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

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### NARRATIVE ABSTRACT

The objective of this study was to assess the burden of endometriosis by obtaining Patient Reported Outcome (PRO) data describing the experience of living with this disease. Survey data from one hundred and seven 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.

### Keywords

Endometriosis; patient-reported outcomes; pelvic pain; menstrual pain; infertility; work performance

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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 is often incapacitating (4). Qualitative studies have shown that endometriosis symptoms have a substantial impact on the physical, emotional, and social wellbeing 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). The yearly total (direct plus indirect) cost of endometriosis has been estimated at €30 billion in Europe and \$22 billion in the US, and direct costs have increased steadily (13,18-20). Despite the fact

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### CAPSULE

The experience of living with endometriosis may be characterized by physical limitations that affect health, work and daily life.

that endometriosis is a common gynecologic disorder that poses a significant economic impact to health care systems around the world, only a few Patient-Reported Outcome (PRO) studies have been conducted to quantify its impact (21-24). These studies concluded that endometriosis impairs health related quality of life (HRQoL), specifically in areas related to physical, psychological, and social function.

The aim of this study was to determine the burden of disease by obtaining PRO data describing the experience of living with this painful disease in patients from Puerto Rico, where a patient registry exists since 2001. This study examined in particular the impact that endometriosis-related and/or coexisting 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 endometriosis patients were identified. The study protocol and survey was approved by the Ponce School of Medicine (PSM) Institutional Review Board (IRB).

Since 2001, the Endometriosis Research Program (ERP) at PSM has been obtaining demographic and clinical information from patients with endometriosis, women with endometriosis symptoms, and controls recruited by Ob-Gyn referrals (29%), a patient support group (12%), and media announcements (web page, newspapers, magazines, radio, and TV; 59%). The ERP registry consists of 2,060 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 PRO instrument was distributed randomly via postal mail (n=200) or electronically to all the e-mail addresses in the ERP (n=361).

The questionnaire included questions in the following categories: *Demographic information and gynecological profile; Symptoms, diagnosis, and treatments; and Impact on daily life activities and work performance*. Only women reporting having been diagnosed by laparoscopy or laparotomy were included in the analyses. The diagnosis of endometriosis was supported by questions regarding the surgical procedure, surgeon, and rAFS endometriosis stage (25,26). Symptoms were reported using 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 (MP; pelvic pain felt “only during menses”), ovulatory pain (OP; “during ovulation”), and non-menstrual pain (NP; “throughout the month”). When asked if the pain interfered with daily life activities, patients who answered “yes” were categorized as suffering from “incapacitating pain” (IP). 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 were also surveyed. A 9-item checklist asked which life activities they felt were affected by pain. Impact of symptoms on work performance were documented in four dimensions: i) quality of work, ii) physical disability, iii) absenteeism, and iv) 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 ERP registry. Patient characteristics were described and frequency, means and standard deviation (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, childcare, sleeping, exercise, and appetite. Independent variables included in the model were those symptoms found to be significantly associated with impairment of daily life activities by univariate analysis (e.g., MP, IP, abdominal pain, depression, dyspareunia, nausea). All tests were two-tailed, and alpha level was set at 0.05 for significance. Statistical analyses were done using SPSS 15.0 (SPSS Inc., Chicago, IL).

All patients in this study were symptomatic and 72% reported having  $\geq 8$  endometriosis-related or coexisting symptoms, being dysmenorrhea, incapacitating pain, and dyspareunia the most common (Table 1). Symptoms started during adolescence (11-19 y/o) for the majority of these patients. The mean delay in diagnosis in these subjects was 8.9 years (SD  $\pm 7.9$ ). This study thus confirms a worrisome trend and worldwide public health problem: patients with endometriosis endure symptoms for years without being diagnosed (8-12,27-29). One important factor in this delay is the fact that, as observed by others and us (Table 1), many patients consulted with five or more physicians before being diagnosed (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/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 non-menstrual (NP) and reported that pain interfered with their daily life activities (IP). 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 US (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 super-ovulation (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 y/o).

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 (OC) (n=43, 40.2%). Reported restrictions on coverage included limitations to a certain number of procedures and pre-set 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 since they were wrongly considered as being infertility treatments. In Puerto Rico, health insurance companies do not usually cover contraceptive drugs (even when prescribed as a treatment for endometriosis) or treatments/procedures related to infertility.

Patients in this study commonly reported that endometriosis-related and co-existing 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 childcare-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 negatively affect the quality of life and mental health of the affected women at rates that are higher than those reported by healthy women or women with other gynecological disorders (6-12,35,36).

It is to be expected that a painful, chronic disease such as endometriosis would also 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 due to pain. Notably, 69% (n=68/101) of the patients reported that they continue working despite feeling pain, a phenomenon that has been termed “presenteeism” (40). Those patients who admitted missing workdays (n=64, 60%) reported a mean of 2.8 days per month (SD±3.7), equivalent to 33.6 days per year, due to being “unable to perform physical activities”. Yearly, patients missed work an average of 19.3 days (SD±19.3) because of treatments, surgeries, and recovery. These absenteeism rates are higher than those reported for other pain conditions such as headaches, arthritis and back pain (39).

The majority of patients reported a noticeable decrease in the quality of their work due to endometriosis-related and/or coexisting symptoms (n=87/103, 84%), and 1 in 5 reported being temporarily disabled due to symptoms. Forty % of patients (n=36/91) perceived that as a direct consequence of this disease their career growth has been negatively affected due to high rates of absenteeism and/or low performance (n=15), not being promoted (n=8), not receiving merit/excellence bonuses (n=3), missing professional seminars (n=2), and loss of clients (n=1). Three patients reported being “totally incapacitated” and three were dismissed from or quit their jobs due to symptoms.

Logistic regression analysis showed that symptoms significantly predict negative impact on daily life activities, work performance, and social life of patients (all  $p < 0.05$  or  $0.01$ ). Patients with menstrual pain (OR=22.8, 95% CI: 2.3–226.7), incapacitating pain (OR=35.2, 95% CI: 4.3–274.6), depression (OR=17.2, 95% CI: 2.2–142.9), and abdominal pain (OR=5.2, 95% CI: 2.3–226.7) were more likely to report that their work (both at home and professionally) was affected by endometriosis. Those patients suffering from dyspareunia (OR=39.8, 95% CI: 8.4–188.1) were more likely to report negative effects of disease on their social and sexual lives. Finally, nausea (OR=6.4, 95% CI: 2.2–18.2) and depression (OR=4.3, 95% CI: 1.5–11.9) were significantly associated with changes in appetite. Therefore, menstrual pain, incapacitating pain, abdominal pain and depression were identified as predictors of poor performance at work and home. In addition, incapacitating pain and dyspareunia predict impairments in social and sexual aspects of life.

In drawing conclusions from this study, it is important to consider the low response rate, relatively small sample size, and the fact that the survey was answered predominantly by patients who were substantially affected by the disease (e.g., all respondents were symptomatic; most presented at least eight endometriosis-related and/or co-existing symptoms; most reported suffering from constant, non-menstrual pain; depression rates were as high as 50%). Therefore, the findings of this study may not be representative of all patients with endometriosis, but rather apply only to those with more severe disease. Also of note, the majority of responders were well-educated women. This specific bias has been noted by other studies (29,30). Recall and reporting errors may have also occurred,

especially when trying to remember the details of medical events (when did they occur, what were the costs), such as treatments, procedures, and days lost from work (41-43). Finally, the low response rate observed may be explained by cultural issues such as the low awareness of the importance of research, which may explain the poor participation rates in biomedical research studies that have been previously reported in Hispanic minorities (44).

Despite these limitations, this study gathered important patient-reported outcomes (PRO) data supporting the notion that endometriosis-related and/or co-existing symptoms could negatively affect the general wellbeing and work performance of affected women. Efforts to improve delivery of care for patients with endometriosis, leading to a prompt diagnosis and effective management of symptoms and complications, should become a research priority. Such efforts should be driven by PRO research on the economic, emotional, and social costs of endometriosis and that will also provide valuable information about effectiveness of clinical management and therapeutic approaches (45-49). These data are important to help establish endometriosis as an important global public-health problem, irrespective of culture, race or ethnicity.

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TABLE 1

Demographics, gynecological and clinical profile of women with self-reported surgically-diagnosed endometriosis in Puerto Rico

Characteristics, N = 107	N (%)
Age, years <sup>a</sup>	34.5 ± 6.6
<b>Education</b>	
High school	8 (7.5)
Some college, technical career	45 (42.5)
College graduate	36 (34)
Graduate studies	17 (16)
<b>Marital Status</b>	
Single	28 (27.2)
Married, committed relationship	62 (60.2)
Divorced/Widow	13 (12.6)
<b>Menstrual cycle characteristics</b>	
Regular cycle	78 (72.9)
Cycle length, days <sup>a</sup>	28.5 ± 7.9
Menstrual flow length, days <sup>a</sup>	5.5 ± 1.7
Age at menarche, years old <sup>a</sup>	11.5 ± 1.6
<b>Obstetric history</b>	
Age at first child birth, years old <sup>a</sup>	26.3 ± 4.7
Nulliparous	74 (69.2)
Live birth (≥1)	33 (30.8)
Miscarriage (≥1)	23 (21.5)
<b>Other gynecological and intestinal conditions</b>	
Chronic Pelvic Pain	70 (65.4)
Constipation	64 (59.8)
Abnormal Uterine Bleeding	34 (31.8)
Uterine fibroids	26 (24.3)
Adenomyosis	6 (5.6)
Cancer	0 (0)
<b>Types of pelvic pain</b>	
Menstrual Pain (MP)	27 (27.6)
Non-menstrual Pain (NP)	70 (65.4)
Ovulatory Pain (OP)	8 (7.0)
<b>Surgical procedures</b>	
Laparoscopy	94 (87.9)
Laparotomy	24 (22.4)
Hysterectomy	18 (16.8)



Characteristics, N = 107	N (%)
<i>Age at diagnosis, years<sup>a</sup></i>	26 ± 7.2
<i>Age at onset of symptoms, years<sup>a</sup></i>	18 ± 6.8
<i>Diagnostic delay, years<sup>a, b</sup></i>	8.9 ± 7.9
<i>Physicians consulted before diagnosis</i>	
1-2	40 (37.4)
3-4	25 (23.4)
5-9	42 (39.2)
<i>Number of visits to the physician before diagnosis, n<sup>a</sup></i>	
1-2	72 (67.3)
3-4	29 (27.1)
≥5	5 (4.7)
<i>Endometriosis-related symptoms</i>	
Dysmenorrhea	101 (94.4)
Incapacitating Pain	78 (74.3)
Dyspareunia	75 (70.1)
Infertility	68 (63.6)
<i>Most common co-existing symptoms</i>	
Back and leg pain	81(75.7)
Gastrointestinal upsets/Diarrhea	74 (69.2)
Dizziness/headaches	65 (60.7)
Depression	55 (51.4)
Low energy/fatigue	48 (44.9)
Dyschezia	48 (44.9)
Vaginal pain	38 (35.5)
Dysuria	24 (22.4)

<sup>a</sup> Mean ± SD.

<sup>b</sup> Diagnostic delay was calculated by subtracting the age at onset of symptoms from the age at laparoscopic diagnosis for each patient.