Painful periods could be a red flag

Many women in Uganda spend years seeking answers for severe menstrual pain that is often dismissed as normal. Experts say delayed diagnosis of endometriosis is leaving thousands to suffer through chronic pain, infertility, and emotional distress.

BY BEATRICE NAKIBUUKA

Living with endometriosis: pain that can be overwhelming but shouldn't be ignored—early help can make a difference in diagnosis, treatment, and quality of life. PHOTO/FILE

For years, Sarah believed the pain was simply part of being a woman. Every month, her menstrual cycle came with crippling abdominal pain that left her curled up in bed, unable to attend school and later, work. Teachers dismissed her absence. Friends told her to be strong. At clinics, she was prescribed painkillers and repeatedly treated for infections that never seemed to go away.

"My mother told me it is normal. That all women go through it," she recalls.

It was not until nearly a decade later, after countless hospital visits and worsening symptoms, that Sarah finally received a diagnosis: endometriosis.

Her story is far from unique. According to Grace Nagawa, founder of Endometriosis Foundation Uganda, thousands of women across Uganda and Africa are silently battling severe menstrual pain that is often dismissed, misunderstood, or misdiagnosed.

"By the time many receive the correct diagnosis, the disease has already progressed, sometimes leading to complications such as infertility," Nagawa says.

Hidden in plain sight

Dr Kato Stephen Ssematimba, a gynaecologist and endometriosis specialist at Crystal Medical Centre in Kampala, says endometriosis is a chronic condition in which tissue similar to the lining of the uterus grows outside the womb, commonly affecting the ovaries, fallopian tubes, and pelvic lining.

During menstruation, this tissue thickens, breaks down, and bleeds, causing inflammation, severe pelvic pain, and sometimes infertility. In rare cases, women may experience bleeding from the nose, ears, lungs, or navel during menstruation.

Globally, endometriosis affects about one in 10 women of reproductive age, translating to an estimated 190 million women worldwide.

Yet awareness remains low, particularly in low- and middle-income countries.

Since its inception in 2019, Endometriosis Foundation Uganda has diagnosed more than 350 women with the condition.

"This is just the tip of the iceberg," Nagawa says. "Many women have this condition, but their pain is dismissed as normal." In Uganda, many women wait nine to 10 years before receiving a correct diagnosis, longer than the global average of six to eight years.

A SYSTEM UNDER PRESSURE

Uganda's health system also faces significant challenges in managing the condition. Dr Ssematimba says only seven specialists in the country are trained to diagnose and manage endometriosis, with most services concentrated in urban areas. While there is no cure, early-stage disease can be managed with medication.

Advanced cases may require laparoscopic surgery to restore anatomy, relieve pain, and improve fertility. The procedure can cost between Shs7m and Shs25m, depending on severity.

Advocates say awareness is slowly improving through community outreach, social media campaigns, and support groups.

Told to endure the pain

Nagawa, who describes herself as an "endo-warrior," says cultural beliefs and silence around menstruation contribute heavily to delayed diagnosis.

"In many homes, when a girl complains about painful periods, she is told to endure," she says. "She grows up believing that level of pain is normal."

In many Ugandan communities, menstruation remains a private and often taboo subject. Conversations about menstrual health rarely go beyond hygiene, leaving little room to discuss abnormalities such as extreme pain.

As a result, symptoms including severe cramps, heavy bleeding, and chronic pelvic pain are normalised. Seeking medical attention is often delayed, especially in rural areas where healthcare access is already limited.

"When pain is normalised, it delays care," says a Kampala-based gynaecologist. "By the time we see some patients, the disease has progressed to advanced stages."

Even when women seek help, diagnosis is rarely straightforward. In Uganda, up to 80 percent of endometriosis cases are initially misdiagnosed, often mistaken for urinary tract infections or pelvic inflammatory disease.

Part of the challenge is that endometriosis presents differently in different women. While some experience severe pain, others struggle mainly with infertility.

Dr Ssematimba adds that diagnosis can be made using a transvaginal scan or, for girls who are virgins, a transrectal scan.

The cost ranges between Shs70,000 and Shs150,000 for transvaginal scans, while transrectal scans cost about Shs200,000.

The hidden toll

One of the most difficult aspects of endometriosis is that it is largely invisible.

"You look fine, so people think you are exaggerating," Sarah says. "But the pain is real. It affects everything: your work, your relationships, your mental health."

Dr Ssematimba says symptoms can include severe painful periods, chronic pelvic pain, painful intercourse, painful urination, general body weakness, and abnormal bleeding.

The condition often leads to missed school days, reduced productivity at work, and social isolation. Living with chronic pain without a diagnosis can also lead to anxiety, frustration, and self-doubt.

For many women, the impact becomes even more visible when they struggle to conceive.

Globally, between 30 and 50 percent of women with endometriosis experience infertility because the disease can cause inflammation, scarring, and blockage of reproductive organs.

"In our society, when a couple cannot have children, the woman is often blamed," Nagawa says. "Yet in many cases, there is an underlying medical condition that has gone undiagnosed for years."