

COMMENTARY

Endometriosis among African women

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Abstract

Endometriosis has long been wrongly perceived to be rare among women of African descent. The misconception about the prevalence of endometriosis among African women has significantly contributed to long diagnostic delays, limited access to diagnosis and care, and a scarcity of research on the condition among African women. In this commentary, we highlight the prevalence of endometriosis among African women, the state of endometriosis care in Africa, and the gaps in knowledge that need to be addressed. Based on the available data, the prevalence of endometriosis in Africa is likely higher than previously thought, with varying subtypes. There is a long diagnostic delay of endometriosis among African women. Additionally, endometriosis care in Africa from the general population and health practitioners is poor; this can be attributed to the high diagnostic cost, scarcity of trained specialists, as well as patients' inability to express their symptoms due to societal taboos surrounding menstrual health. Public sensitization on endometriosis may help improve endometriosis diagnosis and care in Africa.

Lay summary

Endometriosis is a condition in which tissue like the uterine lining is found outside the uterus, causing women to experience pain especially before, during, or after menstruation. Although endometriosis affects an estimated 176 million women worldwide, it has been wrongly reported that endometriosis is a rare condition among African women, mainly due to lack of awareness among healthcare providers and historical bias. In the current commentary, we discuss the prevalence of endometriosis, the diagnostic delays, and the care of endometriosis among black African women living in the African continent. Much of the literature has demonstrated (falsely) that endometriosis is rare in Black women compared to White ethnicity. African women experience a long diagnostic delay and do not receive appropriate care. Public awareness of endometriosis may help improve diagnosis delay and endometriosis care in Africa.

Keywords: ▶ endometriosis ▶ diagnostic delay ▶ endometriosis care ▶ African women

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Key points

- The prevalence of endometriosis in women in Africa is unknown.
- Women in Africa with symptoms caused by endometriosis experience barriers to diagnosis.

- Development and implementation of treatments suitable for African women have been hampered by a lack of research in local populations.
- Social and societal factors need to be addressed to normalize dialogue about menstrual disorder and improve the dignity of women.

Introduction

Endometriosis, one of the most common gynecological conditions affecting women, has been generally perceived to be rare among African women (Kyama *et al.* 2007). Several factors have been implicated: a lack of awareness among the public and healthcare practitioners, poor access to diagnostic and therapeutic facilities, as well as inadequate research on the condition among African populations (Kyama *et al.* 2007). Differences in culture and lifestyle in women living in Africa compared with Europe including earlier age at first pregnancy, multiple pregnancies with large families, higher risk of pelvic inflammatory disease, and taboos surrounding menstruation and pain have also been cited (Wiswedel & Allen 1989). We believe a combination of these factors may impact the risk factors and health outcomes for African women with endometriosis which currently remain poorly understood.

Over the next years, it is predicted that increased access to education and changes in cultural practice will result in a delay in the first pregnancy and a reduction in family size among African women residing in the African continent. Given the strong association between increased exposure to menstrual flow (via fallopian tubes or vasculature) and risk of endometriosis, it is of concern that this may predispose African women to the earlier onset or more severe disease (Zondervan *et al.* 2020). In this commentary, we consider the published evidence related to endometriosis care in Africa and the gaps in knowledge that need to be addressed.

Prevalence of endometriosis in Africa

The exact prevalence rate of endometriosis in Africa is unknown with different studies reporting conflicting results between different countries. A study carried out in South Africa on factors contributing to infertility reported that the prevalence of endometriosis among the black population was lower (2%) than that of the White population (7%) (Wiswedel & Allen 1989). However, in a cross-sectional study in Nigeria, Fawole *et al.* (2015) reported a prevalence of 48.1% in women having a diagnostic

laparoscopy, stating it was one of the highest prevalence rates in Africa. The difference in prevalence reported by the different authors may be attributed to several factors including access to healthcare, differences in methods used to determine and diagnose endometriosis, classification of the condition, and the number of individuals involved in the studies. Additionally, the paucity of research on endometriosis among women of different races and social statuses is likely to be a key contributing factor to the different prevalence rates reported (Kyama *et al.* 2007).

Women living in Africa, as opposed to those of African descent living in countries such as the USA, are under-represented in the genetic studies which have identified common genetic risk factors associated with high-grade disease (Zondervan *et al.* 2020).

Diagnostic delay

Diagnostic delay of endometriosis is seen globally on average 7–10 years, but this delay is a major challenge faced by women in Africa which is exacerbated by lack of trained specialists who can accurately diagnose endometriosis in its early stages (Kyama *et al.* 2007) and lack of education about the symptoms of endometriosis among African women and healthcare workers (Kyama *et al.* 2007). An acute problem is the need to break down taboos and increase the range of accessible information so that women and healthcare providers are better able to discuss issues related to menstruation, infertility, pain symptoms, and when to seek medical attention. In a semi-structured interview conducted with 25 South African women diagnosed with endometriosis, most participants stated that they had little or no knowledge about endometriosis; thus, they relied on the information provided by the healthcare providers, which in some cases was not sufficient (Nnoaham *et al.* 2011).

The first East and Southern Africa regional symposium on improving menstrual health management for adolescent girls and women held in 2018 highlighted key challenges including unmet needs, negative social norms, and beliefs, as well as stigma and discrimination (Department of Women in the Presidency of the Republic of South Africa & UNFPA East and Southern Africa Regional Office 2017). Specifically in African culture, issues surrounding menstruation are considered personal and this means that women often do not feel free to discuss anything unusual about their menstrual cycle for fear of stigmatization leading to diagnostic delay even if symptoms are severe. The report also noted that there was both limited data and

'silence' on vaginal bleeding not related to menstruation, which can be associated with conditions such as fibroids, endometriosis, and post-partum bleeding. One of the conclusions from the meeting was to highlight the urgent need for improved education of healthcare workers and menstruating women on what constitutes normal and abnormal vaginal bleeding.

Subtypes of endometriosis that have been reported among African women

Several studies have reported subtypes of endometriosis among African women. A study in Ghana reported a case of catamenial pneumothorax in which the patient experienced painless abdominal distention during her menses (Okoye *et al.* 2019). The case was first treated as dysmenorrhea because it was not associated with gastrointestinal symptoms. Another study in Ghana involving 12 women reported pneumothorax (50%), hemothorax (41.7%), and hemopneumothorax (8.3%) (Okoye *et al.* 2019). In Nigeria, a case of chronic intestinal obstruction due to rectosigmoid endometriosis was reported in a 29-year-old woman (Tade 2006). These reports show that forms of endometriosis considered rare in European and other countries outside Africa are being detected in African women and suggest that the more common forms of endometriosis that present with milder or less obvious symptoms are being underreported. The reports presented may suggest that African women present only with more severe symptoms but tend not to seek medical attention with dysmenorrhea.

Impacts of endometriosis

Endometriosis severely impacts the quality of life of those affected. Feelings of distress, moodiness, frustration, isolation, low self-esteem, and hopelessness have been reported among African women with endometriosis (Nnoaham *et al.* 2011). Often these feelings are linked to the pain they experience, difficulties in managing the pain, and are compounded by a lack of understanding regarding symptomatic endometriosis (Nnoaham *et al.* 2011). A study on the biopsychosocial predictors of the symptoms of depression in 25 South African women diagnosed with endometriosis reported that 43.1% of the women suffered from moderate to severe symptoms of depression, reporting impacts on physical functioning, as well as negative feelings about the medical profession (Nnoaham

et al. 2011). The women said endometriosis affected their sexual life due to fear of painful intercourse, forcing them to avoid it. Although some participants acknowledged the support they received from their partners, some noted that their partners were suspicious of their reluctance to have sex leading to conflicts and relationship breakdown (Nnoaham *et al.* 2011).

Treatment and care

There is a wide variation on the standards of care experienced by women with endometriosis in Africa. Roomaney and Kagee (Nnoaham *et al.* 2011), reporting on a sample of South African women diagnosed with endometriosis, recorded that they experienced difficulties in explaining their symptoms and asking questions with the fear that they will appear ignorant. They also noted that women who had access to private healthcare found laparoscopy to be expensive, while those who sought care from public facilities had to wait for long periods for diagnostic laparoscopy and surgery to treat endometriosis (Nnoaham *et al.* 2011). Additionally, they noted other concerns such as poor access to treatment, limited treatment options, incorrect diagnosis, and the side effects that are associated with some of the treatments (Nnoaham *et al.* 2011). There are anecdotal reports that most African women resort to nonmedical therapies such as traditional herbal medicines and nutritional and behavioral therapies to manage chronic pelvic pain due to endometriosis. However, there are only limited studies on the effectiveness of herbal medicines and their use (Kyama *et al.* 2007). Of note is that access to, or use of, existing medical therapies, was not favored because they are expensive and most of them act as contraceptives, which were at odds with societal emphasis on fertility (Kyama *et al.* 2007).

Conclusion

The prevalence of endometriosis in Africa is likely to be far higher than currently reported and may rise as women delay childbearing. Information about genetic risk factors is lacking as women residents in Africa have been underrepresented in family linkage and genetic association studies. Diagnostic delay is a major problem for symptomatic women, and this is complicated by variations in access to healthcare as well as awareness among healthcare professionals. Thus, there is a need for further research including potential phenotypic

variation of endometriosis in this population and the goals of care for the patients. The first East and Southern Africa regional symposium on improving menstrual health management for adolescent girls and women made several important recommendations including the need for better communication and community involvement of traditional and religious leaders as a vital step toward changing perceptions, healthcare practices, and reducing societal and social stigma surrounding menstrual health. Establishing such programs is important because it will help in the normalization of menstruation and promotion of self-dignity, self-esteem, and self-worth among African women. In addition, cross-regional collaboration, international collaborations and the establishment of health programs are important approaches in contributing to quality assurance in research and medical care and to improving endometriosis perception in society.

Declaration of interest

The authors declare that there is no conflict of interest that could be perceived as prejudicing the impartiality of this commentary.

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Data availability statement

The data presented in this study are available on request from the corresponding author.

Author contribution statement

Collection of manuscripts and proofreading (E O M, A W H, P T K S), suggestions and proofreading (J N N, C O A O, R M), writing and proofreading

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