The public health toll of endometriosis

Epidemiology: Endometriosis is a chronic disease that can affect women during their reproductive years. It is characterized by ectopic endometrial tissue that bleeds into the peritoneal cavity and triggers local inflammation, pseudocyst (“endometrioma”) formation, smooth-cell hyperplasia and peritoneal adhesion formation. Common sites include the ovaries, uterosacral ligaments, rectovaginal septum and peritoneum. Patients typically experience recurrent bouts of severe pelvic pain that radiate to the rectum or perineal area; the pain is often more severe during sexual intercourse. Paradoxically, some women with insidious, advanced disease marked by extensive peritoneal adhesions that bind and immobilize the reproductive organs have minimal pain but experience the sudden grief of discovering that they are infertile.

The cause of endometriosis is unknown. For decades it has been regarded as some sort of “mechanical mistake,” the consequence of menstrual regurgitation into the peritoneal cavity. It is also believed that some of the ectopic foci represent the scatter of hormonally responsive embryonic remnants along the Müller duct. A more recent theory is that implants of endometrial tissue in the pelvis are physiological in menstruating women and do not constitute disease until recurrent bleeding develops. There is also increasing evidence that endometriosis is part of a pleiotropic response of the reproductive organs to hormone imbalances. Normal ovarian steroidogenesis and impaired oocyte maturation. Although endometriosis causes considerable morbidity, little is known about its prevalence or risk factors other than risk increases with age and with exposure to menstruation (short cycles, longer duration of flow and reduced parity) and decreases with oral contraceptive use. A 1997 review of the literature identified only 3 studies that attempted to estimate the prevalence of endometriosis in the general population. These data suggested a prevalence in the range of 6.2% to 10.2. This rate is consistent with the prevalence reported in a 1988 study that looked at endometriosis-related disability among women in the US Army: active-duty patients required on average 15 days of sick leave per hospital admission related to endometriosis. The total lost duty time over 6 years was 21 746 days, at a cost of $2.6 million. At the time, the cost was sufficient for the authors to support the army’s policy of disqualifying as potential recruits women with a history of endometriosis.

Endometriosis takes a similar toll in the civilian population. Among respondents to the US National Health Interview Survey (1984–1992) who reported experiencing endometriosis, 50% had been bedridden by the disease for 17.8 days on average at some time during the 12 months before the survey. Comparable data are unavailable for Canadian women, but of the 21 723 hysterectomies performed in Ontario in 1992/93, about 10% were done because of endometriosis. This suggests that the disease represents a major burden.

Clinical management: A presumptive clinical diagnosis may be made on the basis of classic symptoms and tenderness elicited upon a vaginal or rectovaginal examination. The traditional “gold standard” for diagnosis is direct visualization of endometrial lesions during the course of laparoscopic or laparotomy surgery, although advances are being made in the development of less-invasive, office-based techniques such as transvaginal ultrasonography. Ultrasound and, increasingly, MRI are also used to characterize endometriomas and recurrent bleeding within the pelvis.

The goals of treatment are to prevent the pain and progression of endometriosis either through suppressive hormonal therapy or through surgical removal of ectopic foci. A review conducted in 1999 identified 4 small systematic reviews that compared continuous suppression of ovulation for 6 months (using danazol, gestrinenone, medroxyprogesterone acetate, dydrogesterone, oral contraceptives or gonadotrophin-releasing hormone analogues) and placebo. Except for dydrogesterone, all treatments were equally effective at reducing severe and moderate pain at 6 months, although the proportion of treated women who experienced adverse effects related to hypoestrogenism (hot flushes and vaginal dryness) or to androgenism (acne, weight gain, hirsutism) was high (11%–15%). The same review concluded that there was evidence supporting cystectomy for ovarian endometrioma and combined ablation of endometrial deposits and uterine nerves but that there was insufficient evidence supporting laparoscopic ablation of deposits on its own. The rate of pain relief after hysterectomy is reported to be 83%–97%.

Prevention: To reduce the public health impact of endometriosis, it is first necessary to understand it. In 1999 the Canadian Consensus Conference on Endometriosis determined that studies on the effects of this disease should be a priority area for future research. — Erica Weir, CMAJ

References