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Self-reported prevalence of endometriosis and its symptoms among Puerto Rican women

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Abstract

Objective—To determine the prevalence of endometriosis and its symptoms in a Puerto Rican cohort, and to describe the menstrual, obstetric, and clinical profiles of the women.

Methods—A self-administered questionnaire was given to 1285 Puerto Rican women. Categorical variables were compared using χ^2 analysis or Fisher exact test.

Results—There were 57 self-reported cases of endometriosis (48 surgically confirmed) among 1193 valid questionnaires, for a point prevalence of 4.0%. A diagnosis of endometriosis was significantly associated with dysmenorrhea, dyspareunia, and chronic pelvic pain, but not with menstrual cycle characteristics. Undiagnosed women commonly reported signs and symptoms of endometriosis.

Conclusions—The estimated prevalence of endometriosis in Puerto Rico is 4.0%, comparable to what has been reported in other populations. Endometriosis symptoms were common in the population surveyed, indicating the need for increased awareness and development of public health policies leading to early diagnosis and appropriate management.

Keywords

Endometriosis; Epidemiology; Prevalence; Puerto Rico

1. Introduction

Endometriosis is a common gynecological disease that causes intractable pelvic pain and infertility in millions of women in their reproductive years. However, the basic epidemiology of endometriosis has been difficult to assess for many reasons, including that diagnosis can only be made definitively by direct visualization during surgery and critically depends on the

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Synopsis:
The estimated prevalence of endometriosis in Puerto Rico is 4.0%; its symptoms are common in undiagnosed women indicating a need for increased awareness of the disease.

clinical expertise of the surgeon; that a large proportion of women with the disease may be asymptomatic, which may lead to an underestimation in the number of cases; and that culturally, women are often misguidedly taught to view severe pain during menses as normal and so do not seek medical care [1–4]. As a result, many affected women remain undiagnosed; therefore, the true prevalence rate of this disease in the general population is unknown. In fact, prevalence rates of endometriosis vary widely from study to study, depending on the population surveyed. Prevalence rates of endometriosis range from 0.7% to 45% in surveys of asymptomatic women [5], 20% to 40% in infertile women [6], 6% to 18% in women undergoing sterilization [7], and 15% to 70% in patients with chronic abdominal pain [8–15]. In general, endometriosis has been estimated to affect approximately 10% of the general female population in the United States, with a reported annual incidence of 1.9 cases per 1000 women, aged 15 to 49 years [16–17].

Studies have shown that African-American women have lower incidence rates than Caucasian Americans, while Asian Americans seem to have higher rates than Caucasian women [18–21]. For Hispanic women however, comparative data are lacking, although this group now represents the fastest growing minority population in the United States [22]. The present study was conducted to determine the prevalence of endometriosis in Puerto Rican women, a largely understudied population. Demographics, menstrual cycle characteristics, and reproductive history of study subjects were obtained.

2. Materials and methods

A self-administered, anonymous questionnaire was given to 1285 Puerto Rican women. Participants were recruited at health fairs, universities, private companies, and shopping centers. The questionnaire inquired about demographics, gynecologic and obstetric history, menstrual cycle characteristics, endometriosis-related symptoms, clinical history (personal and family), and life-style factors. The diagnosis of endometriosis was supported by questions regarding any reported diagnostic procedure. Infertility status was defined by patients' impression only; we did not inquire about the use of assisted reproduction technologies. This study was approved by the Institutional Review Board of the Ponce School of Medicine.

Statistical analysis was performed using SPSS version 12 (SPSS Inc, Chicago, IL, USA). Univariate statistical analyses were performed to describe the study population. Frequencies and proportions of categorical variables of those with and without disease were compared using either Pearson's χ^2 test or Fisher exact test, where appropriate. Continuous variables were compared using the *t* test. The level of statistical significance was set at 0.05 in all of the analyses.

3. Results

We identified 57 cases of endometriosis from a total of 1285 questionnaires. Four cases did not identify surgery as the diagnostic method used, and 5 cases did not answer the question referring to method of diagnosis, leading to a total of 48 surgically-confirmed cases of endometriosis. Of the 1285 participants, 92 did not answer the question regarding diagnosis; therefore, the estimated point prevalence of endometriosis in Puerto Rico is 4.0% (48/1193 valid questionnaires). The majority of cases (33.3%) were 30–39 years old, had at least 1 year of college (55.1%), and were married (58.2%). Most cases (84.0%) had private medical insurance. The mean age of the cases was 33.9 years, (range, 15–68 years) (Table 1).

We then compared the demographic, gynecologic, and obstetric profiles of patients with endometriosis with those of the general female population surveyed (women without a diagnosis of endometriosis). With regards to demographics, significant differences between

cases and the general population were observed in all factors studied, including age ($P<0.01$), educational level ($P<0.05$), marital status ($P<0.001$), and possession of medical insurance ($P<0.001$) (Table 1). No significant differences were observed in any of the menstrual cycle characteristics studied (menarche, regularity, cycle length, menstrual flow length) between the 2 groups (Table 2), despite the widely accepted notion that having a longer length of menses, an earlier menarche, and having shorter cycle length are risks factors for endometriosis [23]. There were also no differences observed between cases and the general population in other obstetric factors, including mean age at first delivery (22.8 years; range, 16–39 years vs. 21.7 years; range, 13–39 years); those with at least 1 miscarriage (21.9% vs. 31%); present oral contraceptive use (19.6% vs. 20%); and family history of endometriosis (34.6% vs. 23.2%), respectively. Of the cases, 18.9% did not have children, compared to 10.2% of the general population, but this difference was not significant. In fact, 59.5% of cases and 61.7% of the general population reported having 2 or more children. Patients with endometriosis were more likely to report a past use of oral contraceptives (84.2% vs. 45.0%; $P<0.001$) and having had a hysterectomy (19.6% vs. 3.3%; $P<0.001$) than women from the general population. The most common gynecological comorbidities in the population of endometriosis patients were ovarian cysts, migraines, and gynecological infections (Table 3).

In regards to clinical symptoms, a significant number of cases with endometriosis reported dysmenorrhea, dyspareunia, problems in conceiving, and chronic pelvic pain. Endometriosis symptoms were also commonly reported by undiagnosed women (Table 4). Significant differences were observed between the groups in the prevalence of all symptoms, except for severe dysmenorrhea.

4. Discussion

This study represents the first assessment of the basic epidemiology of endometriosis in Puerto Rico, a representative Hispanic population. By conducting a survey of Puerto Rican women, we estimated that the prevalence of endometriosis in this cohort is 4.0%. This number is within what has been reported worldwide. Contrary to what has been shown in other populations, no associations were observed between a diagnosis of endometriosis and any of the menstrual cycle characteristics surveyed, including age at menarche, menstrual cycle length, and duration of menses. Significant associations were observed between endometriosis and dysmenorrhea, dyspareunia, fertility problems, and chronic pelvic pain. Hysterectomies were common among the patients surveyed (19.6%). This latter finding is in accordance with a United States Department of Health and Human Services report that the incidence of endometriosis-related hysterectomies increased by 120% between 1970 and 1984 [24].

Approximately 20% of the women with endometriosis did not have children at the time of the study, compared to 10% of women without the disease. Moreover, a smaller proportion of cases, compared with women from the general population, reported having had at least 1 miscarriage (21.9% vs. 31.0%). However, endometriosis cases were more likely to answer affirmatively to the question “Have you had difficulties in getting pregnant?” (70.6% vs 25.2% of the general population). As we did not inquire about the use of assisted reproduction technologies nor about how long it took to achieve pregnancy, we cannot assume that the perception of being infertile is higher in patients with endometriosis based only on the number of children that they have borne. More studies that will look in detail at the endometriosis-related infertility trends in this population are required.

Interestingly, endometriosis symptoms such as dysmenorrhea, severe pelvic pain during menses, and dyspareunia were commonly reported by the general population studied. Of note, the prevalence of severe menstrual pain was not significantly different between the groups. These observations are not surprising if the many limitations to diagnosis—cultural, economic,

and social—are considered. Cultural perceptions that pain with menses, even if severe, is normal may result in delays in diagnosis. In many societies, including Hispanic countries, gynecological issues are generally viewed as taboo, which may deter women from seeking medical help. In addition, the current, often restrictive, regulations of the public health system in Puerto Rico may interfere with timely referrals to specialists, which may further delay—or even prevent—diagnosis. This view is supported by our observation that approximately 40% of the women in the general population group received either the governmental health plan or had no insurance at all.

As occurs in all epidemiological studies of endometriosis, cases are likely to be missed as physician expertise is an important factor for accurate diagnosis [25,26]. Moreover, it has been shown that a significant number of patients may not show any symptoms at all; such cases will remain undiagnosed until another health issue arises that requires pelvic surgery (e.g., infertility, abnormal uterine bleeding, or uterine fibroids). The present study is limited by the fact that the self-reported status of being a patient with endometriosis was not verified by a review of medical records. In an effort to validate diagnosis, the questionnaire asked specific questions about the method of diagnosis and treatments, which allowed us to exclude from the analysis those questionnaires that did not meet the inclusion criteria of surgical diagnosis. If these limitations, as well as the cultural, economical, and social barriers to diagnosis, are taken into account, it should be expected that the prevalence rate of endometriosis in this Puerto Rican population reported here is, at best, underestimated.

This study was conducted using a convenience sample of subjects selected on the basis of their availability. Women who approached an information table were asked to complete a survey about women's health. Using this approach, we collected only 3 incomplete questionnaires. It is important to note that a limitation of this sampling method is that data may not be representative of the target population; it is likely that women who approached the information table and answered the questionnaire were those most interested in the topic, knew someone with the disease, or were themselves patients with endometriosis. Due to the lack of a patient registry and background knowledge of the magnitude of this problem in Puerto Rico, and the difficulties in the diagnosis of this condition, taking a probabilistic sample of this patient population was not possible. However, we were able to include women from all age groups and all socioeconomic strata in Puerto Rico by conducting the study in places such as community-based health fairs (predominantly attended by a low-income, medically indigent population that visit such fairs to seek free health-related services), the state university (attended by students from all social strata), and shopping malls (visited predominantly by a younger, middle/upper class population). In summary, this, the first and—to our knowledge—only study ever conducted on the epidemiology of endometriosis in the Puerto Rican population, has obtained important data and insights about this significant women's health issue that will promote additional research in this area.

Despite its limitations, our approach allowed us to obtain important data in a relatively quick and economical way. Our findings are expected to impact public health campaigns geared towards early diagnosis/management of reproductive problems in the Puerto Rican and other Hispanic populations. In view of the fact that endometriosis is a progressive disease, it is critical to raise awareness of it and the consequences of a delayed diagnosis in the general population, as well as in the medical community beyond gynecologists (e.g., nurses, emergency room specialists, pediatricians). Such consequences include significant damage to the reproductive organs and a decrease in the fertility potential of patients, as well as detrimental effects on the emotional wellbeing and mental health of those living in pain. The first indispensable step to reaching this goal is to convincingly establish endometriosis as an important public health problem in Puerto Rico, which was the main goal of this study.

In summary, this is an exploratory study that aimed to describe for the first time the gynecological, clinical, and demographic profiles of endometriosis patients versus a sample of the general female population in Puerto Rico. We estimate the prevalence of endometriosis at 4.0% in this population, although this number may be higher if we take into consideration the high prevalence of endometriosis-specific symptoms in the general female population of the island. Our data also suggest that endometriosis is a common gynecological condition in Puerto Rico, that menstrual cycle characteristics may not be associated with endometriosis in all populations, and most importantly, that a significant proportion of women may be undiagnosed. Taken together, these results will not only help us better understand this enigmatic disease, but will lead efforts to increase awareness and develop public health policies that will result in the early diagnosis and appropriate management of patients with endometriosis.

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Table 1

Demographic characteristics of patients with endometriosis and of the general female population in Puerto Rico

Characteristics	General population (no endometriosis) (*n*=1228)	Endometriosis patients (*n*=57)	*P* value
Age group, years	27.3 ± 10.4	33.3 ± 10.2	
≤ 19	17.6	8.8	
20–29	45.7	31.6	<0.01
30–39	18.6	33.3	
40–49	13.3	19.3	
≥50	4.8	7.0	
Education level, %			
1 to 12th grade	20.1	13.0	
1 to 4 years of college	71.2	66.6	<0.05
Graduate education	8.7	20.4	
Marital Status, %			
Single	51.6	23.6	
Married	39.1	58.2	<0.001
Divorced	7.8	18.2	
Widowed	1.5	0.0	
Medical Insurance, %			
Private	61.7	84.0	
Public Health System	36.4	16.0	<0.001
No insurance	1.9	0.0	

Table 2

Menstrual cycle characteristics of patients with endometriosis and of the general female population in Puerto Rico

Characteristics	General population (no endometriosis) (*n*=1228)	Endometriosis patients (*n*=57)	*P* value
Age at menarche, mean (range)	11.8 (8–19)	11.7 (9–15)	
≤ 8 years	2.1	5.3	
9–11 years	38.8	38.6	NS
12–13 years	46.3	42.1	
≥14 years	12.8	14.0	
Cycle, %			
Regular	70.2	58.9	NS
Irregular	29.8	41.1	
Menstrual cycle length			
≤ 21 days	6.4	7.8	
22–26 days	12.4	15.7	NS
27–30 days	67.8	58.8	
≥ 31 days	13.4	17.7	
Length of menses, mean (range)	5.4 (2–19)	5.8 (3–19)	
Short (1–4 days)	29.4	36.8	NS
Average (5–6 days)	48.7	40.4	
Long (≥7 days)	21.9	22.8	

Table 3

Prevalence of gynecological and non-gynecological diseases in patients with endometriosis and in the general female population in Puerto Rico

Disease	General population (no endometriosis) (%, *n*=1228)	Endometriosis patients (%, *n*=57)
Cancer	0.6 (7 breast, 1 cervix)	1.8 (1 cervix)
Uterine fibroids	4.9	8.6
Gynecological infections	18.9	10.9
Abnormal PAP smear	5.5	6.3
Ovarian cysts	16.8	21.9
Abnormal uterine bleeding	6.7	8.6
Asthma	17.1	8.3
Migraines	11.3	16.7
Allergies	4.7	0.0
Hypertension	7.6	8.3
Diabetes	5.8	4.2

Table 4

Endometriosis-related symptoms of patients with endometriosis and of the general female population of Puerto Rico

	General population (no endometriosis) (%, *n*=1228)	Endometriosis patients (*n*=57)	*P* value
Dysmenorrhea	59.3	82.5	<0.001
Severe dysmenorrhea	52.9	65.9	NS
Dyspareunia	20.0	52.0	<0.001
Problems to conceive	25.2	70.6	<0.001
Chronic pelvic pain	22.9	80.0	<0.001