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ONE IN SEVEN UGANDAN WOMEN AFFECTED

ENDOMETRIOSIS: DO NOT NORMALISE MENSTRUAL PAIN



IN APRIL, *HER VISION* IS PUTTING THE SPOTLIGHT ON MENSTRUATION; A SUBJECT OFTEN WHISPERED ABOUT YET IS CENTRAL TO WOMEN'S WELL-BEING. THROUGH A FOUR-PART SERIES, WE UNPACK THE REALITIES, MYTHS AND MEDICAL TRUTHS BEHIND MENSTRUAL HEALTH. IN THE SECOND PART, **RITAH MUKASA** FOCUSES ON ENDOMETRIOSIS, A CONDITION WHERE TISSUE SIMILAR TO THE UTERINE LINING GROWS OUTSIDE THE WOMB, OFTEN CAUSING PAIN, ANXIETY, DEPRESSION, INFERTILITY AND YEARS OF MISDIAGNOSIS.

Connie Quandat, 30, a clinical and community nutritionist, has lived with endometriosis for 17 years. The chronic condition affects menstruating girls and women and has left her battling excruciating pain, bloating, fatigue, exhaustion and anxiety. She has also experienced dizziness, weight gain and depression.

Quandat got her first period at 13. However, the period was heavy with cramps that lasted five days. Her mother gave her painkillers and reassured her that she would outgrow the pain. She did not.

At Kyeizooba Girls' School, many of her days were spent in the sickbay. "Everyone knew I had a problem with my periods," she says. Some teachers and students sympathised, others accused her of exaggerating.

By 16, paracetamol and other painkillers no longer worked. The school nurse resorted to injections. One day the pain became unbearable and her grandmother took her to Entebbe Grade B Hospital. "The doctor diagnosed hormonal imbalance and dysmenorrhoea," she says.



Connie Quandat

He prescribed contraceptives, which her grandmother opposed, and instead sought herbal remedies, but

these did not work. "Many people told my grandmother the pain would go away with childbirth," she adds. Quandat noticed her cramps worsened in Kampala compared to the village. "The junk foods, pastries and ice cream I ate in Kampala caused me problems," she says. The bleeding and clots were frightening.

In 2015, she joined the Uganda Institute of Allied Health and Management Sciences - Mulago for a diploma in nutrition. Later she worked in Kyaka II refugee settlement. During this period she gained weight from 65kg to over 80kg and her menstrual issues worsened. She once bled for two weeks continuously. Doctors advised her to get pregnant to balance hormones, but she was not ready. In 2022, a gynaecologist at Kawempe

Women's Hospital recommended an intravaginal scan. It revealed that endometriosis had scarred her pelvic area. "I was relieved to get a name for my condition. I now manage with diet, exercise and psychosocial support from the Endometriosis Foundation of Uganda," she says.

UNDERSTANDING ENDOMETRIOSIS

Endometriosis occurs when endometrium, tissue that is meant to be only in the uterus, grows outside it, explains Dr Martin Sematimba, a gynaecologist and laparoscopic surgeon at Crystal Medical Centre in Kampala. This causes inflammation and the formation of scar tissue. The tissue can travel through tubes or blood and lodge where it should not. According to Dr Sematimba,

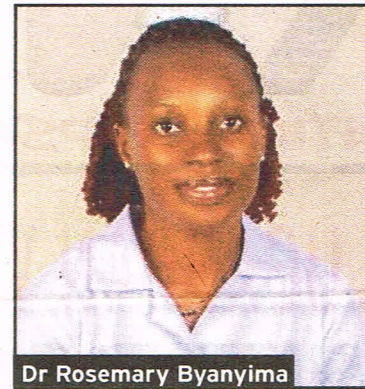
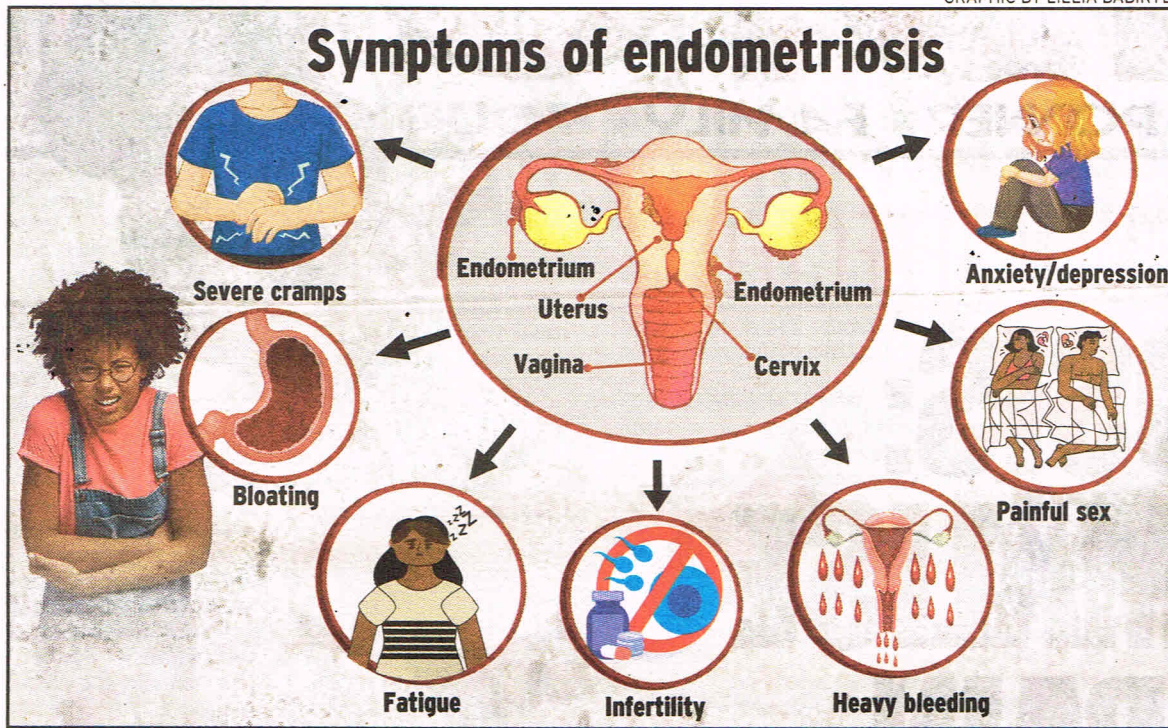
endometriosis most commonly affects the pelvic area, damaging the ovaries, rectum and bladder. In some women, tissue can reach the lungs, eyes, nose and ears. "Such women bleed through the nose, eyes and ears," he says. He has seen cases where the disease affects the chest, making patients struggle to breathe during menstruation. "We have to put chest drains to remove blood," he says. Some women even convulse during menstruation because the tissue affects the brain. Pelvic endometriosis is the most common form, notes Dr Rosemary Byanyima, the executive director at Mulago National Referral Hospital, notes in her paper *Menstruation in an Unusual Place: A Case Of Thoracic Endometriosis in Kampala, Uganda*. It carries grave complications such as infertility and ectopic pregnancies.

Symptoms include severe menstrual pain, heavy bleeding with large menstrual clots, chronic pelvic pain, infertility, bloating and nausea. It manifests through sharp, shooting abdomen pains paired with cramps.

Dr Sematimba urges parents not to normalise period pain. "If your teenager gets cramps that stop her functioning normally, that is a red flag."

ENDOMETRIOSIS AFFECTS SEXUAL INTERCOURSE, CONCEPTION

GRAPHIC BY LILLIA BABIRYE

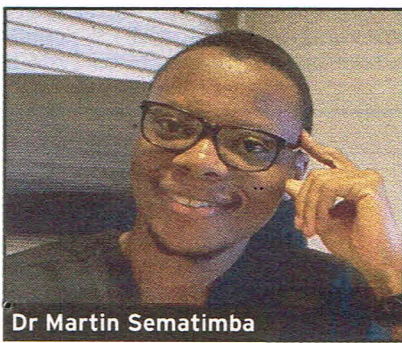


Dr Rosemary Byanyima

wait for the disease to worsen before seeking treatment," he adds. Some patients arrive when organs are already damaged. At that stage, treatment costs can reach sh30m or more. Surgery must be done by experts. The laparoscopic surgeon removes or destroys the abnormal endometrial tissue, implants and cysts hence reducing pain. "The first surgery should be thorough," Dr Sematimba says. "I have seen patients operated on five times yet still in pain."

MYTHS VS FACTS ABOUT ENDOMETRIOSIS

- Some people think that painful periods are 'normal' for women. But experts explain that while mild discomfort can be normal, excruciating pain that causes fainting, or stops a person from going to work or school is not normal.
- Believing that having children will cure endometriosis is wrong. Fact is; pregnancy does not cure endometriosis. While some women experience temporary relief during pregnancy, the disease often returns afterward.
- Endometriosis automatically ends with menopause. The estrogen hormone may drop, causing the symptoms to decrease or disappear for some women, but the lesions can persist, causing pain from the existing scar tissue.
- Endometriosis means infertility. This is wrong. While the disease can lead to infertility, many women with endometriosis are able to conceive. Early diagnosis and proper management can improve the chances of pregnancy.
- A hysterectomy (surgical procedure to remove one's uterus or womb) is a guaranteed cure. This is not true because the endometrial tissue can still grow outside the uterus and pain persists.
- Only older women get endometriosis. This is wrong. Endometriosis can affect girls and women from their first period through menopause.



Dr Martin Sematimba

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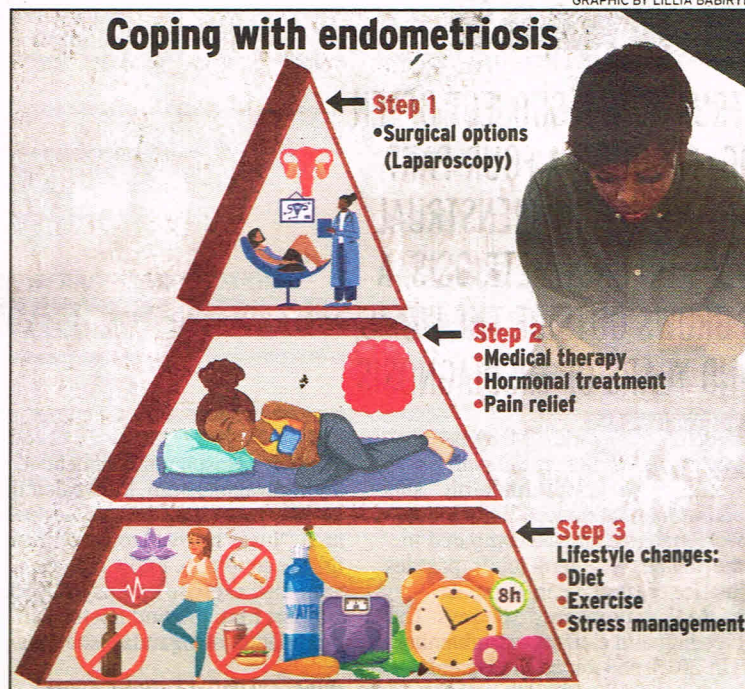
It can also affect sexual intercourse as it scars organs, making sex painful and conception difficult. In cases where the tubes or ovaries are damaged, In Vitro Fertilisation (IVF) or surrogacy is recommended. The condition can also make bowel movements and urination difficult indicating scarring of the bladder and rectum. Mental health is impacted too, with depression and anxiety common.

"We don't know what causes endometriosis. If we knew, we would prevent it," Dr Sematimba says. He notes that family history increases risk. The disease can occur at any age once menstruation begins. Some girls develop it at 11 and suffer severe pain. Dr Sematimba urges parents not to normalise period pain.

"If your teenager gets cramps that stop her functioning normally, that is a red flag," he warns. Girls whose normal lives are interrupted due to severe pain should be examined by an experienced gynaecologist and sonographer. A transvaginal ultrasound can screen the uterus, ovaries and tubes. "Early diagnosis helps to avert damage," he says.

Dr Sematimba cautions against self-medication and clinics without specialists. "Ensure you go to a specialist for proper screening," he advises. "Don't

GRAPHIC BY LILLIA BABIRYE



Coping strategies

Grace Nagawa, a nurse recommends consistent exercises done at least three to four times a week. Stress management through support groups and enjoying one's hobbies is vital. Patients are advised to avoid alcohol and caffeine because they exacerbate inflammation, disrupt hormonal balance and increase pain. Seek health care early. Support systems also play a crucial role in managing endometriosis according to Nagawa, who has lived with endometriosis for over 20 years. Family, friends and groups provide emotional, physical and social support, which helps patients to cope with the chronic pain, anxiety and distress.

For example, the Endometriosis Foundation of Uganda brings together over 300 women who comfort each other, share experiences and get counselling as well. They are also linked to specialists who offer medical care at a subsidised cost. "Families and schools nurses should be trained on endometriosis care," she says. Same way; "Men should be compassionate; offer emotional and practical support to their wives and daughters."

DIET AND LIFESTYLE CHANGES

Beyond surgery, experts emphasise that everyday choices, especially diet and lifestyle, can also ease the burden of endometriosis.

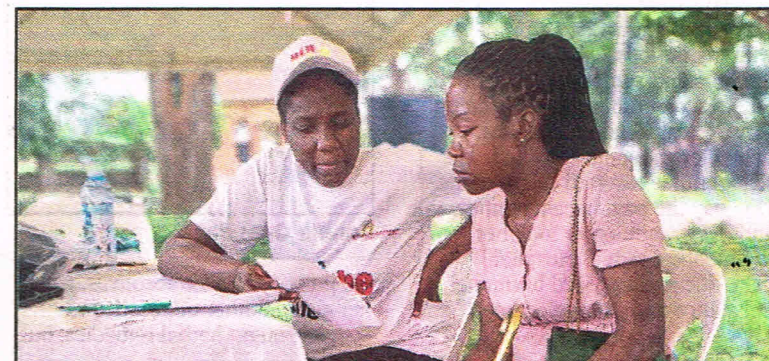
Diet plays a key role in managing endometriosis, according to Dr Joseph Muhumuza, a fertility specialist and laparoscopic surgeon. "Endometriosis is an oestrogen hormone-dependent disease. The more oestrogen you load, the higher the chances of progression," he explains.

A diet that reduces oestrogen levels is therefore important. Fruits provide antioxidants such as vitamins E, C and D plus minerals that reduce inflammation. Vegetables, beans and legumes are good sources of plant protein. Red meat and dairy should be avoided because they are linked to high oestrogen. Non-saturated fats and gluten should also be avoided. White meat such as fish and rabbit is recommended.

STATISTICS AND RESEARCH

There is no official data on the prevalence of endometriosis in Uganda. The Endometriosis Foundation Uganda estimates one in seven Ugandan women

may have the condition. The World Health Organisation estimates 176 million women of reproductive age worldwide are affected. In the United States, it is the leading cause of infertility, affecting over five million women, many in their 30s and 40s. In Europe, five in 10 women who cannot conceive have the disease.



Quandat (left) spreads awareness about endometriosis