Diagnostic experience among 4,334 women reporting surgically diagnosed endometriosis

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Objective: To determine whether first physician seen and symptoms beginning in adolescence have an impact on the diagnostic experience of endometriosis.

Design: Cross-sectional study of self-reported survey data.

Setting: Academic research.

Patient(s): Four thousand three hundred thirty-four Endometriosis Association Survey respondents reporting surgical diagnosis of endometriosis.

Intervention(s): None.

Main Outcome Measure(s): Specialty of first physician seen, timing of onset of symptoms, time to seeking medical care and to diagnosis, number of physicians seen, and satisfaction with care.

Result(s): Almost all respondents reported pelvic pain. Fifty percent first saw a gynecologist and 45% saw a generalist for symptoms related to endometriosis. Two thirds reported symptoms beginning during adolescence; they waited longer to seek medical care than adults did. Those seeing a generalist first took longest to get diagnosed; those seeing a gynecologist first saw fewer physicians. Sometime before diagnosis, 63% were told nothing was wrong with them.

Conclusion(s): Women and girls who reported seeing a gynecologist first for symptoms related to endometriosis were more likely to have a shorter time to diagnosis, to see fewer physicians, and to report a better experience overall with their physicians. The majority reported symptoms beginning during adolescence, also reporting a longer time and worse experience while obtaining a diagnosis. (Fertil Steril® 2009;91:32–9. ©2009 by American Society for Reproductive Medicine.)

Key Words: Endometriosis, diagnosis, physician specialty, adolescence, pelvic pain, symptoms, health care

Endometriosis, the presence of endometrial tissue growing outside of the uterus, has been estimated to affect 10% to 15% of reproductive-age women (1, 2) and 70% of women with chronic pelvic pain (3, 4). Symptoms related to endometriosis vary but most commonly include chronic pelvic pain and subfertility. The time from the onset of symptoms to diagnosis is disturbingly long, and although some report that it is on the decline (5), others indicate that it can last up to 10 to 12 years in the United States (6, 7). There are many possible reasons for the long diagnostic experience, including the variety of pain symptoms (8), which may be related in part to coexisting conditions (6, 9), whether or not subfertility is present (5, 10), and that surgery has been the gold standard for diagnosis. Ballard et al. recently reported that pain symptoms beginning in adolescence and suppression of symptoms with hormones, as well as a perception that the patient is not actually ill, also could lengthen the time to diagnosis (11). Women who first experience symptoms at a younger age typically have a longer time to diagnosis compared with those who experience their first symptoms later in life (5). Fortunately, the long time to diagnosis for adolescents is not universal (12, 13).

In a study of both gynecologists and generalists at a women's health clinic, Lentz et al. found that gynecologists were nearly nine times as likely to diagnose pelvic pain and

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more than eight times more likely to diagnose dysmenorrhea than internists (14). It has also been reported that adult women with pain and an eventual diagnosis of endometriosis have the largest number of diagnoses and highest rates of referrals in the United Kingdom system (15). Although these studies may support the importance of physician specialty for the diagnosis of endometriosis, the first physician a woman sees, and consequently the initial diagnostic label she receives, may play a larger role.

This study, therefore, investigates whether the first physician a woman sees for symptoms related to endometriosis affects her reported diagnostic experience. We hypothesized that women who report having seen an obstetrician/gynecologist first would report a shorter time to diagnosis, seeing fewer physicians, and overall greater satisfaction with medical care. We also investigated how onset of endometriosis-related symptoms during adolescence affects the diagnostic experience of women with endometriosis.

MATERIALS AND METHODS

Information was gathered from a questionnaire developed by the Endometriosis Association (Milwaukee, WI) and mailed in 1998 to approximately 10,000 of its North American members. The 4,745 respondent questionnaires were entered into the Clinical Trials Database at the National Institute of Child Health and Human Development (Bethesda, MD). To ensure confidentiality, all questionnaires were made anonymous and deidentified. The study was approved as exempt from review by the Investigational Review Board of the Office of Human Subjects Research at the National Institutes of Health.

The 10-page survey included questions on demographic characteristics; symptoms related to endometriosis including pain, infertility, and bleeding; and urinary, bowel, and systemic symptoms. Pain symptoms were grouped into three categories: pain at the time of menstruation, at ovulation, or at other times in the menstrual cycle. Reported bleeding symptoms included heavy bleeding and premenstrual spotting. Urinary symptoms included only pain with urination, and bowel symptoms were defined as the presence of abdominal pain, rectal pain, diarrhea, abdominal bloating, painful bowel movements, or other intestinal upset at the time of menses. Nausea or stomach upset and dizziness or headaches at time of menses were characterized as systemic symptoms.

Respondents reported the order and specialty of the first four physicians they saw for endometriosis-related symptoms by selecting from a list of specialists or indicating other types of physicians that were not listed. Independent of the types of physicians seen, they also reported the total number of physicians seen before diagnosis and provided qualitative information about satisfaction with their physicians overall, taking everything into account. How seriously patients reported they were taken by physicians and how helpful physicians had been were grouped into two categories: not taken seriously and physician not helpful, or taken seriously and physician helpful.

Age at onset of pelvic symptoms was gathered in 5-year categories ranging from “under 15” years to “45 years or older.” Respondents reported how long they waited to seek medical attention after experiencing endometriosis-related symptoms, the time it took for diagnosis from seeking medical attention, and the method and year of diagnosis with endometriosis.

Those reporting surgical diagnosis of endometriosis were classified into the following three groups of first physician seen: gynecologist, generalist, and other. Obstetrician/gynecologists ($n = 2141$) and reproductive endocrinologists ($n = 39$) were classified as gynecologists. Generalist was defined as a general/family practitioner ($n = 1897$), internist ($n = 36$), or pediatrician ($n = 22$). All other specialists, including gastroenterologists ($n = 46$), emergency department physicians ($n = 28$), urologists ($n = 23$), surgeons ($n = 9$), psychiatrists/psychologists ($n = 5$), rheumatologists ($n = 4$), neurologists ($n = 1$), nurse/nurse practitioner/physician’s assistants ($n = 4$), and all other nonspecified specialists ($n = 79$) were grouped into the “other” category.

Those selecting onset of pelvic symptoms as “under 15” and “15–19” years old were categorized as adolescents, and all others (age 20–45+ years) were classified as adults at onset of symptoms. Age at diagnosis was determined from year of birth and year of diagnosis.

Data Analysis

Subject characteristics were described by simple descriptive statistics and frequency distributions. Categorical data were compared by χ^2 tests, and continuous data were compared with use of generalized linear models for unbalanced designs in analysis of variance (ANOVA). Least-squares means adjusting for main effects were computed and are reported, unless otherwise indicated. Comparisons of continuous data between adolescent and adult age of onset of symptoms were compared by using *t*-tests. A χ^2 test for trend was performed when appropriate. Post-hoc comparisons were adjusted for multiple comparisons with use of the Bonferroni correction method.

Demographic characteristics, such as race, age at time of survey completion, education, and income, which may influence the type of physician seen first, were analyzed for differences, and subsequent analyses were adjusted for these potential confounders. Analyses involving the comparison of adolescent versus adult onset of symptoms were first conducted for differences in age at time of survey completion, then adjusted if appropriate. Logistic regression modeling or generalized linear modeling in ANOVA was used to adjust for potential confounders for categorical and continuous outcomes, respectively. Because reports of symptoms related to endometriosis represented lifetime prevalence rather than specifically relating to their diagnostic experience, analyses on symptoms were unadjusted.

The data met the assumption of normal distribution for the described statistical tests. Analyses were considered