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Endometriosis

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Key facts

- Endometriosis affects roughly 10% (190 million) of reproductive age women and girls globally.
- It is a chronic disease associated with severe, life-impacting pain during periods, sexual intercourse, bowel movements and/or urination, chronic pelvic pain, abdominal bloating, nausea, fatigue, and sometimes depression, anxiety, and infertility.
- There is currently no known cure for endometriosis and treatment is usually aimed at controlling symptoms.
- Access to early diagnosis and effective treatment of endometriosis is important, but is limited in many settings, including in low- and middle-income countries.

Overview

Endometriosis is a disease in which tissue similar to the lining of the uterus grows outside the uterus. It can cause severe pain in the pelvis and make it harder to get pregnant.

Endometriosis can start at a person's first menstrual period and last until menopause.

With endometriosis, tissue similar to the lining of the uterus grows outside the uterus. This leads to inflammation and scar tissue forming in the pelvic region and (rarely) elsewhere in the body.

The cause of endometriosis is unknown. There is no known way to prevent endometriosis. There is no cure, but its symptoms can be treated with medicines or, in some cases, surgery.

It causes a chronic inflammatory reaction that may result in the formation of scar tissue (adhesions, fibrosis) within the pelvis and other parts of the body. Several lesion types have been described:

- **superficial endometriosis found mainly on the pelvic peritoneum**
- **cystic ovarian endometriosis (endometrioma) found in the ovaries**
- **deep endometriosis found in the recto-vaginal septum, bladder, and bowel**
- **in rare cases, endometriosis has also been found outside the pelvis.**

Symptoms

Endometriosis often causes severe pain in the pelvis, especially during menstrual periods. Some people also have pain during sex or when using the bathroom. Some people have trouble getting pregnant.

Some people with endometriosis don't have any symptoms. For those who do, a common symptom is pain in the lower part of the belly (pelvis). Pain may be most noticeable:

- **during a period**
- **during or after sex**
- **when urinating or defecating.**

Some people also experience:

- **chronic pelvic pain**
- **heavy bleeding during periods or between periods**
- **trouble getting pregnant**
- **bloating or nausea**
- **fatigue**
- **depression or anxiety.**

Symptoms often improve after menopause, but not always.

Endometriosis symptoms are variable and broad, meaning that healthcare workers may not easily diagnose it. Individuals with symptoms may not be aware of the condition.

Causes

Endometriosis is a complex disease that affects many women globally from the onset of their first period (menarche) through menopause, regardless of ethnic origin or social status. Many different factors are thought to contribute to its development. At present endometriosis is thought to arise due to:

- **Retrograde menstruation is when menstrual blood containing endometrial cells flows back through the fallopian tubes and into the pelvic cavity at the time that blood is flowing out of the body through the cervix and vagina during periods. Retrograde menstruation can result in endometrial-like cells being deposited outside the uterus where they can implant and grow.**
- **Cellular metaplasia is when cells change from one form to another. Cells outside the uterus change into endometrial-like cells and start to grow.**
- **Stem cells can give rise to the disease, which then spreads through the body via blood and lymphatic vessels.**

Other factors may also contribute to the growth or persistence of ectopic endometrial tissue. For example, endometriosis is known to be dependent on estrogen, which increases the inflammation, growth and pain associated with the disease. However, the relationship between estrogen and endometriosis is complex since the absence of estrogen does not always mean the absence of endometriosis.

Impact

Endometriosis has significant social, public health and economic implications. It can decrease quality of life due to severe pain, fatigue, depression, anxiety and infertility. Some individuals with endometriosis experience debilitating pain that prevents them from going to work or school. Painful sex due to endometriosis can lead to interruption or avoidance of intercourse and affect the sexual health of affected individuals and their partners. Addressing endometriosis will empower those affected by it by supporting their human right to the highest standard of sexual and reproductive health, quality of life and overall well-being.

Prevention

At present, there is no known way to prevent endometriosis. Enhanced awareness, followed by early diagnosis and management may slow or halt the natural progression of the disease and reduce the long-term burden of its symptoms, including possibly the risk of central nervous system pain sensitization. Currently there is no cure.

Diagnosis

A careful history of menstrual symptoms and chronic pelvic pain provides the basis for suspecting endometriosis. Although several screening tools and tests have been proposed and tested, none are currently validated to accurately identify or predict individuals or populations that are most likely to have the disease. Endometriosis can often present symptoms that mimic other conditions and contribute to a diagnostic delay. Ovarian endometrioma, adhesions and deep nodular forms of disease often require ultrasonography or magnetic resonance imaging (MRI) to detect. Histologic verification, usually following surgical/laparoscopic visualization, can be useful in confirming diagnosis, particularly for the most common superficial lesions. The need for histologic/laparoscopic confirmation should not prevent the commencement of empirical medical treatment.

Treatment

Treatments to manage endometriosis can vary based on the severity of symptoms and whether pregnancy is desired. No treatments cure the disease.

A range of medications can help manage endometriosis and its symptoms.

Non-steroidal anti-inflammatory drugs (NSAIDs) and analgesics (painkillers) like ibuprofen and naproxen are often used to treat pain.

Hormonal medicines like GnRH-analogues and contraceptive (birth control) methods can also help control pain. These methods include:

- **pills**
- **hormonal intrauterine devices (IUDs)**
- **vaginal rings**
- **implants**
- **injections**
- **patches.**

These methods may not be suitable for those wanting to get pregnant.

Fertility medicines and procedures are sometimes used for those having difficulty getting pregnant because of endometriosis.

Surgery is sometimes used to remove endometriosis lesions, adhesions and scar tissues. Laparoscopic surgery (using a small camera to visualize inside the body) allows doctors to keep incisions small.

Discuss your treatment options with a health care provider.

Treatments are based on individual preferences and effectiveness, side effects, long-term safety, costs and availability.

Raising awareness can help people to be diagnosed early. Early treatment can slow or halt the natural progression of the disease and reduce the long-term symptoms.

In addition to talking to their doctor, people may find additional advice and emotional assistance in local patient support groups.

Some treatments are associated with side effects, and endometriosis-related symptoms can sometimes reappear after therapy ends. The choice of treatment depends on effectiveness in the individual, adverse side effects, long-term safety, costs, and availability. Most current hormonal management is not suitable for persons suffering from endometriosis who wish to get pregnant, since they affect ovulation.

Success in reducing pain symptoms and increasing pregnancy rates through surgery are often dependent on the extent of disease. In addition, lesions may recur even after successful eradication, and pelvic floor muscle abnormalities can contribute to chronic pelvic pain. Secondary changes of the pelvis, including the pelvic floor, and central sensitization may benefit from physiotherapy and complementary treatments in some patients. Treatment options for infertility due to endometriosis include laparoscopic surgical removal of endometriosis, ovarian stimulation with intrauterine insemination (IUI), and in vitro fertilization (IVF), but success rates vary.

Challenges and priorities

In many countries, the general public and most front-line healthcare providers are not aware that distressing and life-altering pelvic pain is not normal, leading to a normalization and stigmatization of symptoms and significant diagnostic delay. Patients who could benefit from medical symptomatic management are not always provided with treatments due to limited awareness of endometriosis among primary healthcare providers. Due to diagnostic delays, prompt access to available treatment methods, including non-steroidal analgesics (painkillers), oral contraceptives and progestin-based contraceptives is often not achieved. Due to limited capacity of health systems in many countries, access to specialized surgery for those who need it is sub-optimal. In addition, and especially in low and middle-income countries, there is a lack of multi-disciplinary teams with the wide range of skills and equipment needed for the early diagnosis and effective treatment of endometriosis. Although primary health care professionals should play a role in screening and basic

management of endometriosis, tools to screen and accurately predict patients and populations who are most likely to have the disease are lacking. In addition, many knowledge gaps exist, and there is need for non-invasive diagnostic methods as well as medical treatments that do not prevent pregnancy.

Addressing these issues is the current focus of endometriosis response.

WHO response

The World Health Organization recognizes the importance of endometriosis and its impact on people's sexual and reproductive health, quality of life and overall well-being. WHO aims to stimulate and support the adoption of effective policies and interventions to address endometriosis globally, especially in low and middle-income countries. WHO is partnering with multiple stakeholders, including academic institutions, non-state actors and other organizations that are actively involved in research to identify effective models of endometriosis prevention, diagnosis, treatment, and care. WHO recognizes the importance of advocating for increased awareness, policies and services for endometriosis, and collaborates with civil society and endometriosis patient support groups in this regard. WHO is also collaborating with relevant stakeholders to facilitate and support the collection and analysis of country- and region-specific endometriosis prevalence data for decision making.