

Patients' report on how endometriosis affects health, work, and daily life

The objective of this study was to assess the burden of endometriosis by obtaining patient-reported outcome data describing the experience of living with this disease. Survey data from 107 women with self-reported, surgically diagnosed endometriosis showed that living with this disease may be characterized by physical limitations that disrupt health, work, and daily life. (*Fertil Steril*® 2010;93:2424–8. ©2010 by American Society for Reproductive Medicine.)

Key Words: Endometriosis, patient-reported outcomes, pelvic pain, menstrual pain, infertility, work performance

Endometriosis, the growth of endometrial tissue (glands and stroma) outside of the uterine cavity, causes intractable pelvic pain, dysmenorrhea, dyspareunia, and infertility (1). It is estimated that up to 80% of women with dysmenorrhea and up to 40% of infertile women have endometriosis (2, 3). The pelvic pain can be cyclic or chronic and often is incapacitating (4). Qualitative studies have shown that endometriosis symptoms have a substantial impact on the physical, emotional, and social well-being of patients, who are affected during the most productive years of their lives (5–12).

The high rates of hospital admissions, surgical procedures, and incidence of comorbid conditions make endometriosis a more costly public health problem than commonly known medical conditions in women such as migraine and Crohn's disease (13–17).

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The yearly total (direct plus indirect) cost of endometriosis has been estimated at €30 billion in Europe and \$22 billion in the United States, and direct costs have increased steadily (13, 18–20). Despite the fact that endometriosis is a common gynecologic disorder that poses a substantial economic impact to health care systems around the world, only a few patient-reported outcome studies have been conducted to quantify its impact (21–24). These studies concluded that endometriosis impairs health-related quality of life, specifically in areas related to physical, psychological, and social function.

The aim of this study was to determine the burden of disease by obtaining patient-reported outcome data describing the experience of living with this painful disease in patients from Puerto Rico, where a patient registry has existed since 2001. This study examined in particular the impact that endometriosis-related and/or co-existing symptoms had on the ability of patients both to participate in normal, daily life activities and to be able to work or be successful at work. The main health-related concerns affecting normal life activities of patients with endometriosis were identified. The study protocol and survey were approved by the Ponce School of Medicine Institutional Review Board.

Since 2001, the Endometriosis Research Program at the Ponce School of Medicine has been obtaining demographic and clinical information from patients with endometriosis, women with endometriosis symptoms, and controls recruited by obstetrics-gynecology referrals (29%), a patient support group (12%), and media announcements (web page, newspapers, magazines, radio, and TV; 59%). The Endometriosis Research Program registry consists of 2060 entries, of which 715 are patients reporting a surgical diagnosis of endometriosis, 246 are controls with no endometriosis, and the remaining are women who may have endometriosis. Subjects in this patient registry come from all regions of the island; however, they do not necessarily accurately represent the female population of Puerto Rico. An anonymous patient-reported outcome instrument was distributed randomly via postal mail (n = 200) or electronically to all the e-mail addresses in the Endometriosis Research Program (n = 361).

The questionnaire included questions in the following categories: demographic information and gynecologic profile; symptoms, diagnosis, and treatments; and impact on daily life activities and work performance. Only women reporting that their

endometriosis was diagnosed by laparoscopy or laparotomy were included in the analyses. The diagnosis of endometriosis was supported by questions regarding the surgical procedure, surgeon, and revised American Fertility Society endometriosis stage (25, 26). Symptoms were reported with use of a 36-item checklist. Dysmenorrhea was defined as “always or almost always suffering from pelvic pain during menses” and dyspareunia as “always or almost always suffering from pain during intercourse.” Painful symptoms were categorized as menstrual pain (pelvic pain felt “only during menses”), ovulatory pain (“during ovulation”), and nonmenstrual pain (“throughout the month”). When asked whether the pain interfered with daily life activities, patients who answered “yes” were categorized as having “incapacitating pain.” Infertility status was determined by asking patient’s perceptions regarding difficulty getting pregnant and by taking an obstetric history. Lifetime history of surgical procedures and treatments also was surveyed. A nine-item checklist asked which life activities they thought were affected by pain. Impact of symptoms on work performance was documented in four dimensions: [1] quality of work, [2] physical disability, [3] absenteeism, and [4] professional growth.

A total of 108 patients answered the survey, for a response rate of 24%. One patient was excluded because she did not report a surgical diagnosis. The patients surveyed represent 15% of the total number of patients in the Endometriosis Research Program registry. Patient characteristics were described, and frequency, means, and SD were calculated. Demographic, gynecologic, and clinical characteristics are summarized in Table 1. There were no differences in demographics (e.g., age, marital status, education) between respondents of the electronic versus the mailed questionnaires.

Logistic regression analysis was conducted to determine which endometriosis-related and/or coexisting symptoms were more likely to affect daily life activities and work performance of patients. The following dependent variables were studied, controlling for age as confounding factor: household chores, work, social activities, sexual relationships, studies, child care, sleeping, exercise, and appetite. Independent variables included in the model were those symptoms found to be associated significantly with impairment of daily life activities by univariate analysis (e.g., menstrual pain, incapacitating pain, abdominal pain, depression, dyspareunia, nausea). All tests were two-tailed, and alpha level was set at 0.05 for significance. Statistical analyses were done with use of SPSS 15.0 (SPSS Inc., Chicago, IL).

All patients in this study had symptoms, and 72% reported having eight or more endometriosis-related or coexisting symptoms, with dysmenorrhea, incapacitating pain, and dyspareunia being the most common (Table 1). Symptoms started during adolescence (11–19 years of age) for the majority of these patients. The mean delay in diagnosis in these subjects was 8.9 years (SD \pm 7.9 years). This study thus confirms a worrisome trend and worldwide public health problem: patients with endometriosis endure symptoms for years without the condition being diagnosed (8–12, 27–29). One important factor in this delay is that, as observed by others and us (Table 1), many patients consulted with five or more physicians before being given a diagnosis (29, 30). Lack of disease awareness is also an important issue. In our study, 65% of patients had never suspected having endometriosis and had never heard of the disease before surgery. Those who had heard about the condition did so through the media (n = 15, 14%) or a friend or family member

(n = 9, 8%). Therefore, our study adds evidence to support the need for more aggressive awareness campaigns to help spread the message that painful menstruation is not normal.

Most patients characterized their pain as nonmenstrual and reported that pain interfered with their daily life activities (incapacitating pain). Disease severity was moderate to severe for approximately 70% (n = 74). Interestingly, 40% (n = 43) of the respondents had a self-reported family history of endometriosis. This rate of family history is higher than what has been reported in other published studies of patients from Puerto Rico (20%) (31), Brazil (8.9%) (32), Japan (8.8%) (33), and the United States (8.1%) (34). The majority (71%; n = 76) of patients in this study have tried to get pregnant, and 90% of them (n = 68/76) reported having problems conceiving. However, only 48% (n = 33/68) sought infertility treatments, including superovulation (37%), artificial insemination (13%), surgery (3%), or a combination thereof (22%). Of those reporting problems conceiving, 65% (n = 44/68) did conceive. Seven out of 10 participants were nulliparous. Hysterectomy was reported by 17% (n = 18) of respondents (age range: 31–46 years).

Almost all (96%) of the participants had private medical insurance, which generally covered surgical procedures (n = 117/126, 93%) but not medical treatments (n = 108/214; 50%). Patients reported a total of 248 surgeries (average of 2.3 procedures per patient). The most common treatments for endometriosis reported were GnRH agonists (n = 62, 57.9%) and oral contraceptives (n = 43, 40.2%). Reported restrictions on coverage included limitations to a certain number of procedures and preset limits in total health care costs. Commonly, study subjects reported that full coverage of endometriosis-related treatments (e.g., GnRH agonists) and procedures (e.g., laparoscopy) was denied because they were considered wrongly as being infertility treatments. In Puerto Rico, health insurance companies usually do not cover contraceptive drugs (even when prescribed as a treatment for endometriosis) or treatments or procedures related to infertility.

Patients in this study commonly reported that endometriosis-related and coexisting symptoms disrupted all aspects of their daily lives. Many felt physical limitations to conducting day-to-day tasks, such as household chores (n = 84, 79%), sexual relationships (n = 76, 71%), work (n = 71, 66%), appetite (n = 58, 54%), exercise (n = 60, 56%), sleeping (n = 58, 54%), and social activities (n = 51, 48%). Of those women who had children, 45% (n = 15/33) reported that child care-related activities were affected. This study supports previous findings showing that patients with endometriosis commonly endure both painful symptoms and infertility, both of which could affect the quality of life and mental health of the affected women negatively at rates that are higher than those reported by healthy women or women with other gynecologic disorders (6–12, 35, 36).

It is to be expected that a painful, chronic disease such as endometriosis also would have a substantial negative impact on work performance, as has been shown for other health problems (37–39). For endometriosis, there is paucity of data in that regard, although qualitative studies document patient-reported negative experiences at work (5). The majority of patients in this study (n = 87/103, 85%) perceived that there was a noticeable decrease in the quality of their work and almost 20% (n = 19/101) reported being unable to work because of pain. Notably, 69% (n = 68/101)

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