

# Diagnosis Delay and Assessment of the Quality of Life of Patients with Endometriosis Using the Endometriosis Health Profile 5 Questionnaire in a Sub-Saharan Population

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## Abstract

**Context:** Endometriosis is a pathology that directly affects the daily lives of women with frequent impairment of their quality of life. In our environment, medical, socio-cultural, financial factors and factors related to the organization of the health care system greatly delay its diagnosis. The objectives of the present study were to determine the diagnosis delay and to assess the quality of life before surgery of women with endometriosis using the specific Endometriosis Health Profile 5 (EHP-5) questionnaire. **Methods:** We carried out a descriptive, observational, retrospective study in 8 medical centers in the City of Kinshasa, from January 2019 to October 2022. A total of 80 women with endometriosis confirmed by laparoscopy (16 diagnostic and 64 operative laparoscopies) and histopathology were interviewed. We used the revised American Society for Reproductive Medicine (rASRM) classification, the En-

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ometriosis Fertility Index (EFI) score was calculated for infertile women and the EHP-5 questionnaire to assess quality of life. Our data was entered and analyzed using Statistical Analysis Software 16.1 (STATA 16.1). **Results:** Diagnosis delay of endometriosis was on average  $12 \pm 4.3$  years. The overall mean EHP-5 score of all patients showed a severe deterioration in quality of life ( $604 \pm 235$ ). A negative relationship was observed between the age of the patient, the diagnostic delay, and the alteration of the quality of life in patients over 36 years old and those with about 11 years of diagnostic delay presenting the slight alteration. Patients with a high social level had very severe quality impairment. Women on hormonal treatment, those with a history of pregnancy, childbirth, miscarriage and abortion had a slight and significant deterioration in quality of life ( $p < 0.05$ ). **Conclusion:** Despite some limitations, our preliminary study highlights that in sub-Saharan Africa, the diagnosis of endometriosis is delayed and associated with a severe alteration in quality of life. Moreover, diagnosis of endometriosis seems to be restricted to women with high social levels. Therefore, further efforts are required to develop a health policy to decrease delay for diagnosis with potential benefits on symptoms, quality of life, fertility while limiting stigma and psychological effects of this debilitating pathology.

## Keywords

Diagnosis Delay, EHP-5, Endometriosis, Quality of Life, Sub-Saharan

## 1. Introduction

Endometriosis is a chronic gynecological disease characterized by the presence of endometrial-like tissue outside the uterus [1]. Although diagnosis of endometriosis is mainly suggested in women with dysmenorrhea, dyspareunia, chronic pelvic pain and infertility, recent European Society of Human Reproduction and Embryology (ESHRE) recommendations emphasize the need to evoke the diagnosis for less specific symptoms beyond the genital sphere, in particular back pain, digestive disorders or even chronic asthenia, posing the concern on the feasibility of various investigations to assess the diagnosis, especially in developing countries [2] [3] [4] [5].

Endometriosis is thought to affect 190 million women worldwide [1] with an incidence of 2% to 10% of women of childbearing age [1] [2]. This incidence reaches 12% to 45% in infertile women [6] [7]. However, it should be emphasized that these epidemiological data emanate from developed countries benefiting easily from advanced imaging modalities (transvaginal ultrasound and MRI) [8]-[12]. Conversely, in sub-Saharan countries, diagnostic tools for endometriosis are more limited thus explaining the insufficient epidemiological data, especially on diagnostic delay, impact on quality of life and fertility management [4] [9]-[13].

A recent study suggests the contribution of specific questionnaires to assess the diagnosis of endometriosis, ESHRE guidelines underline their limited value

[4]. Moreover, due to limited availability of imaging techniques in developing countries, the diagnosis of endometriosis is still made during surgery for pain and/or infertility in women with advanced stages and severe alteration of quality of life (QOL). In this specific setting, previous studies have reported the contribution of non-specific (SF-36) and specific endometriosis questionnaires (EHP-30 and EHP-5) to assess QoL [14]-[18].

Therefore, the objectives of the current preliminary study were to determine, in a sub-Saharan population, the time to diagnosis and the evaluation of the quality of life using the EHP-5 questionnaire in women with endometriosis proven by surgery and histology.

## 2. Material and Methods

### 2.1. Selection of Participant

We carried out a descriptive, observational, and retrospective study in 8 medical centers in the City of Kinshasa (CPUA, OMC, CUK, Edith Medical, HJ Hospital, Clinique Diamant, Clinique Médecin de Nuit and Clinique Dr. Lipombi); from January 2019 to October 2022 including 80 women with endometriosis confirmed by laparoscopy and histology were interviewed.

All the women completed symptom questionnaires on gynecological (dysmenorrhea, non-menstrual pelvic pain and dyspareunia), digestive (diarrhea and/or constipation, pain on bowel movement, intestinal cramping, pain on defecation, tenesmus and cyclic rectal bleeding) and non-specific symptoms (lower back pain and asthenia), epidemiological characteristics as well as prior medical treatment and surgery.

All the women completed the EHP-5 composed of 11 questions. First five questions address pain, control and helplessness, emotional well-being, social support, and self-image. The remaining six questions evaluate the impact on work, relationships with children, sexual relationships, and feelings about the medical profession, treatment, and infertility. Patients are asked to answer questions and rate their quality of life based on the past four weeks.

Each question is rated on a scale of 5 (never = 1; rarely = 2; sometimes = 3; often = 4; always 5). The score was calculated by summing the responses to the eleven questions: never = 0 points; rarely = 25 points; sometimes = 50 points; often = 75 points; always = 100 points. The scores can therefore range from 0 to 1100. The quality of life is perfect (score = 0), slight deterioration ( $0 < \text{score} \leq 275$ ), moderate deterioration ( $275 < \text{score} \leq 550$ ), severe deterioration ( $550 < \text{score} \leq 825$ ) and very severe alteration ( $825 < \text{score} \leq 1100$ ). The validated short version of EHP-5 questionnaire was used. The validated French version of the Endometriosis Health Profile-5 or EHP-5 corresponds to a short adaptation of the EHP-30. [17]

All patients were operated on by laparoscopy, including 16 diagnostic laparoscopies and 64 operative laparoscopies. Briefly, the laparoscopy was performed in the modified dorsolithotomy position under endotracheal general anesthesia. Prophylactic antibiotic therapy was given at the beginning of the operation except

for diagnostic laparoscopy. After pneumoperitoneum induction, an umbilical 10 mm trocar was inserted for endoscope and two or three suprapubic 5 mm trocars. After exploration of the abdomino-pelvic cavity and adhesiolysis and resection of endometriotic lesions when required, the extent of the disease was evaluated using the rASMR classification to stage the disease and the EFI score to evaluate the chance of spontaneous pregnancy after surgery. Histological criteria for endometriosis diagnosis included the presence of ectopic endometrial and stromal tissues.

We considered at a high socio-economic level any patient who fully supported these treatment costs and at a low socio-economic level any patient who was unable to support herself and whose support was provided by social assistance

## **2.2. Ethics Approval**

The study was approved by the Ethics Committee of the School of Public Health of the University of Kinshasa according to the Declaration of Helsinki under number ESP/CE/187/2022. All patients signed informed consent.

## **2.3. Statistical Analysis**

Continuous variables were compared with Student's t-test and categorical variables were compared with the  $\chi^2$  test or Fisher's exact test, as appropriate. P values < 0.05 were considered statistically significant. STATA software (version 16.1) was used for data analysis.

## **3. Results**

### **3.1. Epidemiological and Socio-Economic Characteristics of the Population**

The mean patients' age was  $33 \pm 6.9$  years (ranges: 20 to 47 years), and the mean BMI was  $21.2 \pm 4.04$  Kg/m<sup>2</sup>. More than three-quarters of the population had university levels, 78% had a university level, 85% of the patients had a high economic level. One-quarter of the population had sport activity with an average of 5.8 hours per week. Forty-one percent of our patients consumed an average of 196 cubic centimeters of alcohol per day (mostly ethanol) and smoking was observed in 16% of the population. History of depression, pregnancy, abdominal surgery and family history of first-degree dysmenorrhea accounted for 13%, 68%, 59% and 24% respectively. In our series, 50% consulted for a desire to conceive.

### **3.2. Symptoms and Pre-Operative Examinations of the Population**

The average diagnostic delay was  $11.8 \pm 4.8$  years. The main frequent symptoms suggestive of endometriosis were dysmenorrhea (81%), chronic pelvic pain (70%), deep dyspareunia (64%) and infertility (50%). Although half of the patients had infertility, 68% of the population had a history of pregnancy. Moreover, about half of the patients had a history of abortion. It is interesting to note that one-third of the patients had normal clinical examinations. Only two-thirds of the patients underwent a transvaginal sonography while MRI was performed

in 71% of the patients allowing the diagnosis of endometriosis in 91% of them. The clinical and paraclinical characteristics are listed in **Table 1**.

### 3.3. Surgical Characteristics, rASMR Stages and EFI Score of the Population

All the patients underwent a laparoscopy including 80% operative and 20% diagnostic laparoscopy. The diagnosis of endometriosis was confirmed histologically

**Table 1.** Clinical and paraclinical characteristics.

Variables	Population (n = 80)
Duration of complaint (year $\pm$ sd)	11.8 ( $\pm$ 4.3)
Age at first menstruation (year $\pm$ sd)	10.8 ( $\pm$ 1.6)
<b>Clinical manifestations</b>	
• Dysmenorrhea	81%
• Deep dyspareunia	64%
• Dyschesia	38%
• Dysuria	23%
• Pelvic pain	70%
• Metrorrhagia	49%
• Infertility	50%
<b>Presence of endometriosis</b>	
<b>On clinical examination</b>	
• Normal	36%
• Adnexal mass	34%
• Deep pelvic endometriosis	11%
• Adnexal mass and Deep pelvic endometriosis	19%
<b>On Transvaginal ultrasonography</b>	
• Normal	21%
• Endometrioma	38%
• Deep pelvic endometriosis	18%
• Adnexal mass and Deep pelvic endometriosis	23%
<b>Endometriosis on MRI</b>	
• Not done	29%
• Normal	4%
• Superficial peritoneal endometriosis	11%
• Endometrioma	28%
• Deep pelvic endometriosis	16%
• Endometrioma and deep pelvic endometriosis	12%
<b>Ongoing treatment</b>	
• Hormonal contraception	14%
• Hormonal IUD	10%

in all the patients.

Most of the population had a stage III-IV rASRM stages. EFI score was evaluated for the 40 patients wishing to conceive. The majority of our patients had an EFI score between 4 and 6. These results can be found in **Table 2**.

### 3.4. Quality of Life (QoL) of the Population Using EHP-5

Using the EHP-5 questionnaire, the mean QoL score was  $604 \pm 235$ . The distribution of the patients according to QoL quartile is given in **Table 3**. Relations between epidemiologic, economic and symptoms and EHP-5 score are summarized

**Table 2.** Description of surgical parameters.

Variables	Population (n = 80)
<b>Type of surgery</b>	
- Diagnostic laparoscopy	20%
- Therapeutic laparoscopy	14%
• Electro-coagulation of peritoneal lesion	
• Salpingectomy	9%
• Unilateral ovarian cystectomy	12%
• Bilateral ovarian cystectomy	26%
• Torus resection	19%
• Uterosacral ligament resection	21%
• Ureterolysis	5%
• Colpectomy	16%
• Bowel resection	11%
<b>rASRM stage</b>	
• I and II	38%
• III and IV	62%
<b>EFI score (n = 40)</b>	
• (0 - 3)	20.0%
• (4 - 6)	47.5%
• (7 - 8)	22.5%
• (9 - 10)	10.0%

**Table 3.** Distribution of the QoL of the population according to EHP-5.

EHP-5, mean score ( $\pm$ sd)	604 ( $\pm$ 235)
<b>Quality of Life/EHP-5 Score</b>	
- Perfect (score = 0)	0
- Slight alteration ( $0 < \text{score} \leq 275$ )	11% (n = 9)
- Moderate alteration ( $275 < \text{score} \leq 550$ )	34% (n = 27)
- Severe impairment ( $550 < \text{score} \leq 825$ )	37% (n = 30)
- Very severe alteration ( $825 < \text{score} \leq 1100$ )	18% (n = 14)

in **Table 4**. A negative relationship was observed between the age of the patient, the diagnostic delay and the deterioration of the quality of life in patients over 36 years old and those with about 11 years of diagnostic delay presenting the slight alteration. Patients with a high social level had very severe QoL impairment. Women on hormonal treatment, those with a history of pregnancy, childbirth, miscarriage and abortion had a slight deterioration in quality of life.

#### 4. Discussion

The present retrospective study was to evaluate epidemiologic, socio-economic, and quality of life of patients with endometriosis in the context of a sub-Saharan country underlining the limits of the health care system.

Although our population corresponds mainly to women with high economic and educational attainments, it is interesting to note that the delay in diagnosis is well over eleven years although most of the patients exhibited symptoms suggestive of endometriosis such as dysmenorrhea, chronic pelvic pain, deep dyspareunia and infertility. Indeed, our delay in diagnosis of 11 years contrasts with those reported in USA (4.4 years) and between 7 and 9 years in France [14]-[18].

**Table 4.** Relation between epidemiologic, economic and symptoms and EHP-5 score.

Variables	Alteration quality of life				p-value
	Mild	Moderate	Severe	Very Severe	
Age	36 (6.8)	36 (5.6)	31 (7.0)	31 (6.3)	<0.05*
Complaint duration	10.6 (2.0)	13.3 (5.2)	12.1 (3.8)	9.1 (3.0)	<0.05*
Married status	78%	70%	50%	50%	0.24
University level	89%	78%	77%	71%	0.81
High social level	89%	70%	90%	100%	0.05*
Sports practice	22%	26%	27%	21%	0.98
Dysmenorrhea	67%	85%	83%	79%	0.64
Dyspareunia	56%	52%	73%	71%	0.33
Dyschesia	22%	33%	43%	43%	0.64
Dysuria	22%	11%	30%	29%	0.35
Pelvic pain	67%	70%	67%	79%	0.87
Metrorrhagia	33%	52%	53%	43%	0.70
Infertility	56%	44%	50%	57%	0.87
Hormonal treatment	67%	56%	10%	7%	<0.05*
Pregnancy history	100%	93%	53%	29%	<0.05*
History of childbirth	100%	93%	53%	29%	<0.05*
History of miscarriage	22%	37%	7%	7%	<0.05*
Abortion history	56%	56%	47%	29%	0.40

This apparent discrepancy can be explained by the fact that no abnormality at clinical examination was observed in one-third of the patients in our study. Moreover, even after transvaginal sonography, the diagnosis of endometriosis was considered in only two-thirds of the patient. All these data suggest that practitioners are insufficiently aware of the disease thus efforts must be made to improve not only medical awareness but also socio-cultural and financial factors in the health care system in our environment contributing to delayed diagnosis. Also, the availability of a new test based on the expression of miRNAs in the saliva of endometriosis patients could be a good option to overcome the diagnosis delay of endometriosis but raises the issue of its cost especially in developing countries.

The normalization of pain by patients and by professionals during menstruation and/or during sexual intercourse, the various taboos such as sexuality, menstruation and the female body, the discrediting of women's words; the causes explained by religion as the suffering and punishment of original sin; sexist prejudices explaining the fact that women are less well cared for and under-diagnosed compared to men. We believe that raising awareness on the enhancement of women's rights and gender equality should be encouraged to awaken women in our community. This would contribute to reducing the diagnostic delay in our environment.

QoL is a crucial concern for patients with endometriosis and practitioners and interventions should be tailored accordingly depending on each patient's needs. In our series, the average EHP-5 score showed a severe deterioration in quality of life. To our knowledge, the current study is the first to evaluate QoL in patients with a validated questionnaire in a sub-Saharan population. We opt to use the EHP-5 questionnaire, a validated short version of the EHP-30 questionnaire exhibiting the same picture of health items but with less restrictive to complete [18]. Moreover, the simplicity and relevance of the EHP-5 questionnaire has been proven to assess the QoL of patients with endometriosis representing an adequate tool to assess the impact of medical and surgical management [2] [19] [20]. In addition, we demonstrated the relation between the degree of QoL alteration with some characteristics such as an inverse correlation with the age of the patients. Indeed, patients over 36 years old had a slight alteration compared to younger patients. Similarly, we observed that patients with history of labor had a lower impact on QoL. This agrees with a previous multicentric international study evaluating the QoL using SF-36 questionnaire in patients with colorectal endometriosis showing that patients with previous childbirth or without infertility had a better QoL, especially concerning the Mental Component Summary (MCS). On the other hand, we noted that women with a high socio-economic level presented a very severe alteration in the quality of life. This could be explained by the fact that these groups of patients have access to care because they have financial means, but unfortunately, they consulted several doctors who could not find a solution to their solution on the grounds that there was no precise diagnosis whereas these patients had signs suggestive of the dis-



ease so most of them were thrown into the beliefs that it was a curse. We must also emphasize that beyond the severity of the symptoms, it is important to consider all the epidemiological characteristics of the patients.

The EFI score was developed as a reproductive tool to predict the likelihood of spontaneous conception after surgery for infertile patients with endometriosis [20]-[24]. Our results go hand in hand with those found by Ferrier and collaborators, we all note that the EFI score 4 to 6 were the most found in our studies and this reinforces the orientation of infertile patients with endometriosis towards medically assisted procreation whose cost is already very high and less accessible in our environment not only for financial constraints but also and above all a lack of technical support for medically assisted procreation.

Some limitations of this study are worth highlighting. First, the retrospective nature of the study may be a source of bias. Patients' answers regarding their quality of life before the procedure cannot be as precise as would be desirable, as it depends entirely on the patients' recollection over a variable time scale. However, we believe this is offset by the fact that people with chronic pain, including endometriosis, usually live with their condition for long periods of time and therefore tend to have a clear idea of the nature of their symptoms. Second, the small sample size is also a potential bias. However, our goal was to have a homogeneous population with the diagnosis of endometriosis assessed not only on symptoms or imaging criteria but by systematic laparoscopy although Pascoal *et al.* pointed out that they found that the respective sensitivity and specificity of laparoscopy are 90% - 94% and 40% - 79% justifying, as in the current study, histological confirmation [25]. Finally, no attempt was made to evaluate the changes in QoL after operative laparoscopy while previous studies have reported on the relevance of QoL questionnaire post treatment to evaluate if patients had improvement in their quality of life after treatment [19]. Despite some limitations of the present study, its strength is that it will create a national awareness of the problems of endometriosis and therefore lead to system wide changes that will improve the care of women with endometriosis in sub-Saharan Africa.

## 5. Conclusion

Despite some limitations, our preliminary study highlights that in sub-Saharan Africa, the diagnosis of endometriosis is delayed and associated with a severe alteration in quality of life. Moreover, diagnosis of endometriosis seems to be restricted to women with high social levels. Therefore, further efforts are required to develop a health policy to decrease delay for diagnosis with potential benefits on symptoms, quality of life, fertility while limiting stigma and psychological effects of this debilitating pathology.

## Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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