

# **A RE-ECHO ON ENDOMETRIOSIS BY ECCU.**

## **Introduction**

This is a continuous echo and re-echo on endometriosis and the experience that persons with endometriosis go through in terms of the healthcare, the devastating effects and complications that come along with the disease, statistics on the magnitude of the problem, and the average cost of care and the QALYS/DALYS.

Endometriosis is a condition where cells similar to the ones lining the womb (the endometrium) are found elsewhere in the body. Each month these cells react in the same way to those lining the womb, building up and then breaking down and bleeding. Unlike the cells lining the womb that leave the body as a period, this blood has no way to escape. This can cause inflammation, pain and the formation of scar tissue.<sup>1</sup>

Endometriosis is a common debilitating condition, yet one of the neglected reproductive disorders affecting women and girls of reproductive age. There is lack of awareness on Endometriosis and as a result, endometriosis cases are initially misdiagnosed as urinary tract or pelvic infections. This often leads to under management (diagnostics and medication) of the disease as the condition worsens.

This is worsened when symptoms of endometriosis are often mistaken for monthly menstrual period and therefore “normal”. The condition becomes severe and this is because many women and girls suffer for years without receiving care. This often results in delays in making a diagnosis, exacerbating the negative impact of endometriosis on those affected<sup>2</sup>

Eventually severe symptoms are presented to include; cramping or pain in the lower abdomen, low back pain, and pelvic pain spreading down the legs, nausea, vomiting, diarrhea, fatigue, weakness, fainting, or headaches, prolonged and heavy menstrual periods, chronic pelvic pain, pain during sexual intercourse and bowel movement, and even infertility.

There are also myths where girls are told to brave the pain because even their mothers went through it and that it goes away with child birth. Many girls then

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<sup>1</sup> Endometriosis in the UK: time for change APPG on Endometriosis Inquiry Report 2020.

<sup>2</sup> <https://pubmed.ncbi.nlm.nih.gov/33347170/>

grow up believing that severe menstrual cramps go away after child birth, due to ignorance, women and girls experience chronic menstrual pain for over eight years with the misconception that its “normal” and yet this pain can progress into endometriosis, a disease that attacks the uterus, ovaries and fallopian tubes and makes it difficult for women to have children.

### **Statistics on the Magnitude of Endometriosis.**

The highest percentage of women state that endometriosis has negatively impacted on their well-being. Endometriosis is a common disease affecting women and girls in Uganda and it is estimated that every two in 10 girls and women have endometriosis however, the statistics are under reported because many people including health practitioners, do not know about the disease<sup>3</sup>. About 80 per cent of endometriosis cases are initially misdiagnosed as urinary tract or pelvic infections.<sup>4</sup>

Endometriosis affects roughly 10% (190 million) of reproductive age women and girls globally.<sup>5</sup> Presently, there is no known cure for endometriosis and treatment is aimed at controlling symptoms and improving quality of life<sup>6</sup>.

It occurs in up to 20% of women of reproductive health and is a common cause of pelvic pain and infertility. Chronic pelvic pain and dyspareunia impacts on the physical and mental constituents of quality of life of a woman (*De Graaff et al., 2013*). Endometriosis is, therefore, connected to discomfort/pain, anxiety/depression and social dysfunction, which affect health related quality of life.

In women afflicted with endometriosis, the physical activity is remarkably reduced when compared with women with no endometriosis and reduced effectiveness in work has been estimated to lead to a loss of 10.8 hours per week (*Wanyoike et al., 2017*). Poor yield at work was expressed into remarkable costs per woman/week from US \$4 in Nigeria to US \$456 in Italy (*Wanyoike et al., 2017*).

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<sup>3</sup> Monday, April 17, 2023 New vision-uganda

<sup>4</sup> <https://www.monitor.co.ug/uganda/magazines/healthy-living/lifestyle-changes-can-provide-relief-from-endometriosis-3762564>

<sup>5</sup> [https://www.who.int/news-room/factsheets/detail/endometriosis#:~:text=Endometriosis%20affects%20roughly%2010%25%20\(190%20million\)%20of%20reproductive%20age%20women%20and%20girls%20globally.](https://www.who.int/news-room/factsheets/detail/endometriosis#:~:text=Endometriosis%20affects%20roughly%2010%25%20(190%20million)%20of%20reproductive%20age%20women%20and%20girls%20globally.)

<sup>6</sup> <https://www.who.int/news-room/fact-sheets/detail/endometriosis>

A study conducted by World Vision International (WVI) reported girl child school dropout at 10% out of 3,039,346 girls in primary school (*Kampire, 2019*) due to menstruation hygiene management related conditions.

### **Average Cost of Care for Endometriosis.**

The cost of care and treatment of endometriosis is extremely high and it has a high economic burden. This economic burden is comparative to that of managing chronic diseases such as rheumatoid arthritis, diabetes, among others.

Treatment is based on individual preferences and effectiveness, the side effects presented, long-term safety, costs and availability. The available treatment options are so costly and some patients may not be able to afford leading to under management of the condition.

While there is no cure for endometriosis, the treatment options that are available to help manage the symptoms include but are not limited to;

- ✓ physical therapy, specifically for pelvic floor
- ✓ painkillers (such as ibuprofen)
- ✓ certain hormonal contraceptives (such as the Pills, and the IUS)
- ✓ surgery to cut away endometrial tissue (which may help to increase on the fertility)
- ✓ a hysterectomy (to remove part or all of the womb)

### **Cause & Complications of Endometriosis.**

The causes of endometriosis are unclear. It could be genetic, or a problem with the immune system. It could also be linked to the menstrual cycle, or something else entirely or a combination of all of these. At this stage, no one fully understands why endometriosis happens, which unfortunately may contribute to the problem of identifying it in people.<sup>7</sup>

Endometriosis comes along with complications that range from cramping or pain in the lower abdomen which is usually worse during one's period, low back pain, and pelvic pain spreading down the legs, nausea, vomiting, diarrhea, fatigue, weakness, fainting, or headaches, period pain that stops one from doing their

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<sup>7</sup> [Endometriosis: what you should know | IPPF](#)

normal activities, pain during or after sexual intercourse, pain when peeing or pooing during periods, feeling sick, constipation, or blood in the pee during periods, difficulty getting pregnant, heavy flows, there is also a higher risk of getting other chronic diseases. In some cases, this pain can be debilitating. Studies show that dysmenorrhea is a major gynaecological issue among people around the world, contributing to school dropouts, absenteeism from school and work, as well as diminished quality of life.

Endometriosis is a progressive disease that keeps growing, after six to seven years, if the adolescent does not get help, the disease becomes aggressive causing scarring; eventually the victims menstruate in the intestines, lungs, brain, eyes, umbilical and ears.

### **QALYS and DALYS**

Endometriosis impacts on the physical, psychological and social life of women and girls suffering from the disease.

Some Respondents state that endometriosis/ symptoms of endometriosis had:<sup>8</sup>

- 95% – impacted their wellbeing negatively or very negatively.
- 81% – impacted mental health negatively or very negatively.
- 89% – affected their ability to lead life as they want to negatively or very negatively
- 90% – would have liked access to psychological support, but were not offered this.
- Pelvic pain – 95%
- Fatigue – 93%
- Heavy menstrual bleeding – 85%
- Painful bowel movements – 84%
- Pain during or after sex – 83%
- Difficulty getting pregnant – 73% (of 6600 responded for whom this was relevant)

Endometriosis is, therefore, connected to discomfort/pain, anxiety/depression and social dysfunction, which affect health related quality of life.

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<sup>8</sup> Endometriosis in the UK: time for change APPG on Endometriosis Inquiry Report 2020.

Endometriosis and its complications impact day-to-day life, education, work, and mental health of sufferers<sup>9</sup>. It curtails the socio-economic engagement of women and girls in their communities, reduces their ability to work, and significantly impairs their quality of life and that of their immediate families. The associated prolonged heavy bleeding and painful sexual intercourse renders women unable to engage in consensual marital sex creating rifts between families.<sup>10</sup> These women are often ostracized and victimized for what is beyond their control.

The affected school going girls on the other hand are forced to drop out of school and enter early marriages where they are exposed to domestic violence and ridiculed by some cultural practices and beliefs.

Some Respondents have stated that struggling with endometriosis gives a new dimension, it is a nightmare, the cramps are unbearable, they can't work, can't the bleeding is usually extremely heavy with clots. It is like giving birth every month, it is traumatizing, devastating, walking is almost impossible, all activities have to be planned depending on their menstrual cycle or else they miss out on opportunities.

### **Conclusion.**

From the foregoing, endometriosis is a devastating condition that has affected the social and economic wellbeing of women and girls, rendering them entirely dependent on their family and other care givers. There is need for intervention, empowerment, advocacy and sensitization about Endometriosis, the effects of the condition, how it should be managed, the care and support victims of endometriosis need in order to build the capacity of women and girls affected by endometriosis and improve the sexual health of young girls and women hence improved quality of life for girls and women.

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<sup>9</sup> <https://www.medicalnewstoday.com/articles/endometriosis-why-is-there-so-little-research>

<sup>10</sup> <https://dailymedia.co.ug/2019/07/12/pastor-bujingo-spills-undesirable-bedroom-secrets-about-ex-wife/>