

Disparities in Trends in Endometriosis Diagnosis before and After the Affordable Care Act: Policy Implications, 2006-2019

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Abstract

Background – Endometriosis is a significant public health problem in the United States (US), with an estimated prevalence of as much as 10% among women of reproductive age. This study examines disparities in the prevalence of self-reported endometriosis among females aged 15-44 before and after the passage of the Affordable Care Act (ACA) to understand the potential impact of the ACA on endometriosis diagnosis.

Methods – We analyzed data from the National Survey of Family Growth, collected in 2008 and 2018, from 522 and 292 females, respectively. We conducted bivariate and multivariable logistic regression analyses to identify factors associated with self-reported endometriosis. Analyses were conducted using SAS version 9.4.

Results – The prevalence of endometriosis decreased after the passage of the Affordable Care Act (ACA) among females aged 30-39 years (47.9% vs. 36.6 %; $p=0.002$), among females with no high school diploma (14.4% vs. 7.5 %; $p=0.005$), and among females with no health insurance (18.4% vs. 7.5 %; $p<0.0001$). The prevalence of endometriosis increased after the ACA among females aged 40-44 years (28.5% vs. 45.9 %; $p<0.0001$) and among females who completed college-level education versus those who completed high school only (30.7% vs. 42.5 %; $p=0.001$). Factors associated with higher odds of reporting endometriosis before ACA included being in the 100%–199% Federal Poverty Line (FPL) (AOR= 1.51; 95% CI=1.08, 2.13) and being in the 200%–300% or higher FPL (AOR= 1.52; 95% CI=1.07, 2.14). Furthermore, females with no high school diploma (AOR=3.12; 95% CI=2.07, 4.72) and those who completed high school only (AOR=1.78; 95% CI=1.32, 2.40) also had higher odds of reporting endometriosis, as did those who were college graduates (AOR=1.17; 95% CI=1.20, 2.17).

Conclusion – The prevalence of endometriosis in the US varies significantly by socio-demographic factors before and after the ACA was passed.

Keywords: Endometriosis, women, Affordable Care Act, US

1. Introduction

Endometriosis, defined as the growth of endometrial tissue outside the uterus, affects women of reproductive age and can significantly decrease the quality of life of those affected [1-3]. The disease can cause women to experience debilitating symptoms that negatively impact their quality of life, proportional to the severity of their symptoms [4, 5]. Such symptoms include chronic pain, infertility, and organ dysfunction [2]; however, women can also be asymptomatic. An accurate and timely diagnosis is necessary to reduce pain and prevent long-term systemic effects of the disease [2]. Obtaining an endometriosis diagnosis can be lengthy, with an average delay of 6 to 10 years from the onset of symptoms to diagnosis [2, 3]. The symptomatic presentations of endometriosis can overlap with other morbidities, which adds to the difficulty of diagnosing the condition [3]. Combined oral contraceptive pills are often the first course of treatment for endometriosis-related symptoms; however, laparoscopic surgery has been considered the gold standard for accurate diagnosis of endometriosis [1, 2, 6]. As many as 30% of endometriosis patients are initially misdiagnosed, and women with endometriosis must visit a primary care physician an average of seven times before being referred to a gynecologist who can diagnose the condition [3]. Almost three-quarters of endometriosis diagnoses are from obstetrician and gynecologist physicians versus primary care providers [7], supporting the notion that physician expertise is a requirement for an accurate diagnosis of endometriosis [8]. Women's health experts have yet to reach a consensus on the most appropriate and effective treatments for the pain associated with endometriosis [2], and there is no cure for the condition. Any treatment targets pain reduction, and even the most highly recommended practices can only suppress the symptoms of endometriosis. There is a risk of symptoms recurring after treatment has ceased [2].

The prevalence of endometriosis varies based on the population being assessed [3], but it is estimated to affect 10% of women in the United States (US) [8]. A 2012 cross-sectional survey of reproductive-aged women in the US assessed the prevalence of endometriosis at 6.1% [5]. However, given the difficulties in diagnosis, these figures may be underreported. A 2017 study found that African American women had a lower incidence of endometriosis than White Americans, while Asian Americans had a higher incidence of endometriosis than White women [8]. However, results from another study indicated that African American women were less likely to be diagnosed with endometriosis when compared to White women, and Asian women were more likely to be diagnosed with endometriosis than White women [9], which could explain the observed differences in the incidence of endometriosis across racial groups. A retrospective cross-sectional study of Puerto Rican women with endometriosis demonstrated disparities in access to health care between publicly insured women and privately insured women. Notably, within three years, the group of publicly insured women had half as many endometriosis-related medical claims filed as privately insured women, suggesting that access to care in cases of endometriosis extends beyond simply having insurance coverage [10]. Access

to clinical care appears to determine the presence or absence of disparities in endometriosis diagnosis between racial and ethnic groups [9]. Additionally, non-White women may encounter more significant barriers to accessing and receiving the surgery necessary for endometriosis diagnosis when compared to White women [6]. A 2021 report found disparities in the median length of diagnostic delay of endometriosis by race: 13.6 months for White women, 15.2 months for Black women, 39.4 months for Latina women, and 48.1 months for Asian women [6].

The Affordable Care Act (ACA) is a comprehensive healthcare reform law enacted in the US in 2010. Its primary goals were to increase the quality and affordability of health insurance, expand access to healthcare, and reduce the overall costs of healthcare. Before the ACA implementation 2010, "nearly one in three women aged 19-64 years were uninsured" [11]. Though the ACA included a package of preventive health services for women, the Health Resources and Services Administration guidelines do not include screening for endometriosis in their recommendations [12]. Studies have shown that although the ACA improved healthcare access for minorities through insurance coverage, existing health disparities remained unaffected [13]. Even after the implementation of the ACA, barriers remain to members of minority groups' access to primary care, and the systemic and social determinants that cause racial/ethnic disparities in healthcare access persist [13].

Previous studies on endometriosis in the US have been limited in generalizability and scope, often focusing on a key population over a short period and not considering the potential impact of national health policy on healthcare access and health diagnoses. While the ACA does not explicitly target endometriosis, it encourages women to seek regular check-ups and screenings, which can aid in the early detection and management of conditions like endometriosis and reduce the prevalence of endometriosis. Generally, endometriosis studies have not considered the effects of the ACA on the prevalence of endometriosis diagnoses. Instead, studies often focus on best practices regarding the diagnosis and treatment of endometriosis [2, 14, 15]. While one study does analyze endometriosis data from before and after the implementation of the ACA, the authors focus on a single geographic region [7]. Thus, researching the role of the ACA in reducing the prevalence of endometriosis is relevant because it can contribute to our understanding of the impact of health policies on this widespread gynecological condition, inform strategies to improve access to care, reduce disparities, and guide future healthcare reforms.

2. Methods

2.1. Data Source

Data for this cross-sectional study came from the female respondents' files of 2006-2010 and 2017-2019 National Surveys for Family Growth (NSFG). The NSFG is jointly planned and funded by the National Center for Health Statistics and several other U.S. Department of Health and Human Services programs. For this analysis, the pre-ACA period is listed as 2008, and the post-ACA period is listed as 2018. The NSFG uses a multistage

probability sampling design and gathers information on family life, marriage and divorce, pregnancy, infertility, use of contraception, and men's and women's health. The NSFG conducts in-home, face-to-face interviews of men and women aged 15–44 living in households and includes persons temporarily living away from the family in a college dormitory, sorority, or fraternity house. Thus, the NSFG data provides the most comprehensive, nationally representative information on endometriosis in the US. More detailed information on survey methodology is published elsewhere [16, 17]. Data use agreements were not required for this study since the NSFG data files are publicly available via the National Survey for Health Statistics website [18]. Furthermore, as the NSFG data do not contain personally identifiable information, this study is exempt from the Institutional Review Board review.

2.2. Dependent Variable (Measures for endometriosis diagnosis)

The dependent variable in this study is a self-reported history of an endometriosis diagnosis. Self-reported endometriosis was determined if the participants answered yes to the following question: "Has a doctor or other medical care provider ever told you that you had endometriosis?" Possible responses included "yes," or "no." Records with "unknown" or "refused" answers or missing data were excluded from the analysis to minimize errors in estimation.

2.3. Independent Variables

We examined individual's characteristics related to the self-reported history of an endometriosis diagnosis, which included socio-demographics (age, race/ethnicity, income as a percentage of the federal poverty level (FPL), nativity, relationship status, and education), health insurance coverage, parity, and the number of future births expected.

2.4. Statistical Analysis

Initially, for each year, we performed a bivariate logistic regression analysis to assess a statistically significant difference between the two reference years (2008 and 2018) regarding age, race/ethnicity, poverty status, whether the respondents were born in the US, relationship status, level of education, health insurance coverage, parity, and the number of future births expected. We present significant differences between percentages in endometriosis diagnosis by health insurance coverage, level of education, age group, and race/ethnicity between the two-time points (2008 and 2018) in Figure 1. For each year, we used multivariable logistic regression to estimate the Adjusted Odds Ratios (AORs) and 95% Confidence Intervals (95% CIs) for factors associated with self-reported endometriosis diagnosis in 2008 and 2018 to understand factors that influence self-reported endometriosis when controlling for multiple simultaneous characteristics. All multivariable models included age, race/ethnicity, poverty status, education, level of education, birthplace, relationship status, health insurance coverage, parity, and the number of future births expected regardless of significance due to their theoretical relevance to the models. A 2-sided P-value of $\leq .05$ indicates statistical significance. All analyses were conducted using SAS version 9.4 [19].

3. Results

Figure 1 summarizes the distribution of self-selected endometriosis by age group, race/ethnicity, level of education, insurance coverage in 2008 and 2018. The prevalence of endometriosis decreased after the ACA among females aged 30-39 years (47.9% vs. 36.6 %; $p=0.002$), among females with no high school diploma (14.4% vs. 7.5 %; $p=0.005$), and among females with no health insurance (18.4% vs 7.5 %; $p<.0001$). The prevalence of endometriosis increased after the ACA among females aged 40-44 years (28.5% vs. 45.9 %; $p<.0001$) and among females with college graduate levels of education (30.7% vs. 42.5 %; $p=0.001$).

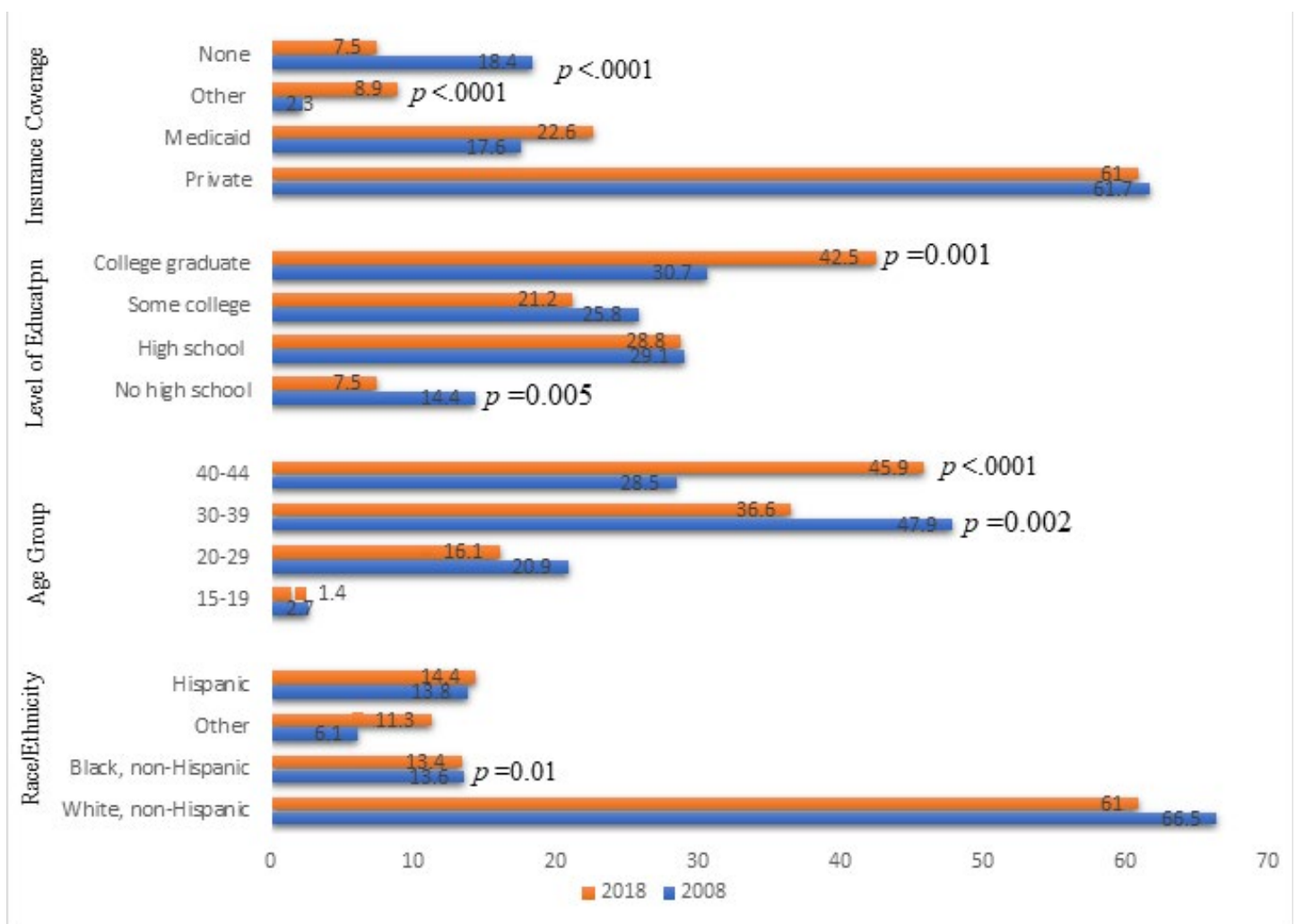


Figure 1: Percentage of self-reported endometriosis by insurance coverage, level of education, age group, and race/ethnicity- National Survey of Family Growth, United States, 2008 and 2018

Table 1 presents the results of multivariable logistic regression analyses. After adjusting for demographic and socioeconomic factors, characteristics associated with higher odds of reporting endometriosis after the ACA included living at <100% the FPL (AOR=1.52; 95% CI=1.08-2.12) and being in 100%–199% the FPL (AOR= 1.51; 95% CI=1.07-2.13). A similar pattern was observed in the level of education, as those with no high school diploma (AOR=3.12; 95% CI=2.07, 4.72) and those with a high school lev-

el of education (AOR=1.78; 95% CI=1.32, 2.40) also had higher odds of reporting endometriosis than those who were college graduates (AOR=1.17; 95% CI=1.20, 2.17) in the pre-ACA period. Being insured by non-Medicaid government insurance was associated with higher odds of endometriosis diagnoses in the post-ACA period. Women covered by non-Medicaid government insurance were three times more likely to report an endometriosis diagnosis than privately insured women (AOR=3.17; 95% CI=1.65, 6.08).

	Pre-Affordable Care Act 2008 aOR (95% confidence interval)	Post-Affordable Care Act 2018 aOR (95% confidence interval)
Total		
Age Group		
15-19	REF	REF
20-29	0.78 (0.36-1.71)	1.28 (0.59-2.80)
30-39	0.94 (0.42-2.08)	1.06 (0.48-2.36)
40-44	0.64 (0.28-1.44)	1.57 (0.69-3.54)
Race/Ethnicity		
White, non-Hispanic	REF	REF
Black, non-Hispanic	1.08 (0.77-1.51)	0.92 (0.66-1.29)
Other or multiple races, non-Hispanic	0.75 (0.48-1.17)	1.34 (0.86-2.09)
Hispanic	0.98 (0.69-1.41)	1.02 (0.71-1.45)
Poverty status		
< 100% federal poverty level	0.65 (0.46-0.93)	1.52 (1.08-2.12)
100%-199%	0.66 (0.47-0.92)	1.51 (1.07-2.13)
200%-300% or higher	REF	REF
Born outside the United States		
No	REF	REF
Yes	0.82 (0.53-1.28)	1.22 (0.78-1.91)
Relationship status		
Married	REF	REF
Cohabiting	0.78 (0.55-1.11)	1.28 (0.90-1.82)
Not living with a partner	0.91 (0.70-1.19)	1.10 (0.84-1.43)
Education		
No high school diploma	3.12 (2.07-4.72)	0.32 (0.21-0.49)
High school or GED	1.78 (1.32-2.40)	0.56 (0.42-0.76)
Some college	1.17 (1.20-2.17)	0.62 (0.46-0.83)
College Graduate	REF	REF
Type of health insurance		
Private	REF	REF
Medicaid	0.75 (0.53-1.05)	1.34 (0.96-1.87)
Other	0.32 (0.16-0.60)	3.17 (1.65-6.08)
None	1.24 (0.89-1.73)	0.81 (0.58-1.21)
Parity		
0	REF	REF
1-2	0.87 (0.65-1.16)	1.15 (0.86-1.55)
3 or more	1.01 (0.70-1.45)	0.99 (0.69-1.43)
Number of future births expected		
0	REF	REF
1-2	1.71 (0.86-1.59)	0.85 (0.63-1.16)
3 or more	0.92 (0.51-1.65)	1.09 (0.61-1.96)

Table 1. Adjusted odds ratios and 95% confidence intervals assessing self-reported endometriosis pre-Affordable Care Act and post-Affordable Care Act by select characteristics- National Survey of Family Growth, United States, 2008 and 2018

4. Discussion

Our results show that women living at less than 199% of the Federal Poverty Level (FPL) had higher odds of reporting endometriosis after the ACA. The possible explanation for these significant findings is that individuals living at less than 199% of FPL might have improved access to healthcare and insurance coverage. Before the ACA, individuals with lower incomes often faced barriers to accessing healthcare due to a lack of insurance or limited coverage options. [8, 11]. The ACA expanded Medicaid eligibility in many states, providing insurance coverage for low-income individuals who previously fell through the gaps in coverage. Medicaid coverage includes essential health benefits, encompassing reproductive healthcare, diagnosing, and treating conditions like endometriosis. With increased access to healthcare services and insurance coverage, women living at less than 199% of the FPL may have had more significant opportunities to seek medical attention for their symptoms and receive a diagnosis of endometriosis [20]. Consequently, the odds of reporting the condition might have increased after the ACA implementation among this specific population [21]. However, it's important to note that various factors may influence the association between the ACA and endometriosis reporting, and further research would be required to provide a comprehensive understanding of this association.

Our findings also indicate that after the implementation of the ACA, compared with those with a college graduate level of education, those without a high school diploma, those with a high school diploma or General Educational Development certification, and those with some college levels of education were 68%, 44%, and 38%, respectively, less likely to report endometriosis diagnosis (Table 1). The possible explanations include: First, higher education may give individuals more access to health information, including awareness about endometriosis symptoms, available treatments, and the importance of seeking medical attention. This knowledge gap can lead to lower diagnosis rates among those with lower education levels. Secondly, healthcare quality, availability, and provider-patient communication disparities can affect endometriosis diagnosis rates. Endometriosis can be a complex and poorly understood condition, and people with higher education levels might have better access to healthcare providers who are knowledgeable about endometriosis and its symptoms, leading to more accurate diagnoses. It is important to note that these explanations should be considered in the context of a broader range of factors. To understand the specific relationship between education levels, the ACA, and the prevalence of endometriosis diagnosis, it is necessary to conduct detailed studies on the impact of social, economic, and healthcare-related variables on the prevalence of endometriosis and not solely by the implementation of the ACA.

Though we expected that women insured by Medicaid would report a greater prevalence of self-reported endometriosis in the post-ACA period when compared to privately insured women, we found a significant increase in the likelihood of reporting an

endometriosis diagnosis for women insured by non-Medicaid government insurance programs versus privately insured women. The government programs under this category include Worker's Compensation, TRICARE (formerly known as CHAMPUS), Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA), Title V, and other programs. TRICARE is an insurance program that serves active duty service members, National Guard and Reserve members, retirees, their families, survivors, and certain former spouses [22], and enrollees have two options for coverage: option one, in which the member pays "little to no" outside costs, but their options are limited by the health management organization, or option two, in which the member has more freedom to choose their health care, but the plan only covers 80% of medical costs [22]. On the other hand, CHAMPVA insurance is offered to families of veterans who died in or as a result of their military capacity and are thus eligible to receive Dependency and Indemnity Compensation (DIC) [23]. CHAMPVA coverage is a cost-sharing program with no premiums, and coverage is free and available to spouses, former spouses, and children of disabled or deceased veterans [24]. Deductibles and co-pays are associated with this coverage, and members must pay 25% of the covered amount after paying a \$50 deductible. According to the Veterans Aid Benefit website, once the participant has paid \$3,000 out-of-pocket, there is no cost for health services after that [25]. These programs are undoubtedly helpful to beneficiaries; however, women will likely still face barriers to endometriosis diagnosis and treatment even with low or no-cost health coverage. In the US, Title V Maternal and Child Health (MCH) Block Grant programs offer services to mothers and children but focus most of their programmatic efforts on the needs of infants, children, and adolescents. According to the National Title V Snapshot (published November 2021), only one National Performance Measure could embody treatment for endometriosis-related symptoms, known as a "Well-Woman Visit" [26]. The MCH Block Grant is administered by HRSA's Maternal and Child Health Bureau and focuses on maternal, child, and family health. While a combined 70% of NSFG respondents reported a parity of one or more in 2018, it is entirely possible that the remaining 30% of women who reported an endometriosis diagnosis and no children were not eligible for coverage under the Title V grant.

There is no clear indicator of why the likelihood of endometriosis diagnosis increased drastically in women who identified as having non-Medicaid government insurance and not privately or Medicaid-insured women. However, it is essential to note that in 2019, the National Center for Veterans Analysis and Statistics reported that since 1990, the total number of veterans had been steadily decreasing while the number of service-connected disabilities in veterans was increasing [27]. In 2018, the number of veterans dropped to just over 19 million, down from over 21 million in 2008. The total number of veterans with a service-connected disability rose from about 3 million in 2008 to over 4.5 million in 2018 [27]. The increase in service-connected disabilities, which would lead to coverage for millions of spouses and children of disabled veterans, could shed light on the increase in reporting

non-Medicaid government insurance programs among women with endometriosis from 2008 to 2018.

A 2020 article by Colorado attorney Mack Babcock details how a chronic condition such as endometriosis could be eligible for coverage under WC in the US. To be eligible for WC, chronic pain must result from a work-related injury or occupational disease, and the employee must prove that [their] pain arises from an incident or exposure at work [28]. Although endometriosis and its symptoms can impair a woman's physical, mental, and socio-emotional well-being [14] and thus has the potential to be very debilitating [20, 21], it is not formally recognized as a disability in the Social Security Administration (SSA) Blue Book. However, those with endometriosis may be eligible for Social Security Disability (SSD) payments via the medical-vocational allowance program. To be considered for this program, women must prove that they are unable to work by completing a Residual Functional Capacity (RFC) assessment with their doctor. The application for SSD assistance requires women to submit an overwhelming amount of medical and financial evidence to prove that one is unable to work due to endometriosis. These documents include medical records detailing one's diagnosis, treatments, laboratory results, surgical history, and a written statement from a treating physician that explains how the condition impacts one's "day-to-day abilities [29]. Unfortunately, this form of compensation may be unattainable for women with endometriosis who cannot procure extensive documentation. The many barriers to an endometriosis diagnosis [6, 9, 10] can take over a decade [2, 3]. Even after being diagnosed, one will still need to supply a plethora of evidence suggesting treatment programs or surgical procedures. It is reasonable to suggest that women who need disability compensation because of endometriosis may not be able to access coverage in this way due to barriers in the application and approval process. From the point of application, it can take several months to receive a decision from the SSA, and even then, more than half of all initial applications are denied, with approval coming for some only after appealing the denial within two months of the decision being made [29]. Such a lengthy bureaucratic process can be discouraging for women who urgently need assistance.

Even insured women who can afford quality health care may experience barriers to endometriosis diagnoses [10]. We found that the prevalence of self-reported endometriosis decreased, consistent with the findings of a study by Christ et al., in which endometriosis diagnoses decreased from 2006-2015 [7]. Although our study demonstrated that the observed prevalence of endometriosis decreased, it does not necessarily mean the burden of the disease decreased. Interestingly, Christ and colleagues also found that the decrease in endometriosis diagnoses was associated with an equal increase in chronic pelvic pain diagnoses, a symptom commonly associated with endometriosis [7]. Additionally, it has been shown that clinically, endometriosis symptoms overlap with many other pain-associated syndromes [3, 14, 20]. Decreased endometriosis diagnoses among privately insured women reflects a similar

shift in diagnostic trends. These trends may result in women with endometriosis receiving effective treatment of symptoms of endometriosis (i.e., pelvic pain) without pursuing the often-lengthy process of an endometriosis diagnosis and subsequent treatment.

The implementation of the ACA brought benefits to improve access to endometriosis diagnosis. The ACA mandated that health insurance plans cover essential health benefits, including preventive services and women's reproductive health. These policy changes and provisions can reduce the financial barriers for individuals seeking an endometriosis diagnosis and potentially lead to earlier detection and intervention.

5. Limitations

Despite sourcing data from a nationally representative sample, this study has limitations. The NSFG collects data via face-to-face interviews in respondents' homes using a computer-guided and computer-assisted self-interview questionnaire. The NSFG excludes institutionalized populations such as prisons, homes for juvenile delinquents, homes for the intellectually disabled, long-term psychiatric hospitals, those living on military bases, and people experiencing homelessness. For this reason, generalizability to the entire US population is limited. Second, the data are based on self-reports, which can be subject to recall or reporting bias.

6. Conclusion

This study reports disparities in the prevalence of endometriosis among females aged 15-44 between 2008 and 2018. Using data from the National Survey of Family Growth, we examined differences in the prevalence of endometriosis among females aged 15-44 before and after the passage of the Affordable Care Act (ACA). The findings of this study suggest that socio-demographic factors and type of health insurance were predictors of self-reported endometriosis in the US before and after the ACA. Health insurance is a key determining factor in one's access to quality health care in the US, along with income and educational attainment. Women with endometriosis face unique barriers to care and treatment based on their social determinants of health. While the ACA, its expansion, and other policies have sought to extend insurance coverage to all Americans, coverage gaps still adversely impact women with endometriosis. There must be a concerted effort by policymakers to make data-driven decisions to inform the policies that allow healthcare providers to provide care to the millions of American women who have endometriosis.

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