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REVIEW ARTICLE

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A Review of the Prevalence of Endometriosis in African Women

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Abstract

Endometriosis is a chronic condition where growth of endometrial tissue is located outside the uterine cavity. Endometriosis has been shown to impact negatively on all aspects of the patient's life. The aim of this paper is to show the prevalence of endometriosis in African women to encourage more research and clinical innovations to increase access and awareness to African indigenous women with endometriosis. Existing research have focused on the prevalence of endometriosis in developed countries. There is a dearth of research focused on developing countries, especially in Africa. This is likely due to underreporting or underestimation of rates due to inadequate facilities or specialised skills. Results showed that there is a significant prevalence of endometriosis in African indigenous women. This was common among women aged 31-40 years and the prevalence is higher among infertile women with moderate or severe endometriosis with majority in low socioeconomic status. There is a need to understand the prevalence of endometriosis in African women to help provide more support and management of the disease. Further research is necessary to increase awareness about the condition as these women tend to suffer in silence. This paper shows the importance of support and awareness of the disease especially to disadvantaged women in Africa who have no access to advanced medical amenities or insurance.

Keywords

Endometriosis; Prevalence; Africa; Women; Menstruation

Introduction

Endometriosis occurs when cells that act like those in the line of the womb are found elsewhere. This is usually found in the pelvis lining of the peritoneal wall (this is the inside lining of the abdomen and pelvis), ovaries, vagina, bowel, or bladder and sometimes/rarely in areas like diaphragm, lungs etc. [1].

According to the American Society of Reproductive Medicine, the stage of endometriosis is based on the appearance of endometrial tissue, pelvic adhesions, anatomic location of the disease and blockage of fallopian tubes [2]. The classification is also based on the location, depth and size of the endometrial tissue [3]. Stage one or two are cases of minimal or mild disease of endometriosis and characterised as superficial. This means that the disease did not penetrate deeply into the surface of affected organs. Stages three or four are cases of moderate or severe cases of endometriosis. The areas affected may be isolated or widespread, penetrating deep into affected organs such as ovaries forming cysts or 'endometrioma also known as chocolate cysts and/or penetrate organs such as bowel or bladder. Although the symptoms of endometriosis varies from woman to woman, some of the common symptoms are; pain with periods, pain with sex, pain at any time interfering with daily life, bowel symptoms such as diarrhoea, constipation and painful bowel movements, bladder symptoms e.g. Pain when urinating, fatigue and infertility. While some experienced this only during menstruation, others experienced it all the time and unrelated to periods such as bladder pain, pain passing urine, opening bowel, during and after intercourse, joint pains (thighs), feeling bloated and weight gain. Studies also showed that almost all the women said that their mobility, appetite, and sleeping were negatively affected [4]. They were also descriptions of inability to take part in daily activities and roles due to fatigue as a result of pain [4].

Endometriosis is a chronic condition that is under diagnosed, underreported and under researched [1,4]. It is found in women of all ethnic and social groups. One of the myth concerning endometriosis is that African women do not have endometriosis but Horne and Pearson, [1] have stressed that endometriosis does not affect any ethnic group more than another but the importance of racial and cultural differences may affect attitude towards pain and infertility resulting in low levels of awareness among African women [5-7].

Little research has been conducted to explore the impact of endometriosis symptoms on health-related quality of life from the patient's perspective. The major issue patients had was dealing with pain and its effects on their quality of life [8,9]. Similar results were found with studies conducted in Africa [10].

The symptoms of endometriosis significantly impact on a woman's work and social life. Studies showed the quality of life of women with endo is seriously compromised [10,11]. Social isolation is likely to occur due to personal nature of the illness as a result of unpleasant and painful symptoms [8,11]. This disease also affects confidence and self-esteem impacting negatively on family and intimate relationships. There were also feelings of frustration due to inability to cope with pain making them feel miserable and sometimes depressed. These findings agreed with a similar study among South African women, found that the symptoms of the disease among participants results in psychological distress and depression [12].

A study by Denny found that women with endometriosis affected their working lives with regards to regular requests for sick leave and sometimes lack of understanding from employers and colleagues [9]. This finding was supported by Mortimer [13] also found the symptoms of endo such as fatigue, mood swings and heavy bleeding lead to absenteeism or inability to work long hours. The women revealed that issues around endo were very private affair (such as menstruation, bowel, or bladder problems) and are not easily disclosed. Disruption in life such as education, work and social relationships were interrupted including maintaining relationships with peers and friends due to the disease. Some had to resort to flexible or part time jobs due to health needs [9,13].

Participants who were sexually active described feelings of pain during

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and after intercourse and some described it as 'intense'. Some had to avoid intercourse resulting in feelings of guilt and inadequacy [4,14].

A study by Prescott et al. said 40% of the study participants were nulliparous and had undergone or currently undergoing IVF for endometriosis-associated infertility [15]. They described feeling worried or depressed about possibility of not conceiving and feeling incomplete as a woman. Another recent study by Ajayi et al. [16], among 61 infertile patients in Nigeria showed that 37 patients out of the total number were in severe stages of endometriosis. The study concluded that women with moderate to severe endometriosis were more likely to be younger, have primary infertility, dysmenorrhea (pain during menstruation), menorrhagia (abnormal and/or heavy bleeding) and dyspareunia (pain during sexual intercourse) than those with minimal or mild endometriosis.

Many women developed coping mechanisms to manage the impact of endometriosis on their lives especially with the possibility of remissions by becoming knowledgeable both personally and from health professionals. They also stated that support groups and information from other women and guest speakers helped. Unfortunately, most African women are not aware of these symptoms because of the belief that menstrual pain should be endured, and it is normal [10,16].

A major concern among women suffering with endometriosis was worries about uncertainty and treatment including symptoms returning. There are issues around uncertainty about the future especially due to the fact that there is no cure. The study revealed that these women were afraid that they are not sure how long the treatment relief will last [9].

Another major concern was frustration at lack of knowledge about endometriosis by doctors and delay in diagnosis including misdiagnosis. They also shared stories about people assuming that 'the symptoms are all in their head including assumptions that pregnancy is the only solution'. They expressed difficulties talking to people about the disease resulting in feelings of loneliness. They identified three reasons for their inability to talk to people such as:

- People did not understand what they were going through
- People thought they were moaning
- Endometriosis is linked to menstruation and other women thought if some could cope, why can't they [9]

Existing research has showed that most patients' quality of life is impacted by pain, emotional impact of infertility, anger to disease reoccurrence and uncertainty about the future due to repeated operations and medical therapy [4,9].

Endometriosis has a negative impact on the quality of life, relationships, work and social life of the patient irrespective of race or background. Therefore, the aim of this paper is to show the prevalence of endometriosis in African women to encourage more research and clinical innovations to increase access and awareness to African indigenous women with endometriosis.

Methodology

The search strategy contain terms pertaining to endometriosis, prevalence and African women. The databases searched were Google Scholar, MEDLINE (EBSCO), Health and Medical Collection (ProQuest), Health Management Database (ProQuest), Nursing and Allied Health Database (ProQuest). The searches were undertaken from May 01, 2020 to July 31, 2020. All references were imported into the reference management software (Refworks) and duplicate references were manually removed.

The eligibility criteria in this review were peer-reviewed journal papers, contained primary data, participants were African and papers were written in English.

The selection process involved two stages. The first stage involved manually screening all papers for their relevance to the review's aim using the information in the title/abstract. The second stage involved retrieving and reading the full text of all papers to determine their eligibility for inclusion in the review. All papers included in the review were subjected to a thorough reading and followed by data extraction which was recorded using a tabular spreadsheet in Microsoft Excel 2016.

Results

A total of fifty peer-reviewed papers were retrieved from the search. Thirty papers met the eligibility criteria following the title and abstract screening. After removing irrelevant and duplicate papers, twenty-two papers were obtained and screened. Nine papers met the inclusion criteria and were included in the review.

Findings from selected papers

The results revealed that the prevalence of endometriosis was high among African indigenous women aged 31-40 years with primary infertility and symptoms of dysmenorrhea (pain during menstruation). Influencing factors responsible for low prevalence rates and diagnosis were low economic status, low education, ethnicity and poor diagnostic resources at the hospitals. A significant amount of women with primary infertility had moderate or severe endometriosis [5,10,16-22].

Discussion

The prevalence among Nigerian women aged 31-40 years was significant and reported having symptoms of dysmenorrhea and pelvic pains [19,20]. A study by Fawole et al., reported an overall prevalence of 48.1% among women reporting symptoms which they reported as the highest in Africa [10]. The study also found that women who reported symptoms of dysmenorrhea (painful menstruation) were more likely to have endometriosis than those who did not. A significant finding from this review is that a significant amount of infertile women have moderate to severe endometriosis with associated symptoms of pelvic pains, dysmenorrhea and tubal blockage [18,20-22]. Endometriosis was quite common among Nigerian women and that the condition is prevalent among African women as it is with other populations [10,14,23].

The findings from this review agreed with papers that described the prevalence of endometriosis in women from developed countries. The prevalence of endometriosis was common in infertile women, aged less than 35 years and increased with symptoms of dysmenorrhea [15,24]. The prevalence of endometriosis is well known in developed countries. It is generally believed that endometriosis hardly affects African-indigenous women, but it is surprising to note that African-American women in the USA have the highest numbers of patients with endometriosis [6].

Existing studies conducted among African women showed that majority of the patients were blacks with majority from low socioeconomic backgrounds even though previous research has insisted that this disease is rear in women from African backgrounds [10,14,23]. This reflects the low number of citations in Africa as reported by Brüggmann et al. [25]. Kyama et al. reported that the low rates in African women were as a result of under-estimation resulting in low rate of studies conducted and under-diagnosis as a result of low awareness of all parties involved such as the patients and doctors [6]. Also, factors such as lack of access to health care and surgical facilities (such as state-of-the-art laparoscopic equipment) have also resulted in under-estimation. This was supported by Ajayi et al. [16]. Protective lifestyles such as early childbearing were factors that research considered to contribute to low rate of the condition in African women. However, due to globalisation, indigenous African women are experiencing lifestyle changes and undergoing career prospects, therefore marrying later, and having children at older ages. These lifestyles may expose them to retrograde menstruation, which are major risk factors for endometriosis [26,27]. A recent study in Nigeria, found that early menarche was a risk factor for endometriosis and the mean age of participants were 12.8 years [14]. The finding agreed with work by Hediger et al. and Treloar et al. that menarche at or after 14 years greatly reduced the risk of endometriosis [28,29]. Kyama et al. calls for more collaborative efforts in sub-Saharan Africa with the exception of Kenya, who has made about 41 co-operations with other countries such as Belgium in areas of advanced research [6,25]. It is very important to understand the prevalence of endometriosis in indigenous African women to help manage the disease in African women, as the assumption that endometriosis is rare in African women is completely baseless [6].

Conclusion

Existing research has shown that endometrioses affects all women in all age groups and backgrounds. This paper is written to critique the assertion that endometriosis is rare in black African women. However, it is more challenging and traumatising when you have a distressing condition like endometriosis and everyone around you including yourself have no idea what is happening to your body. These are the challenges women face especially from African backgrounds. More research needs to be conducted among African women to ascertain the prevalence and in the long run help provide basic treatment facilities and opportunities especially to disadvantaged African women who have no access to such opportunities. More awareness needs to be created to women from African backgrounds to let them know about the disease as it is a very complex condition and one can have it without any symptoms. This will help create more support for women batting with the condition. This suggestions are in agreement with Kyama that there is a need to establish centres to create awareness about the disease among physicians and patients, encourage research and give more attention to the impact and implication of the disease as reflection from my personal experience. There is also a need to have state of the at diagnostic equipment to provide laparoscopic service (as laparoscopy is usually the golden standard to diagnosing endometriosis) especially in government owned or public hospitals to encourage women from disadvantaged backgrounds who cannot afford private treatment costs.

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