter being defined as a compilation of symptoms that precede a woman’s menstrual cycle. These symptoms can be either primarily physical (such as bloating and fatigue) or emotional (including irritability and sadness), or a combination of both (Cleveland Clinic, n.d.). Therefore, it is imperative that teenage girls are equipped with knowledge about these diverse symptoms and possess the confidence and autonomy to discuss these matters openly and seek the information they need.

1.3. Factors contributing to stigma and challenges to diagnosis

When women and girls defy the norms surrounding menstruation and seek assistance, they step into a realm of uncertainty. Endometriosis, being a chronic condition, involves a process of trial and error in finding effective treatments. There is an unpredictable risk of recurrence, and questions linger about its impact on future fertility (Culley et al., 2013). In the Gulf and wider Arab Peninsula, particularly among Muslims, the desire to have a family with children is a significant cultural aspiration (Akouri et al., 2017). Parenthood is not just a personal choice, but it is also seen as a religious and social responsibility, providing emotional and sexual fulfillment within the frameworks of marriage. In our Arab context, parents often believe that a young woman finds safety and protection once she is married. They are less apprehensive about the uncertainties she might encounter later in life if she has a husband.

Muslims perceive marriage as a religious obligation, a moral safeguard, a societal necessity, and a means of emotional and sexual satisfaction. Therefore, when a girl receives an endometriosis diagnosis, it can jeopardize potential marriage prospects, potentially viewed as a threat to her future well-being. This engenders parental worry, manifesting in a series of anxious questions, met with responses from the medical community that do not always provide definitive reassurance. The prolonged need for medication raises concerns that she might not lead a conventional life without continual reliance on treatment. Will she be able to maintain a fulfilling intimate relationship?

Can she conceive a child? Will the condition exacerbate? What should she disclose to her future spouse? This conundrum entails navigating social, ethical, and religious considerations.

Genetics and genetic disorders play a significant role in both the development and likelihood of experiencing endometriosis. In the Arab region, consanguineous marriages, a prevalent aspect of our cultural practices, contribute to an increased risk of various diseases, including endometriosis. The presence of a positive family history in endometriosis is crucial in the diagnostic process (Nouri et al., 2010). This dynamic places considerable social pressure on the young woman. Given the commonality of marrying within one's extended family, she is more likely to enter into such a union. If there are genetic mutations related to endometriosis within the family, this increases the likelihood of her being at risk for or facing reproductive challenges. This situation creates a psychological burden, weighing on the thoughts of the teenage girl and impacting her mental and emotional well-being.

This disease not only inflicts internal damage but also exerts a significant emotional toll. Regrettably, research on endometriosis for teenagers remains limited, highlighting the urgency of early diagnosis for the benefit of these young girls. Awareness and timely diagnosis are paramount, as many girls presently grapple with symptoms and face the risk of misdiagnosis. Till recently, the gold standard for the diagnosis was laparoscopy, a procedure necessary for definitive confirmation (Ragab et al., 2015). However, cultural stigma and lack of awareness serve as formidable barriers, impeding these girls from obtaining proper diagnosis. The lack of trans-vaginal ultrasound or laparoscopy results in diagnostic delays, particularly affecting unmarried girls, intensifying their distress (Ragab et al., 2015). There is a reluctance among some girls to undergo these diagnostic procedures due to the perception and the concern that these procedures may compromise their virgin status by involving the vaginal canal. This apprehension is rooted in the fear that such actions might jeopardize their future, as they believe cultural misconceptions regarding hymen integrity may impede their chances of marriage. It is imperative to educate and dispel unfounded concerns surrounding these procedures. Normalizing laparoscopy is crucial, reframing it as a means to expedite diagnosis or treatment if required to mitigate the potential long-term consequences of endometriosis, including infertility.

2. Policy Recommendations

Overcoming Stigma: Initiatives and Awareness Programs

1. Public Awareness Campaigns for both Genders: Launching comprehensive public awareness campaigns within schools is pivotal. These campaigns should not only educate teenagers but also involve school staff to create a supportive environment. Workshops, seminars, and informative materials can be utilized to explain endometriosis, its symptoms, and the importance of seeking professional medical advice when experiencing related issues. The goal is to break down the barriers of ignorance and silence surrounding this condition.

2. Comprehensive Education: Integrating comprehensive reproductive health education, including detailed information about endometriosis, into school curricula is essential. This educational approach aims to empower girls with the knowledge needed to recognize abnormal symptoms, thereby reducing the stigma associated with discussing menstruation-related topics openly. By including endometriosis in the curriculum, it becomes a normalized aspect of reproductive health discussions.

3. Specialized School Healthcare: Ensuring that school healthcare providers, including doctors and nurses, are well-informed about endometriosis is crucial. These professionals are often the first point of contact for students experiencing symptoms. Equipping them with the knowledge to identify early signs of endometriosis and guide students toward appropriate care can significantly impact early diagnosis.

4. Encourage Regular Check-ups: Normalizing routine gynecological check-ups for young girls is vital in shifting the perspective toward proactive health management. Encouraging teenagers to visit gynecologists periodically promotes a culture of preventive healthcare. Regular check-ups can help detect endometriosis or other reproductive health issues early, ensuring timely intervention and management.

5. Support from Gynecologists: Gynecologists play a central role in early diagnosis. Encouraging them to take symptoms related to pelvic pain seriously, even in young patients, is crucial. Gynecologists should be trained to recognize the signs of endometriosis and conduct appropriate diagnostic tests, such as laparoscopy, when necessary. This proactive approach can lead to quicker diagnosis and better outcomes.

6. Specialized Centers: Establishing specialized endometriosis centers is a significant step toward ensuring accurate diagnosis and effective treatment. These centers can serve as hubs of expertise, bringing together healthcare professionals with specialized knowledge in endometriosis. Additionally, they can conduct research to improve diagnostic methods and identify biomarkers that facilitate early detection.

7. Telehealth Services: To increase accessibility to information and consultations, expanding telehealth services focused on endometriosis and women's health is crucial. Telehealth platforms can provide a convenient and non-threatening space for teenagers to seek guidance, ask questions, and share concerns related to endometriosis. This approach helps bridge geographical gaps and ensures that all girls have access to valuable information.
8. Open Dialogue: Promoting open discussions about reproductive health and endometriosis within families, schools, and communities is key to reducing stigma. These discussions should be framed in a way that encourages empathy and understanding. By normalizing conversations about menstruation and reproductive health, society can break free from cultural taboos.
9. Cultural Sensitivity: Developing culturally sensitive educational materials and programs is essential. These resources should be tailored to address the unique challenges and concerns of Arab teenagers with endometriosis. By acknowledging cultural norms and sensitivities, the information becomes more relatable and acceptable within the community.
10. Empowerment Through Peer Support: Creating support networks and peer mentorship programs for teenagers with endometriosis can be highly effective. Peer support provides a safe space for girls to share their experiences, seek advice, and gain emotional support. This initiative can reduce feelings of isolation and empower affected teenagers to navigate their condition confidently.
11. Advocacy and Policy Change: Advocating for policy changes that prioritize women's reproductive health is essential. Policymakers should ensure that healthcare services related to endometriosis are accessible, timely, and affordable. By focusing on policy change, society can create an environment that supports early diagnosis and improved outcomes for those affected by endometriosis.

In conclusion, combating the stigma surrounding endometriosis and enhancing early diagnosis among Arab teenagers demands a comprehensive approach that encompasses education, heightened awareness, cultural sensitivity, and advocacy for policy change. By integrating these strategies, we aim to create a future where endometriosis is not a source of silent suffering, but rather a condition that is openly discussed, comprehended, and effectively managed. It is crucial to recognize that these issues extend beyond the affected girls and their families; they need to be addressed on a community-wide scale (Hufnagel, 2012).

A call for proactive measures and intensified interventions is crucial. This necessitates broadening the discourse on endometriosis beyond the confines of gynecological circles to encompass all healthcare providers and communities, including pediatricians, adolescent health physicians, and general practitioners. Engaging the public sphere would encourage the community, employers of women with endometriosis, young men considering marriage to a woman with endometriosis, and policy makers to view endometriosis symptoms in the same light as any other debilitating condition, thereby accepting them as valid reasons for absence from work.

Such a shift in perception may lead to a surge in support, understanding, and empathy from employers, partners, and family members. The practical benefits of this heightened awareness will be twofold: first, it will empower affected women and girls to openly discuss menstrual pain and seek assistance for day-to-day management. Second, parents, particularly mothers and fathers, will be less apprehensive about their daughters' future marriage prospects, allowing them to redirect their focus toward enhancing their overall quality of life. In tandem with treating the casualties of entrenched cultural messages, it is imperative that we actively strive for cultural transformation in society where endometriosis is met with compassion, support, and informed understanding.

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Author Biography

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She has consistent efforts to disseminate the knowledge and practice of safe endoscopic surgery through different activities including training OBGYN residents, workshops, conferences and visiting surgeons' trips supporting different hospitals in Oman. As a gynecologic surgeon, endometriosis comprises significant aspects of her clinical practice. Her interest and expertise in endometriosis is evident through some publications and a strong advocacy for a lifelong approach to managing women and girls with endometriosis to improve their quality of life and improve community understanding of the disease.

Eng. Maryam Almarzooqi is a master's student in biomedical engineering who is working in the center of biotechnology in Khalifa University. She has a bachelor's degree of science in Biomedical Engieering. She is comitted and passionate about researching on endometriosis, and her thesis title is about ”Role of Genetic Polymorphisms in Endometriosis in Women of Arab Ancestry”, in which she conducted a systematic review of the genetic variants associated with endometrio-sis. Eng. Maryam wishes to pursue her PHD in biomedical engineering, focusing on endometriosis disease and women's health.

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