Actuarial Analysis of Private Payer Administrative Claims Data for Women With Endometriosis

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ABSTRACT

BACKGROUND: Endometriosis is a painful, chronic disease affecting 5.5 million women and girls in the United States and Canada and millions more worldwide. The usual age range of women diagnosed with endometriosis is 20 to 45 years. Endometriosis has an estimated prevalence of 10% among women of reproductive age, although estimates of prevalence vary greatly. Endometriosis is the most common gynecological cause of chronic pelvic pain, but published information on its associated medical care costs is scarce.

OBJECTIVE: The aim of this study was to determine (1) the prevalence of endometriosis in the United States, (2) the amount of health care services used by women coded with endometriosis in a commercial medical claims database during 1999 to 2003, and (3) the endometriosis-related costs for 2003, the most recent data available at the time the study was performed.

METHODS: This study was a retrospective review of administrative data for commercial payers, which included enrollment, eligibility, and claims payment data contained in the Medstat Marketscan database for approximately 4 million commercial insurance members. All claims and membership data were extracted for each women aged 18 to 55 years who had at least 1 medical or hospital claim with a diagnosis code for endometriosis (International Classification of Diseases, Ninth Revision, Clinical Modification [ICD-9-CM] codes 617.00-617.99) for 1999 through 2003. Claims data from 1999 through 2003 were used to determine prevalence and health care resource utilization (i.e., annual admission rate, annual surgical rate, distribution of endometriosis-related surgeries, and prevalence of comorbid conditions). The cost analysis was based on claims from 2003 only. Cost was defined as the payer-allowed charge, which equals the net payer cost plus member cost share.

RESULTS: The prevalence of women with medical claims (inpatient and/or outpatient) containing ICD-9-CM codes for endometriosis was 1.1% for the age band of 30 to 39 years and 0.7% over the entire age span of 18 to 55 years. The medical costs per patient per month (PPPM) for women with endometriosis were 63% greater ($706 PPPM) than those of the average woman per member per month ($433) in 2003; inpatient hospital costs accounted for 32% of total direct medical costs. Between 1999 and 2003, these women with endometriosis who were identified by either inpatient and/or outpatient claims had high rates of hospital admission (53% for any reason; 38% for an endometriosis-related reason) and a high annual surgical procedure rate (64%). Additionally, women with endometriosis frequently suffered from comorbid conditions, and these conditions were associated with greater PPPM costs of 15% to 50% for women with an endometriosis diagnosis code, depending on the condition. Interstitial cystitis was associated with 50% greater cost ($1,061 PPPM); depression, 41% ($997 PPPM); migraine, 40% ($988 PPPM); irritable bowel syndrome, 34% ($943 PPPM); chronic fatigue syndrome, 29% ($913 PPPM); abdominal pain, 20% ($846 PPPM); and infertility, 15% ($813 PPPM).

CONCLUSIONS: Women with endometriosis have a high hospital admission rate and surgical procedure rate and a high incidence of comorbid conditions. Consequently, these women incur total medical costs that are, on average, 63% higher than medical costs for the average woman in a commercially insured group.

KEYWORDS: Endometriosis, Chronic pelvic pain, Women’s health, Prevalence, Comorbidity, Resource utilization

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ENDOMETRIOSIS IS A PAINFUL, ESTROGEN-DEPENDENT GYNECOLOGICAL CONDITION THAT CAN BE CATEGORIZED AS MILD, MODERATE, OR SEVERE, AND IS DEFINED AS THE PRESENCE OF ENDOMETRIAL GLANDS AND STROMA OUTSIDE THE UTERINE CAVITY AND MUSCULATURE. It is a long-term condition and usually lasts until menopause.

The clinical manifestations of endometriosis are variable and unpredictable and include secondary dysmenorrhea, worsening primary dysmenorrhea, dyspareunia, noncyclic lower abdominal pain, backache, uterosacral ligament nodularity, and adnexal mass.3,4 Interestingly, the stage and localization of pelvic endometrioses are not associated with the frequency of symptoms. The pathogenesis of the disease remains unclear, although leading theories suggest retrograde menstruation, hematogenous or lymphogenous transport, and coelomic metaplasia.

Menstruating women of any age or race can develop endometriosis, although the usual age range of women diagnosed with the condition is 20 to 45 years. The estimated prevalence of the disease is 10% among women of reproductive age,6 making it more common than diabetes in this population.7 A much higher prevalence occurs in women with chronic pelvic pain (CPP, 33%-82%), premenopausal women (50%), and in women undergoing investigation of infertility (21%).6,8-11 Indeed, endometriosis is the most common gynecological cause of CPP; a disabling condition responsible for 10% of hysterectomies and 40% of laparoscopies12 and affecting up to 40% of women receiving primary care.13 Other disorders associated with CPP are secondary muscular adaptations and psychological conditions, such as depression.12,14 While no conclusive evidence supports endometriosis as a cause for infertility, there is general agreement that infertility is often associated with endometriosis and that anatomical distortion from endometriosis often causes infertility.1,15

This disease usually becomes apparent in the reproductive years when the lesions are stimulated by ovarian hormones. However, endometriosis pain has little relationship to the site or color of lesions.16 Risk factors favoring endometriosis...
development include a shorter menstrual cycle, longer bleeding periods, and early menarche.\(^6\)\(^{17-21}\) Women who smoke and those who are overweight have a reduced risk of developing the condition.\(^9\) Despite recent advances, endometriosis is still difficult to diagnose and treat. Many women with CPP do not receive diagnostic testing, are never diagnosed, and are not referred to a specialist.\(^5\)

Endometriosis is often mistaken for other conditions that cause pelvic pain, such as pelvic inflammatory disease, ovarian cysts, or irritable bowel syndrome (IBS). Left undiagnosed or untreated, painful periods caused by endometriosis can lead to absenteeism from work and school and can strain relationships. Recurring pain can lead to depression, irritability, anxiety, anger, and feelings of helplessness. Infertility linked to endometriosis can also cause emotional distress.

The disease is associated with significant morbidity rates. Between 1990 and 1998, it was the third most common gynecological diagnosis listed in the hospital discharge summaries of women aged 15 to 44 years.\(^8\) Endometriosis results in lost productivity, hospitalizations, and surgical procedures, as well as outpatient and prescription drug costs. Many women resort to bed rest during bouts of endometriosis-related pain, with almost half the women with endometriosis in one study reporting the need for an average of 17.8 days of bed rest in the previous 12 months.\(^6\)

\(^{6}\) HMO and EPO claims tend to be unreliable for determining cost and utilization rates because not all services are submitted as encounters, so utilization and cost can be underestimated.

\(^{1}\) Member-year = total days of eligibility divided by 365.

\(^{2}\) Allowed charges = net payer cost + member cost share.

\(^{3}\) HMO = health maintenance organization; ICD-9-CM = International Classification of Diseases, Ninth Revision, Clinical Modification; POS = point of service; PPO = preferred provider organization.

Note: HMO and EPO claims tend to be unreliable for determining cost and utilization rates because not all services are submitted as encounters, so utilization and cost can be underestimated.

* Member-year = total days of eligibility divided by 365.

† Allowed charges = net payer cost + member cost share.

EPO = exclusive provider organization; ER = emergency room; ESRD = end-stage renal disease; HMO = health maintenance organization; ICD-9-CM = International Classification of Diseases, Ninth Revision, Clinical Modification; POS = point of service; PPO = preferred provider organization.
months as a direct result of endometriosis.23

The aims of endometriosis treatment are to eliminate symptoms, reduce the process of inflammation, and limit tissue destruction that might result from long-standing disease.4

Endometriosis can be treated effectively with medical therapy or surgery or both.5,24-26 Symptoms such as pain can be controlled with medical therapy alone, thus avoiding the need for surgery.5,24-26 Surgical treatment is considered second-line therapy; reserved for patients who have failed medical treatment or who have evidence of extensive disease.26

The American College of Obstetrics and Gynecology (ACOG) clinical practice guidelines2 for the medical treatment of endometriosis state that, for pain relief, treatment with a gonadotropin-releasing hormone (GnRH) agonist or with danazol appears to be effective in most women. The guidelines state that when pain relief is achieved by treatment with a GnRH agonist (thus endorsing continued therapy), the addition of add-back therapy reduces or eliminates GnRH-induced bone mineral loss without reducing the efficacy of pain relief. Therapy with a GnRH agonist is an appropriate approach to pain management in a woman with CPP, even in the absence of surgical confirmation of endometriosis, provided that a detailed initial evaluation fails to demonstrate some other cause of pelvic pain.2

Endometriosis-related hospitalizations and surgical procedures are a major burden on health care systems, but there is little information in the literature regarding the direct medical costs of endometriosis.27 Endometriosis-related surgery for women in the U.S. Army was associated with an average of 15 days of hospital and convalescent days per procedure.28 Others in the United States have reported average length of stay and hospital charges for endometriosis of 3.8 days and $6,597 in 1991 and 3.5 days and $7,450 in 1992, representing total annual charges of $504 million and $579 million, respectively.29

This study aimed to determine (1) endometriosis prevalence, (2) the volume and cost of health care services used by women coded with endometriosis during 1999 to 2003, and (3) endometriosis-associated costs for 2003 (the most recent data available at the time the study was performed). To our knowledge, this is the first study to report actuarial analysis of administrative data for women coded with endometriosis for private commercial insurance payers.

Methods

Data Source

This study was a retrospective review of payer administrative enrollment, eligibility, and claims payment data for women coded with endometriosis for 1999 through 2003, the most recent data available at the time the study was performed. This information was obtained from Milliman, Inc. (New York), which maintains proprietary medical claims databases, including the Medstat Marketscan database (Figures 1a, 1b). Milliman maintains administrative claim databases that link paid claims and encounter data that give detailed patient information across treatment sites and types of providers over time.

The Medstat Marketscan database contains all paid claims generated by roughly 4 million (male and female) commercially insured lives. Member identification codes are consistent from year to year and allow multiyear longitudinal studies. Information includes diagnosis codes; procedure codes and diagnosis-related grouping codes; national drug classification codes, together with site of service information; and the amounts paid by commercial insurers. These data were used to generate medical condition incidence rates and cost.

Database Inclusion/Exclusion Criteria

In this analysis, only commercial claims were reviewed for persons aged ≤65 years with employer-sponsored insurance categorized as basic/major medical (<1%), comprehensive (18%), point of service (28%), and preferred provider organization (54%). Health maintenance organization (HMO) and exclusive provider organization (EPO) claims were specifically excluded from our cost and utilization analysis (Figure 1a) since they include encounter data, (also called zero-dollar claims), which are not used to reimburse providers. HMO and EPO claims tend to be unreliable for determining cost and utilization rates because not all services are submitted as encounters, so utilization and cost can be underestimated.

The endometriosis population was a subset of the Medstat Marketscan database, using data for eligible persons with commercial claims.

Endometriosis Population

The endometriosis population was defined as women of child-bearing age (18 through 55 years) with at least 1 of the following types of claims with an endometriosis diagnosis (International Classification of Diseases, Ninth Revision, Clinical Modification [ICD-9-CM] codes 617.00-617.99):

- 1 inpatient claim
- 1 emergency room (ER) claim
- 2 outpatient claims (other than laboratory or radiology claims) on different dates, with endometriosis already identified

Once a woman was identified for the endometriosis population, all claims were assessed for that woman for the entire period in which she appeared as an eligible member. It was not required for a woman to be enrolled for the entire 5-year period. The database comprises actual employer data and is therefore subject to normal employee turnover.

Endometriosis Episode

Endometriosis is a chronic intermittent condition with no definitive endpoint. To perform the analysis, we needed to arbitrarily determine a time period during which a woman was deemed to have endometriosis and was potentially receiving treatment. In this study, we referred to this time period as the
“endometriosis episode.” An endometriosis episode was deemed to have started when a claim with an endometriosis diagnosis code was first made. The episode was deemed to have ended 12 months after the date of the last endometriosis claim or symptom. Women could thus be included in both the endometriosis population and the nonendometriosis population at some point within the 5-year period (sequentially). A woman was required to be a member for the full endometriosis episode time period (i.e., a minimum of 12 months) in order to be included in the endometriosis population analysis. Adnexal pain (ICD-9-CM code 625.9) and dysmenorrhea (ICD-9-CM code 635.3) were chosen as the symptoms of endometriosis; other symptoms, such as IBS or CPP, may or may not be related to endometriosis so were not used to determine endometriosis episodes.

Use of Benchmarks
Milliman’s Health Cost Guidelines were used for benchmarking the results found for the endometriosis population to the average adult female population. The guidelines are a database and a model used to provide a flexible but consistent basis for determining health claim costs and premium rates for a wide variety of health plans. The guidelines are developed from a number of claims databases, including Medstat Marketscan and other data sources that are proprietary to Milliman. These other data sources include private insurance companies and data vendors. Milliman’s Health Cost Guidelines are updated annually and are continually monitored. The standard demographics in the guidelines were developed using data from large insurers combined with Department of Labor sources to represent the age and sex distribution for a typical large insured group. These demographics are useful comparators to give an indication of the magnitude of difference between the endometriosis population and the average adult female population.

Actuarial Analyses
Actuaries work with insurers, HMOs, employers, and other clients to assign a financial value to future unknown health care events, such as endometriosis. They use standard mathematical and statistical techniques, including the law of large numbers, to analyze historical use and cost information and predict the use and cost of future contingent events. Actuarial analysis is the foundation for all types of insurance, and every insurance company relies on actuaries to estimate use, claims expense, and financial reserves and to set premium rates. Actuarial analyses were used throughout this study.

Prevalence and resource utilization rates were determined using member-years or member-months. “Member-year” was defined as total days of eligibility divided by 365. “Member-month” was defined as total days of eligibility divided by 30. Member-months were converted to member-years by dividing by 12. Member-years and member-months were therefore the actual years or months an individual was eligible for enrollment in a health insurance benefits program. Any particular individual might be enrolled for only part of a year, and using member-years or member-months accurately reflects that fact. For example, a woman eligible from January 1, 2002, through July 15, 2003, had 561 days of eligibility, 18.7 member-months, or 1.56 member-years.

Prevalence was calculated as the sum of member-years for the endometriosis population divided by the sum of member-years for all members.

Annual admission rate was calculated as the number of admissions divided by the sum of member-years for the endometriosis population.

Annual surgical rate was calculated as the number of surgical procedures divided by the sum of member-years during the endometriosis period for the endometriosis population.

Distribution of endometriosis-related surgical procedures was calculated as the number of surgeries (defined by Current Procedural Terminology [CPT-4 or ICD-9-CM code] divided by the sum of member-years during the endometriosis period for the endometriosis population. This was calculated separately for each endometriosis-related surgery (i.e., hysterectomy, laparoscopy, laparotomy, oophorectomy, endometrial ablation)

Prevalence of comorbid conditions was calculated as the sum of member-months for women with endometriosis and a comorbid condition divided by the sum of member-months for the endometriosis population. In this case, women were required to be enrolled for a minimum of 12 months, which would ensure an opportunity for a comorbidity to show up if one existed.

For resource utilization analyses, claims data were taken from the Medstat database from 1999 through 2003. The cost analysis was based on inpatient, outpatient, and prescription drug costs for the endometriosis population in 2003 only. That was the most recent year for which cost data were available. In addition, use of a single year’s data eliminated the need to adjust for trend from year to year.

Administrative claims data were grouped into 3 categories: inpatient, outpatient, and prescription drugs. Inpatient claims included care received at an inpatient facility and billed using a UB-92 claim form. This category included room and board and ancillary services, such as use of surgical and intensive care facilities, inpatient nursing care, pathology and radiology procedures, drugs, and supplies. It did not include professional charges unless performed by the staff of the facility. Outpatient claims included care received at an outpatient facility or a physician’s office and billed using a Health Care Financing Administration (HCFA)-1500 claim form. This category also included prescription drugs administered in the physician’s office, which were usually covered under a person’s medical insurance. The prescription drug category included all drugs obtained from a pharmacy, with the claims commonly processed through a pharmacy benefits manager.
Statistical Analyses

Distribution of endometriosis-related surgeries and the prevalence of comorbid conditions in women coded with endometriosis were compared with the general female population using the $z$ test. The $z$ test was used instead of the more commonly used $t$ test because of the large numbers of women involved in the analyses, ranging from hundreds of thousands to millions. $p$ values $\leq 0.05$ were judged to be significant.

Results

Prevalence of Endometriosis

In this study, the prevalence of endometriosis in administrative data collected between 1999 and 2003 was 0.7% (40,150 member-years), with the highest prevalence occurring in women aged 25 to 49 years (Table 1). Endometriosis prevalence varied slightly by U.S. geographic region, from a low of 0.5% for the western and eastern regions to a high of 0.7% for the southern, southeastern, and midwestern regions (data not shown).

Costs for Women with a Diagnosis Code for Endometriosis

Significant expense was associated with women with an endometriosis diagnosis code. As shown in Figure 2, these women had total costs in 2003 of $706 per patient per month (PPPM) compared with $433 per member per month (PMPM) for the average woman. Women coded with endometriosis incurred higher inpatient, outpatient, and prescription drug costs (Figure 2). Outpatient costs, which include costs for physician, radiology, laboratory, and outpatient hospital services, represented the most expensive category for women coded with endometriosis (Figure 2).

![Table 1](image)

**Table 1** Age Distribution of Prevalence* of Women With Endometriosis Diagnosis Codes† in Administrative Data (1999-2003)

<table>
<thead>
<tr>
<th>Age (Years)</th>
<th>With Endometriosis</th>
<th>All Eligible Members</th>
<th>Prevalence (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-19</td>
<td>552</td>
<td>291,299</td>
<td>0.2</td>
</tr>
<tr>
<td>20-24</td>
<td>2,159</td>
<td>587,126</td>
<td>0.4</td>
</tr>
<tr>
<td>25-29</td>
<td>4,160</td>
<td>499,537</td>
<td>0.9</td>
</tr>
<tr>
<td>30-34</td>
<td>7,486</td>
<td>671,209</td>
<td>1.1</td>
</tr>
<tr>
<td>35-39</td>
<td>8,621</td>
<td>798,336</td>
<td>1.1</td>
</tr>
<tr>
<td>40-44</td>
<td>8,141</td>
<td>961,753</td>
<td>0.9</td>
</tr>
<tr>
<td>45-49</td>
<td>5,804</td>
<td>1,052,226</td>
<td>0.6</td>
</tr>
<tr>
<td>50-54</td>
<td>2,923</td>
<td>1,138,785</td>
<td>0.3</td>
</tr>
<tr>
<td>55</td>
<td>304</td>
<td>220,078</td>
<td>0.3</td>
</tr>
<tr>
<td>Total</td>
<td>40,150</td>
<td>6,220,349</td>
<td>0.7</td>
</tr>
</tbody>
</table>

Data source: Medstat Marketscan administrative claims database.
* Prevalence was calculated as the sum of member-years for endometriosis population/sum of member-years for all eligible members.
† ICD-9-CM diagnosis codes for endometriosis: 617.00–617.99.
‡ Member year = total days of eligible membership divided by 365.

![Figure 2](image)

**Figure 2** 2003 Total Allowed Charges per Patient per Month for Women With an Endometriosis Diagnosis Code Compared With Allowed Charge Per Member Per Month the Average Woman*

Data source: Medstat Marketscan administrative claims database.
* Allowed charges (net payer cost + member cost share) for the average woman, aged 18 to 55 years, were derived from Milliman’s Health Cost Guidelines.
Endometriosis code cohort includes the number of member-years in 2003 for women with endometriosis 1999-2003 (ICD-9-CM diagnosis codes for endometriosis: 617.00–617.99) excluding HMO and EPO claims; n = 30,235 member-years.
Member year = total days of eligibility divided by 365.
EPO = exclusive provider organization; HMO = health maintenance organization; ICD-9-CM = International Classification of Diseases, Ninth Revision, Clinical Modification.
Actuarial Analysis of Private Payer Administrative Claims Data for Women With Endometriosis

### Table 1

<table>
<thead>
<tr>
<th>Age (Years)</th>
<th>Annual Admission Rate for Any Reason*</th>
<th>Rate of Endometriosis-Related Surgery†</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-19</td>
<td>16 (88/552)</td>
<td>5 (29/552)</td>
</tr>
<tr>
<td>20-24</td>
<td>21 (454/2,159)</td>
<td>9 (204/2,159)</td>
</tr>
<tr>
<td>25-29</td>
<td>36 (1,486/4,160)</td>
<td>16 (674/4,160)</td>
</tr>
<tr>
<td>30-34</td>
<td>42 (3,129/7,486)</td>
<td>23 (1,731/7,486)</td>
</tr>
<tr>
<td>35-39</td>
<td>49 (4,239/8,621)</td>
<td>35 (2,975/8,621)</td>
</tr>
<tr>
<td>40-44</td>
<td>62 (5,054/8,141)</td>
<td>50 (4,071/8,141)</td>
</tr>
<tr>
<td>45-49</td>
<td>73 (4,233/5,804)</td>
<td>61 (3,564/5,804)</td>
</tr>
<tr>
<td>50-54</td>
<td>77 (2,241/2,923)</td>
<td>64 (1,866/2,923)</td>
</tr>
<tr>
<td>55</td>
<td>80 (244/304)</td>
<td>65 (199/304)</td>
</tr>
<tr>
<td>Overall % (total n)</td>
<td>53 (21,108/40,150)</td>
<td>38 (15,313/40,150)</td>
</tr>
</tbody>
</table>

Data source: Medstat Marketscan administrative claims database.
* Annual admission rate was calculated as the number of admissions divided by the sum of member-years for the endometriosis population in a given age distribution.
† Annual surgical rate was calculated as the number of surgeries during the endometriosis period divided by the sum of member-years during the endometriosis period for the endometriosis cohort.

### Table 2

<table>
<thead>
<tr>
<th>Age Distribution of Women With an Endometriosis Diagnosis Code Who Underwent Hospital Admissions Between 1999 and 2003</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inpatient</td>
</tr>
<tr>
<td>Outpatient</td>
</tr>
<tr>
<td>Prescription drug</td>
</tr>
<tr>
<td>Total average PPPM charge</td>
</tr>
<tr>
<td>18-19</td>
</tr>
<tr>
<td>20-24</td>
</tr>
<tr>
<td>25-29</td>
</tr>
<tr>
<td>30-34</td>
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<tr>
<td>35-39</td>
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<tr>
<td>40-44</td>
</tr>
<tr>
<td>45-49</td>
</tr>
<tr>
<td>50-54</td>
</tr>
<tr>
<td>55</td>
</tr>
<tr>
<td>Overall % (total n)</td>
</tr>
</tbody>
</table>

Data source: Medstat Marketscan administrative claims database.
* ICD-9-CM diagnosis codes for endometriosis 617.00–617.99.
† Member-year = total days of eligible membership divided by 365.

### Table 3

<table>
<thead>
<tr>
<th>Average PPPM Charges 1 Year Postdiagnosis (n = 7,933 Member-Years) ($)</th>
<th>Average PPPM Charges 2 Years Postdiagnosis (n = 5,204 Member-Years) ($)</th>
<th>2003 Average Charges (n = 30,235 Member-Years) ($)</th>
<th>Medical Charges for the Average Woman ($)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Year Postdiagnosis</td>
<td>2 Years Postdiagnosis</td>
<td>2003 Average Charges</td>
<td>Medical Charges for the Average Woman</td>
</tr>
<tr>
<td>Inpatient</td>
<td>Outpatient</td>
<td>Prescription drug</td>
<td>Total average PPPM charge</td>
</tr>
<tr>
<td>530</td>
<td>135</td>
<td>120</td>
<td>1,210</td>
</tr>
<tr>
<td>560</td>
<td>280</td>
<td>115</td>
<td>530</td>
</tr>
<tr>
<td>120</td>
<td>115</td>
<td>Total average PPPM charge</td>
<td>706</td>
</tr>
</tbody>
</table>

Data source: Medstat Marketscan administrative claims database.

* CPT-4 codes:
  - Hysterectomy: 56308, 58150-58200, 58260-58294, 58546-58554
  - Oophorectomy: 56307, 58940
  - Laparotomy: 49000, 49010, 49200-49201, 58740, 58805, 58925
  - Laparoscopy: 44200, 49320, 49321-49329, 56300-56306, 56309-56310, 58578, 58660-58679, 58800
  - Endometriosis ablation: 58563, 58535-58536

* ICD-9-CM codes:
  - Hysterectomy: 68.3-68.9
  - Oophorectomy: 65.3-65.64
  - Laparotomy: 65.89, 70.32, 57.59, 68.21, 68.29
  - Laparoscopy: 65.81, 54.21
  - Endometriosis ablation: 68.23

During the first year after diagnosis, women with an endometriosis diagnosis code had approximately 3-fold higher total medical costs compared with the average age-adjusted woman. Table 2 shows 2003 costs, by service category, for women coded with endometriosis who are in their first- and second-year postdiagnosis. Total medical costs for women with endometriosis were higher than average for the entire 2-year postdiagnosis period analyzed, with second-year costs being $530 PPPM in 2003.

For women coded with endometriosis, the mean annual hospital admission rate during the years 1999 to 2003 for any reason was 53% and for an endometriosis-related reason was 38% (Table 3). Sixty-four percent of women coded with endometriosis had an endometriosis-related inpatient or outpatient surgical procedure. The average time lost from work as a consequence was estimated as 13 days per procedure (data not shown). These days lost from work were not factored into the cost of endometriosis. Table 3 and Figure 3 show the hospital admission and surgical procedure rates by age for women coded with endometriosis.

Forty-three percent of women with an endometriosis diagnosis code during 1999 to 2003 underwent a major surgical procedure (such as hysterectomy, laparotomy, or oophorectomy). Indeed, 17% had 2 and 24% had 3 or more endometriosis-related surgeries. Thirty-one percent of women with an endometriosis code underwent hysterectomies, compared with an age-adjusted average of 1% for all women (P <0.001). Table 4 shows the distribution of endometriosis-related surgical procedures for women coded with endometriosis.

Women with an endometriosis diagnosis code had a significantly higher (P <0.001) incidence of claims for infertility, depression, migraine, interstitial cystitis (IC), IBS, chronic fatigue syndrome, and abdominal pain than the general adult female population (Table 5). The existence of these comorbid conditions with endometriosis was associated with greater PPPM costs, depending on the condition; IC contributing to a 50% increase in cost ($1,061 PPPM); depression, 41% ($997 PPPM); migraine, 40% ($988 PPPM); IBS, 34% ($943 PPPM); chronic fatigue syndrome, 29% ($913 PPPM); abdominal pain, 20% ($846 PPPM); and infertility, 15% ($813 PPPM) (Table 5).

**Discussion**

The results of this study showed that the prevalence of endometriosis determined from administrative data obtained between 1999 and 2003 was low (0.7%). Significant inpatient, outpatient, and prescription drug costs were incurred in 2003 by women with endometriosis ($706 PPPM) compared with the average commercially insured woman ($433 PMPM). These costs continued to be higher for the entire 2-year postdiagnosis period. In addition, between 1999 and 2003, women with endometriosis experienced high rates of endometriosis-related surgery (64%) as well as hospital admissions. Women coded with endometriosis frequently suffered from comorbid conditions, which increased costs by 15% to 50%, depending on the condition.

It is not surprising that the prevalence of endometriosis determined by clinical data is greater (10% vs. 0.7%) than the prevalence obtained from our administrative data. This finding implies that endometriosis is both underdiagnosed and undertreated. The ACOG management guideline estimates the prevalence of endometriosis as approximately 33% in women with CPP. The results of this study showed that the prevalence of endometriosis determined from administrative data obtained between 1999 and 2003 was low (0.7%). Significant inpatient, outpatient, and prescription drug costs were incurred in 2003 by women with endometriosis ($706 PPPM) compared with the average commercially insured woman ($433 PMPM). These costs continued to be higher for the entire 2-year postdiagnosis period. In addition, between 1999 and 2003, women with endometriosis experienced high rates of endometriosis-related surgery (64%) as well as hospital admissions. Women coded with endometriosis frequently suffered from comorbid conditions, which increased costs by 15% to 50%, depending on the condition.

It is not surprising that the prevalence of endometriosis determined by clinical data is greater (10% vs. 0.7%) than the prevalence obtained from our administrative data. This finding implies that endometriosis is both underdiagnosed and undertreated. The ACOG management guideline estimates the prevalence of endometriosis as approximately 33% in women with CPP on the basis of evidence from 11 studies. However, within these studies, the reported prevalence of endometriosis varied widely, ranging from 2% to 74%. Such a large variation in prevalence rates raises the question of whether it is appropriate to use a single prevalence rate of endometriosis for all women with CPP.

Guo and Wang found identifiable sources of heterogeneity in prevalence estimates for endometriosis, with year of publication, sample size, and difference in evaluation of CPP being 3 apparent sources. Therefore, having a single prevalence rate estimate may be too simplistic. Insurer claims data show a much lower prevalence because not all cases of endometriosis will generate an interaction with the health care system and not all cases will
be coded or even recognized. It appears that only one quarter to
one tenth of women with endometriosis are formally diagnosed
and appropriately coded. This is common for conditions
such as endometriosis, for which physicians tend to treat the
symptoms rather than the condition itself. Endometriosis may
often be missed because it is one of several underlying diseases
causing CPP. Women with CPP are often evaluated, diagnosed,
and treated according to the specialist directing their care.12
The cause of CPP remains undiagnosed for the majority of
women.31 A definitive diagnosis of endometriosis requires
direct visualization of ectopic endometrial lesions (usually via
laparoscopy) accompanied by histological confirmation of
the presence of at least 2 of the following features: hemosiderin-
laden macrophages or endometrial epithelium, glands, or
stroma.2 Therefore, most women with suspected endometriosis
undergo surgery as part of their diagnostic workup.1
Diagnosis based solely on visual inspection requires a surgeon
with experience in identifying the many possible appearances of
endometrial lesions. Even so, there is poor correlation between
visual diagnosis and confirmed histology.32 Additionally, deep
endometriosis lesions (type III) can be easily missed clinically.33
There are currently no sufficiently sensitive and specific signs
and symptoms or diagnostic tests for the clinical diagnosis
of endometriosis, and no diagnostic strategy is supported by
evidence of effectiveness. The risks and diagnostic limitations
of laparoscopy and the inaccuracy of clinical examination
have led to considerable efforts to improve diagnosis with
imaging techniques. Unfortunately, imaging studies, such
as ultrasonography or magnetic resonance imaging, do not
show peritoneal disease or adhesions unless there are large
endometriomas.34 In addition, although the specificity of cancer
antigen (CA) 125 measurement has been reported as >85%
with sensitivities between 20% and 50%,35-38 the clinical utility
of measuring CA125 as a diagnostic marker for endometriosis
appears to be limited.
Not surprisingly, women are frequently misdiagnosed. For
example, in a British study of women with pelvic pain, many
patients who eventually were diagnosed with endometriosis

### TABLE 4 Distribution of Endometriosis-Related Surgeries in Women With an
Endometriosis Diagnosis Code Compared All Eligible Female Members (1999-2003)

<table>
<thead>
<tr>
<th>Type of Surgery</th>
<th>Women With an Endometriosis Diagnosis Code and a Surgical Procedure (% of 33,564 Member-Years)</th>
<th>All Women With This Surgical Procedure* (n = 7,144,896 Member-Years) (%)</th>
<th>P Value†</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hysterectomy</td>
<td>30.9</td>
<td>0.9</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Therapeutic laparoscopy</td>
<td>25.7</td>
<td>0.7</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Diagnostic laparoscopy</td>
<td>7.6</td>
<td>0.2</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Laparotomy</td>
<td>6.6</td>
<td>0.2</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Oophorectomy</td>
<td>5.4</td>
<td>0.3</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Endometrial ablation</td>
<td>1.9</td>
<td>0.2</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

Data source: Medstat Marketscan administrative claims database.
* The all-women group consisted of the total population of eligible members between ages 18 and 55 years.
† Statistical test used = z test.
Endometriosis code cohort includes the number of member-years for women with endometriosis 1999–2003 (ICD-9-CM diagnosis codes for endometriosis: 617.00–617.99), including HMO and EPO claims. Distribution of endometriosis-related surgeries was calculated as the number of surgeries (defined by CPT-4 or ICD-9 code) divided by the sum of member-years during the endometriosis period for the endometriosis cohort population. Note: 41% of women had 2 or more endometriosis-related surgeries.
Member year = total days of eligibility divided by 365.

* CPT-4 codes:
- Hysterectomy: 56308, 58150-58200, 58260-58294, 58546-58554
- Oophorectomy: 56307, 58940
- Laparotomy: 49000, 49010, 49200-49201, 58740, 58805, 58925
- Laparoscopy: 44200, 49320, 49321-49329, 56300-56306, 56309-56310, 58578, 58660-58679, 58800
- Endometrial ablation: 58563, 56356, 58353-58356

* ICD-9-CM codes:
- Hysterectomy: 68.3-68.9
- Oophorectomy: 65.3-65.64
- Laparotomy: 65.89, 70.32, 57.59, 68.21, 68.29
- Laparoscopy: 65.81, 54.21
- Endometrial ablation: 68.23

Delays in the diagnosis of endometriosis occur at an individual patient level and at a medical level, as both women and physicians normalize symptoms, suppress symptoms through hormones, and rely on nondiscriminatory investigations. Once diagnosed correctly, endometriosis is an expensive condition, with 2003 costs of $706 PPPM compared with $433 PMPM for the average commercially insured woman. The cost information reported in this study may be similar to previously published figures. For example, Zhao et al. published hospital charges for endometriosis of $6,597 in 1991 and $7,450 in 1992. Others have shown that estimated direct medical costs for outpatient visits for CPP for the U.S. population of women aged 18 to 50 years are $881.5 million per year. However, it is difficult to directly compare the results of the current study with previously published work. For instance, the results of Zhao et al. are based on hospital charge data or “billed charges,” which is the amount that a hospital bills a payer for services rendered. But this is not the amount paid by the health plan or the insurer because each payer has negotiated a payment rate with each hospital. This payment rate (allowed charge) is usually considerably less than the amount billed. The cost information in the current study is based on payer claims information and, as such, is the lower negotiated rate or “allowed charges.” Whether measured by provider-submitted charges or allowed charges, the high cost incurred by women with endometriosis is due to the high rates of hospital admissions as well as surgical procedures and by the presence of significant comorbid conditions such as infertility, depression, and migraine. Interestingly, when 2004 endometriosis costs are extrapolated from 2003 figures using a 12% trend to account for inflation, the cost of endometriosis rises to $791 PPPM. This is similar or higher to previously and similarly calculated 2004 costs incurred for such high-profile conditions as hypertension ($500), diabetes ($916), and rheumatoid arthritis ($1,121) and is almost double the average 2004 medical costs for women ($485 PMPM). High rates of endometriosis-related surgery have been previously reported, with one case of a 36-year-old woman with a history of 11 surgical procedures related to pelvic pain or endometriosis over 20 years. Endometriosis requires histological confirmation, most commonly laparoscopy, for diagnosis. This and other gynecological surgical procedures have the potential for unexpected complications, such as blood loss and transfusion, bladder injury, pulmonary embolism, wound complications, and problems due to general anesthesia.

The high hospital and surgery rates observed in the current analysis are in line with these findings. In this study, women with endometriosis diagnosis codes had 35 times more hysterectomies and laparotomies and 20 times more oophorectomies compared with women in the general population.

### Table 5

<table>
<thead>
<tr>
<th>Comorbid Condition</th>
<th>Women With Endometriosis Diagnosis (n = 33,364 Member-Years) (%)</th>
<th>Women in the General Population (n = 7,144,896 Member-Years) (%)</th>
<th>P Value*</th>
<th>2003 Charge (PPPM)†</th>
<th>% Higher Charge</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abdominal pain</td>
<td>46.5</td>
<td>18.5</td>
<td>&lt;0.001</td>
<td>846</td>
<td>20</td>
</tr>
<tr>
<td>Infertility</td>
<td>11.6</td>
<td>1.6</td>
<td>&lt;0.001</td>
<td>813</td>
<td>13</td>
</tr>
<tr>
<td>Migraine</td>
<td>8.9</td>
<td>4.0</td>
<td>&lt;0.001</td>
<td>988</td>
<td>40</td>
</tr>
<tr>
<td>Depression</td>
<td>6.8</td>
<td>3.9</td>
<td>&lt;0.001</td>
<td>997</td>
<td>41</td>
</tr>
<tr>
<td>Interstitial cystitis</td>
<td>1.2</td>
<td>0.3</td>
<td>&lt;0.001</td>
<td>1,061</td>
<td>50</td>
</tr>
<tr>
<td>Irritable bowel syndrome</td>
<td>4.4</td>
<td>1.7</td>
<td>&lt;0.001</td>
<td>943</td>
<td>34</td>
</tr>
<tr>
<td>Chronic fatigue syndrome</td>
<td>1.3</td>
<td>0.7</td>
<td>&lt;0.001</td>
<td>913</td>
<td>29</td>
</tr>
</tbody>
</table>

Data source: Medstat Marketscan administrative claims database.

* Statistical test used = z test
† 2003 plan-allowed charges (net payer cost + member cost share) for inpatient, outpatient and prescription drug charges.
Endometriosis code cohort includes the number of member years for women with endometriosis 1999–2003 (ICD-9-CM diagnosis codes for endometriosis 617.00–617.99) including HMO and EPO claims.
Member year = total days divided by 365.
EPO = exclusive provider organization; HMO = health maintenance organization; ICD-9-CM = International Classification of Diseases, Ninth Revision, Clinical Modification; PPPM = per patient per month.

had been diagnosed previously with IBS.

with an age-adjusted average for all women.

The higher costs incurred by women with endometriosis might also be the result of the high incidence of serious comorbidities associated with this condition. The current analysis revealed that compared with the average for all women, women coded with endometriosis had more than 7 times the incidence of infertility, 4.5 times more IC, 2.5 times more IBS, 3 times more migraines and chronic fatigue syndrome, and 1.8 times more depression. Others have published similar results. For example, it has been previously estimated that between 30% and 50% of women with endometriosis are infertile44,45 and that as many as 86% of women suffering from endometriosis with CPP have depression.19

Women with endometriosis also experience impaired health-related quality of life, especially in the domains of pain and psychological and social functioning.31,46 In the current study, the presence of these comorbidities increased costs by 15% to 50%, depending on the condition.

Gao et al.27 found that approximately 50% of endometriosis-related ambulatory patient visits involved specialist care and realized a need to coordinate services and treatment plans among specialists. Efforts should be undertaken to deliver more and better education on endometriosis and related conditions to all professionals providing health care to women. Health plans and employers should consider endometriosis to be one of the important high-cost chronic conditions deserving a focused disease management program similar to that developed for diabetes and rheumatoid arthritis.

Limitations

First and foremost among the limitations of this analysis is the reliance on accurate diagnosis and procedure coding in hospital and medical claims. Neither the hospital medical claims nor the eligibility data were audited for accuracy. Second, this analysis pertains only to the dataset of commercial health plans, excluding HMOs and EPOs. Third, we limited our analyses to adult women aged 18 to 55 years, which may underestimate the direct medical costs of endometriosis since Gao et al.27 found that children and adolescents aged 10 to 17 years also account for endometriosis-related hospital admissions. A further underestimation may have resulted from the arbitrary determination of the length of an endometriosis episode because women might not have experienced any further endometriosis (and thus resource utilization) after their final coded event. Fourth, while we attempted to examine administrative claims data over a fairly wide time period (1999 through 2003), the definition of the inclusion criteria (i.e., an endometriosis ICD-9-CM code (617.00–617.99) on at least 1 inpatient claim or 1 ER claim or 2 outpatient claims other than laboratory or radiology claims) may have led us to overestimate the incidence of the rates of hospitalization and endometriosis-related surgical procedures and associated costs.

Conclusions

Endometriosis diagnoses are associated with significant costs compared with women in the same age bands without these diagnosis codes. Specifically, this study found that endometriosis is expensive, with total costs in 2003 of $706 PPPM compared with $433 PMPM for the average woman. Endometriosis is a condition that is associated with frequent medical and surgical procedures and comorbidities.

What is already known about this subject

• Endometriosis is a painful, long-term, estrogen-dependent gynecological condition that usually lasts until menopause.
• Endometriosis is difficult to diagnose and treat, contributing to difficulty in determining the economic burden of the disease.

What this study adds

• This is the first study to report actuarial analysis of private (commercial insurance) payer administrative claims data for women coded with a diagnosis of endometriosis.
• The prevalence of endometriosis as actuarially derived from hospital and medical claims in adult women aged 18 to 55 years in a large commercial health insurance database was 0.7% overall and 1.1% for the age band 30 to 39 years.
• In the first 2 years after the initial diagnosis, women with endometriosis accounted for 63% greater direct medical costs compared with women without endometriosis diagnosis codes, $706 PPPM versus $433 PMPM in 2003 dollars.

DISCLOSURES

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Mirkin served as principal author of the study. Study concept and design were contributed by all authors. Data collection was the work of Iwasaki, with input from Mirkin and Murphy-Barron; data interpretation was primarily the work of Murphy-Barron, with input from Mirkin. Writing of the manuscript was primarily the work of Mirkin, with input from Murphy-Barron; its revision was the work of Mirkin, with input from Murphy-Barron and Rx Communications, Ltd., Flintshire, United Kingdom.

REFERENCES


