

# Endometriosis in African women

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Endometriosis is a gynecological disorder characterized by the growth of endometrial tissue outside the uterine cavity. Although the prevalence of endometriosis is well documented in women living in developed countries, studies on the prevalence of this disease among African women are still wanting. The current view is that endometriosis rarely affects women of African descent. However, in African-American women in the USA, endometriosis is one of the common indications for major gynecological surgery and hysterectomy and is associated with a long hospitalization and high hospital charges. Endometriosis may be more commonly found in infertile Caucasian or African-American women than in African-Indigenous women, but it is likely that the true prevalence of endometriosis in African-Indigenous women is under reported owing to inadequate facilities and demands of specialized skills for adequate assessment of the pelvis and recognition of the various types and appearances of the disease. Understanding the prevalence of endometriosis among African women will be instrumental in proper management of this disease in the African continent.

Endometriosis is a gynecological disease of pathological endometrial-like tissue growing outside the uterine cavity. It is the most common cause of pelvic pain and occurs in 30–40% of women with infertility [1] and represents the third leading cause of gynecologic hospitalization in USA [2,3]. Although endometriosis has been known for over a century, the disease has been erroneously perceived to affect women of higher social status, probably because these women have more resources to seek continuous medical care. A neglected subject of investigation is the difference in the prevalence of endometriosis among different races and socioeconomic status. Some clinical investigations have shown that the prevalence of endometriosis may be lower in black women and higher in oriental women than in the Caucasian population [4,5]. By contrast, other investigators studying populations that were comparable for both indication for diagnostic procedure and socioeconomic class failed to find substantial differences in the prevalence of endometriosis in women of different races [6].

Although the prevalence of endometriosis is well documented in women living in the developed world, studies on the prevalence of this disease among African-Indigenous women are still scarce. The current belief is that endometriosis rarely affects women of African descent. However, in African-American women in the USA, endometriosis is one of the common indications

for major gynecological surgery and hysterectomy and is associated with a long hospital stay and high hospital charges [7–9]. It has also been substantiated that endometriosis is more commonly found in African-American patients seeking care in private practice than in African-American patients attending public hospitals [8,9]. However, genetically, African-American and African-Indigenous women are not necessarily identical, given the known genetic admixture among the African-American population [10]. In this review, we underscore that endometriosis may be more common in African-Indigenous women (born and living in Africa) and in African-American women (born and living in North America) than is generally claimed. This review is important, in view of the increasing interest from patients, physicians and scientists in sub-Saharan Africa, in order to improve the awareness, diagnosis and treatment of endometriosis. The purpose is to provide an update on endometriosis in African women, after we reviewed this subject a few years ago [9].

## Prevalence of endometriosis in African women according to indications for hysterectomy

It is recognized that hysterectomy is a major burden on healthcare systems. An estimated 590,000 women in the USA undergo this surgery annually [11,12] and endometriosis contributes to more than 100,000 hysterectomies each year [13].

**Keywords:** African-American, African-Indigenous, Caucasian, endometriosis, prevalence, race

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Endometriosis was the indication for hysterectomy in 9% of black women and 20% of white women in the USA during the period 1988–1990 [7]. The estimated rate of hysterectomies for endometriosis per 10,000 women aged 15 years or older in the US civilian population was 5.5% in black women and 11.2% in white women. In comparison, uterine leiomyoma accounted for 61% [7] of hysterectomies for black women and 29% [7] for white women. In another study, endometriosis was reported as an indication for hysterectomy in 11% of white women [12], while uterine leiomyoma accounted for 19% of hysterectomies for white women and 51% for nonwhite women [12].

The prevalence and cost of endometriosis-related hospitalizations has been determined in a retrospective analysis based on nationwide clinical-practice data in the USA [8]. Most endometriosis admissions occurred in women aged 35–49 years, and the most common procedure was a total abdominal hysterectomy (55–60%) [8]. Older and African–American patients had the longest length of hospital stay and the highest total charges. The estimated total hospitalization costs, as represented by the hospital charges, for women with endometriosis as the primary diagnosis in the USA were US\$540 million in 1991 and US\$579 million in 1992, suggesting that endometriosis-related hospitalization is a major burden on healthcare systems [8]. Similarly, a review of all private patients admitted for major gynecological surgery to a private US clinic indicated that the prevalence of endometriosis was similar in African–American women (6.9%) and white women (7.7%) [14]. Collectively, these data clearly show that endometriosis is a common indication for major gynecological surgery in African–American women. In contrast to data available regarding the prevalence of endometriosis in African–American women undergoing hysterectomy, few studies are available in African–Indigenous women. In Nigeria, endometriosis has been found in either 0.2% [15] or 0.4% [16] of women undergoing gynecological operations, excluding laparoscopy. It is possible and even likely that this is an underestimation of the true prevalence of endometriosis in African–Indigenous women receiving hysterectomy, as explained in the next section.

#### Prevalence of endometriosis in African women presenting with pain & infertility

It has been estimated that infertility affects between 37 and 70 million married couples in

the world [101] and that chronic pelvic pain contributes to 10% of all outpatient visits to a gynecologist and is responsible for approximately 40% of laparoscopies and 10–15% of hysterectomies [17].

Among infertile Caucasian women, the prevalence of endometriosis has been reported to vary between 13% in the period 1970–1987 and 33% in the period 1988–2000 [18]. This positive correlation between prevalence estimates and the year of publication has been confirmed recently by Guo and Wang, and may reflect increasing prevalence of endometriosis observed worldwide. It may also reflect increasing diagnostic capacity, owing to improved skills of detecting the various appearances of endometriotic lesions, increased use of laparoscopy in diagnosis and improved quality in laparoscopic equipment [19]. In African–American women [20], the laparoscopic prevalence of endometriosis in patients aged 18–40 years with pain, infertility, menstrual disorders or benign gynecological conditions was 23%, suggesting that endometriosis is also a frequent condition in African women of younger age than the older age group studied in the hysterectomy studies mentioned above. In a later report, the prevalence of endometriosis in 43 adolescent African–American women aged 18–19 years presenting with pain or abnormal vaginal bleeding was 65%, including mild (50%), moderate (39%) or severe (11%) endometriosis [21], according to the Acosta classification [22]. In a more recent study, the prevalence of endometriosis in infertile women in Cincinnati, OH, USA, was relatively low, but comparable in white patients (4.7%) and black patients (2.6%) [23].

In African–Indigenous women at a fertility clinic in Groote Schuur Hospital in Cape Town, South Africa [24], the prevalence of endometriosis was lower in black patients (2%) than in South Africans of mixed race (4%) or white patients (6%). In Nigeria, the prevalence of endometriosis in infertile African–Indigenous women was apparently in the same range (1.8 [25] and 1.4% [26]) and did not increase between 1987 and 1997. This observation is in contrast to the report from Guo and Wang showing an increasing prevalence of endometriosis with the year of publication [19]. However, these investigators also mentioned that this increase may be caused by better diagnostic techniques, rather than a true increase in the prevalence of endometriosis [19], as mentioned above. It is likely that the prevalence of

endometriosis in African–Indigenous women will increase in studies performed by gynecologists who have state-of-the-art laparoscopic equipment and who are fully trained in the laparoscopic recognition of endometriosis. Indeed, underdiagnosis of endometriosis in African–Indigenous women may be an important factor, owing to the inadequate laparoscopic facilities and specific training of African gynecologists to diagnose and treat this disease. The lower prevalence of endometriosis among African–Indigenous women with infertility may also be explained by a different lifestyle (early pregnancy, increased risk for pelvic inflammatory disease and blocked Fallopian tubes) that is associated with a reduced risk for development of endometriosis. However, the change of lifestyle among the middle class in many African countries may also affect the prevalence of endometriosis in these countries.

#### **Specific presentations of endometriosis in African women**

Endometriosis has been reported among African women with various forms of presentation. Some cases of the rare form of the disease have been documented. Specific manifestations, such as cervical, uterine or umbilical endometriosis and ascites caused by endometriosis, appear to be more frequently observed in African–Indigenous or African–American women than in women of other ethnic backgrounds, without adequate explanation. These will be reviewed in the next pages.

##### ***Cervical endometriosis***

Cervical endometriosis appears to be a specific manifestation of endometriosis that is more common in African–Indigenous women. Cervical endometriosis needs to be considered as a possible cause of intermenstrual bleeding, perimenstrual spotting or contact bleeding [27]. In a series of 570 African–Indigenous patients undergoing colposcopic evaluation for abdominal cervical smears, vaginal discharge and abnormal vaginal bleeding, the prevalence of cervical endometriosis was 2.4% (16/570) [27]. Approximately 56% of these patients with cervical endometriosis had previously documented cervical procedures, including cone biopsy, cervical curettage, laser surgery or electrocautery [27]. Internal pelvic or extrapelvic endometriosis could not be detected during clinical examination, but could not be ruled in or out since a laparoscopy was not performed to diagnose pelvic endometriosis.

##### ***Uterine endometriosis***

According to a recent study, African–American women appear to have a predilection for uterine implants to form [28]. Endometriosis implants on the uterus, considered to be rare, were found in more than 90% of the women studied [28], were coexistent with ovarian implants (62%), posterior cul de sac disease (51%), Fallopian tube involvement (44%), abdominal wall spread (48%) and bowel implants (21%).

##### ***Endometriosis-related ascites***

Endometriosis-related ascites also appear to be a specific manifestation of endometriosis that is more common in African women than in Caucasian women. Overall, ascites due to endometriosis are a rare manifestation of endometriosis [29,30] and represent a refractory form of endometriosis simulating ovarian cancer. In Nigeria, a case of endometriosis with massive ascites was reported in a 19-year-old African–Indigenous woman [31]. In a review paper, 20 cases were reported and 82% were nulliparous young black women [29]. The main presenting symptoms of endometriosis-associated ascites include abdominal distention and pain (chronic pelvic pain or dysmenorrhea). Pelvic endometriosis was found in all 20 patients. In addition, omental and pleural endometriosis was observed in four and two patients, respectively [32–34]. Although the pathogenesis of endometriosis-associated ascites remains elusive, it has been hypothesized that rupture of chocolate cysts in the abdominal cavity, with release of endometrial cells and blood, causes peritoneal irritation leading to ascites [35].

##### ***Pulmonary/thoracic endometriosis***

Case reports of pulmonary/thoracic endometriosis, a known extrapelvic presentation of the disease, has also been reported in women of African origin, but it is not clear if women of African origin are at a higher risk to develop this type of endometriosis. Margolis and colleagues published a symptomatic case of pulmonary endometriosis in a 38-year-old African–American woman who had initiated GnRH analogue therapy for pelvic endometriosis [36]. The woman experienced pleuritic chest pain with menses. Another case of thoracic endometriosis, confirmed by histological examination, was reported in a 34-year-old African–Indigenous woman who had experienced unusual thoracic menstruation with signs of pleural effusion [37].

### ***Umbilical endometriosis***

Various cases of umbilical endometriosis have been reported in African–Indigenous women presenting with umbilical nodules, sometimes associated with a history of previous uterine surgery [25,38–40]. In these cases, umbilical nodule enlargement occurred during menstruation and was associated with occasional bleeding and pain. Therefore, endometriosis should be considered in African women who manifest subcutaneous nodules, particularly those with cyclic pain or bleeding or a history of uterine surgery [25].

### **Endometriosis in African–Indigenous women: why are there few cases?**

In general, it seems that endometriosis may be more commonly found in infertile Caucasian or African–American women than in African–Indigenous women. Obviously, this difference can be related to nonracial factors protecting against endometriosis, since it is known that African–Indigenous women have children at an earlier age, have more children than Caucasian women in developed countries or than African–American women, and have been claimed to suffer from tubal infertility as leading cause (57%) of female infertility [24]. All these factors may limit the cumulative number of menstrual cycles with retrograde menstruation that is positively correlated with the risk of endometriosis [18,41,42]. It would be interesting to study the prevalence of endometriosis in parous women of African origin with secondary infertility and control for the number of menstrual cycles since their last delivery. Furthermore, it is very likely that the true prevalence of endometriosis in African–Indigenous women is under-reported owing to several reasons.

### ***Factors contributing to inadequate reporting of endometriosis among African–Indigenous women***

Low awareness of endometriosis & poor access to diagnostic & therapeutic facilities

A higher prevalence of endometriosis has been reported among affluent women [43–45]. However, this might be owing to early and better diagnosis, possibly because they recognize pelvic pain or infertility as an important health problem and have access to excellent diagnostic and therapeutic facilities. Lack of awareness of endometriosis as a potentially important health problem among African–Indigenous women and poor access to state-of-the-art

diagnostic and therapeutic facilities may contribute to the meager epidemiological data on endometriosis in African women.

### **Limited training in diagnosis & treatment of endometriosis**

The prevalence of endometriosis may vary with the diagnostic method used [46]: laparoscopy is generally accepted to be a better method for the diagnosis of minimal-to-mild endometriosis than laparotomy and this technique may not be accessible to most women in African countries.

Laparoscopic diagnosis of endometriosis demands specific training to enable gynecologists to perform an adequate assessment of the pelvis based on knowledge regarding the numerous types and localizations of the disease [47]. Few African gynecologists are trained and sufficiently experienced to diagnose and treat endometriosis by laparoscopy and in recognizing the wide variability in appearance of the disease, especially with respect to the subtle visual appearance of endometriosis [48,49]. The concept of subtle endometrial lesions and deep endometriosis has been reported since 1985, and is not yet fully appreciated by all gynecologists. Furthermore, pathological confirmation (histological presence of endometrial glands and stroma) of the laparoscopic appearance is essential for the diagnosis of endometriosis [18,49,50]. Accurate diagnosis of endometriosis by both macroscopic surgery and microscopy may lead to an increased prevalence of endometriosis even in groups of women incidentally unsuspected to have endometriosis [48].

### **Underdeveloped endometriosis research programmes**

The lack of studies on prevalence of endometriosis among African–Indigenous women may be explained by the lack of research interest and programmes in this field. It is essential to understand that, through the current wave of globalization, African–Indigenous women are experiencing a fast change in both lifestyle and social economic wellbeing. This is because they are equally competing for resources with their male counterparts in many aspects, such as career development. Consequently, they marry later, have their first child at an older age and have fewer children. This kind of lifestyle is exposing them to long duration of uninterrupted menstrual flow with retrograde menstruation and can be considered to increase the risk of developing endometriosis [18,46]. Therefore, there

**Executive summary*****Prevalence of endometriosis in African women according to indications for hysterectomy***

- Hysterectomy is a major burden to the healthcare systems. An estimated 590,000 women in the USA undergo this surgery annually.
- Endometriosis contributes to more than 100,000 hysterectomies each year.
- Endometriosis was the indication for hysterectomy in 9% of black women and 20% of white women in the USA during the period 1988–1990.
- Private patients admitted for major gynecological surgery indicated that the prevalence of endometriosis was similar in African–American women (6.9%) and in white women (7.7%).
- The estimated total hospitalization costs, as represented by the hospital charges, for women with endometriosis as the primary diagnosis in the USA were US\$540 million in 1991 and US\$579 million in 1992, suggesting that endometriosis-related hospitalization is a major burden on healthcare systems.

***Prevalence of endometriosis in African women presenting with pain & infertility***

- In African–American women, the laparoscopic prevalence of endometriosis in patients aged 18–40 years with pain, infertility, menstrual disorders or benign gynecological conditions was 23%, suggesting that endometriosis is also a frequent condition in African women of younger age.
- The prevalence of endometriosis in infertile women in Cincinnati, OH, USA, was relatively low but comparable in white patients (4.7%) and in black patients (2.6%).
- Among African–Indigenous women, the prevalence of endometriosis was lower in black patients (2%) than in South Africans of mixed race (4%) or white patients (6%).

***Specific presentations of endometriosis in African women***

- Cervical endometriosis appears to be a specific manifestation of endometriosis, more commonly in African–Indigenous women.
- African–American women appear to have endometriosis implants on the uterus, which are considered to be rare.
- Endometriosis-related ascites also appear to be a specific manifestation of endometriosis that is more common in African women than in Caucasian women.
- Pulmonary/thoracic endometriosis, an extrapelvic presentation of the disease, exists among women of African origin.
- Various cases of umbilical endometriosis have been reported in African–Indigenous women presenting with umbilical nodules, sometimes associated with a history of previous uterine surgery.

***Endometriosis in African–Indigenous women: why are there few cases?***

- Lack of awareness of endometriosis as a potentially important health problem among African–Indigenous women and the physicians treating them.
- Poor access to state-of-the-art diagnostic and therapeutic (laparoscopic) facilities may contribute to the meager epidemiological data on endometriosis in African women.
- Limited training on the diagnosis and treatment of endometriosis may contribute to low prevalence of endometriosis, since few African gynecologists are trained and sufficiently experienced to diagnose and treat endometriosis by laparoscopy and in recognizing the wide variability in appearance of the disease, especially with respect to the subtle visual appearance of endometriosis.
- Lifestyle factors that may protect African–Indigenous women against endometriosis include multiparity, parity at a young age, pelvic inflammatory disease (leading cause of female infertility) with blocked Fallopian tubes, and so on.
- Lack of research interest in endometriosis among gynecologists in Africa.

is a need to establish centers that will raise the awareness of endometriosis among physicians and patients, highlight the general lack of information, facilitate endometriosis research efforts and draw attention to the impact and implications of the disease to healthcare systems in Africa. The first East African Scientific Conference on Endometriosis Meeting was held in Kampala, Uganda in March 2006. The meeting highlighted the need for developing integrative and multidisciplinary endometriosis research programmes in the region. It was mentioned that a published poll revealed women have to wait an average of 11.7 years in the USA and 8.0 years in the UK [51] to get a correct diagnosis after the

initial onset of symptoms for endometriosis. This is an indication that women with the condition face misdiagnosis, ignorance and misunderstanding. Therefore, patient organizations, together with scientists and physicians, need to set programme goals to raise endometriosis awareness, provide education for patients and initiate research programmes that will provide data on the prevalence of endometriosis among women in the East African region.

**Conclusion**

Endometriosis is a disease that may have far-reaching, devastating effects and negatively affects the social wellbeing of women and society

in general. It appears to be an important indicator for major gynecological surgery and a significant cause of infertility in African–American women. The prevalence of endometriosis appears to be lower in African–Indigenous women than in Caucasian women, but has not been studied adequately, possibly owing to early and/or high parity and tubal infertility, and may also be owing to underdiagnosis by gynecologists. The impact of a merely racial factor is probably limited, since the prevalence of endometriosis appears to be higher in African–American women than in African–Indigenous women. African–Indigenous women are changing, both in their lifestyle and their socio-economic status, by delaying marriage and having fewer children than before. Endometriosis should be considered as a potential cause of pelvic pain and subfertility in all women, including African–Indigenous women. Therefore, there is a need to raise awareness, highlight the general lack of information and draw attention to the implications of the disease to healthcare systems. It is critical to carry out more studies to elucidate the prevalence and dynamics of this disease among women of African origin.

### Future perspective

This review substantially argues against the perception that endometriosis is rare in the population of black women. A lack of significant studies on the incidence of endometriosis among African women could be a reflection of diagnostic problems.

We share the view that the need to establish centers is imminent in order to raise the awareness of endometriosis among physicians and patients, highlight the general lack of information, facilitate endometriosis research efforts and draw attention to the impact and implications of the disease to healthcare systems in Africa.

To achieve increased awareness, there is a need for state-of-the art diagnostic and therapeutic facilities in Africa. Hence, patient organizations, together with scientists and physicians, need to set programme goals to provide education and influence health policy makers on that aspect.

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