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The impact of endometriosis on women's life decisions and goal attainment

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The impact of endometriosis on women's life decisions and goal attainment

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ABSTRACT

Objective To examine women's perceptions of endometriosis-associated disease burden and its impact on life decisions and goal attainment.

Methods: An anonymous online survey was distributed in October 2018 through the social media network MyEndometriosisTeam.com to women aged 19 years and older living in several English-speaking countries who self-identified as having endometriosis.

Results: A total of 743 women completed the survey (69% from North America, 17% United Kingdom, 6% Oceania/Australia). Women reported high levels of pain when pain was at its worst (mean score, 8.9 on severity scale of 0 [no pain] to 10 [worst imaginable pain]) and most (56%) experienced pain daily. Women reported other negative experiences attributed to endometriosis, including emergency department visits (66%), multiple surgeries (55%), and prescription treatments for symptoms of endometriosis (72%). Women indicated that they believed endometriosis had a negative impact on their educational and professional achievements, social lives/relationships, and overall physical health. Most women "somewhat agreed"/ "strongly agreed" that endometriosis caused them to lose time in life (82%), have a less positive opinion about their future (80%), and had prohibited them from reaching their full life potential (76%).

Conclusion: Pain and negative experiences related to endometriosis were perceived to negatively impact major life-course decisions and attainment of goals. Greater practitioner awareness of the impact endometriosis has on a woman's life-course and the importance of meaningful dialogue with patients may be important to improve long-term management of the disease and help identify women who are most vulnerable.

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3 **Abstract Word Count: 241**
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7 **Strengths and limitations of this study**
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- 11 • Strength: Quantitative survey of meaningful sample size spanning multiple countries
 - 12 • Strength: Targeted research questions were made possible by use of a social network
13 that allowed questions to be developed based on existing conversations on the platform
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 - 15 • Strength: Use of social network familiar to patients may have led to increased honesty in
16 responses to sensitive topics
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 - 18 • Limitation: No comparisons were made between women who had endometriosis versus
19 women who did not have endometriosis or women who had other chronic conditions,
20 particularly those associated with pain
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 - 22 • Limitation: Patient responses were self-reported and not confirmed by medical records
23 or other data
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BACKGROUND

Endometriosis is an often chronic gynecologic disorder that impacts 10% of women of reproductive age.¹ Endometrial-like tissue thriving outside the uterus leads to local and systemic inflammation that can result in a wide range of life-impacting effects, including pelvic pain, dysmenorrhea, dyspareunia, and infertility.²⁻⁴ These debilitating effects have an immense impact on a patient's quality of life and overall well-being.^{5,6} For example, symptoms of endometriosis may have a negative impact on women's psychological health,^{7,8} strain social and intimate relationships,^{5,9-11} and lead to losses in productivity both at home and in the workplace.¹²

Outside the physical and emotional toll, the collective symptoms of endometriosis are also associated with direct and indirect costs that are burdensome to patients. Visits to physicians, visits to the emergency department, pharmacy claims, and other direct expenses are estimated to cost between \$12,000 to \$15,000 per patient per year in the United States, and the loss of work and productivity may amount to additional thousands of dollars lost per patient.¹²⁻¹⁶

Most studies examining chronic diseases like endometriosis focus on one or two specific areas of the disease, such as its social, physical, or psychological impact at a specific point in time.^{17,18} In contrast, few studies have examined the life-course impact of endometriosis and how symptoms and experiences resulting from the disease influence major life events, decisions, and the overall ability of patients to attain their life goals.^{17,18} The few existing studies have small sample sizes or are qualitative, relying on informational interviews to ascertain life-course impact of the disease.^{11,19,20} Understanding life-course impairment as opposed to focusing on the symptoms of the disease (such as pain or infertility that are most often addressed individually not holistically) is vital because of the complicated interrelationship among symptoms and their downstream effects. Individual symptoms can influence critical life

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3 decisions (eg, work, education, or personal relationships) in ways that are interrelated and can
4 impact other areas of a patient's life. For example, chronic pain may influence the type and
5 amount of work performed or whether a patient decides to work at all, which in turn can have
6 financial implications on the patient's lifestyle, family, relationships, or sense of personal
7 fulfillment.^{17,18} Symptoms may determine where a patient chooses to live because of financial
8 considerations, healthcare access, or proximity to support networks. Similarly, dyspareunia
9 related to endometriosis may lead some women to avoid intimate relationships, which may have
10 downstream implications for marriage, family planning, and mental and emotional health.^{21,22}
11 Cumulatively, persistent symptoms of endometriosis and their impact on daily activities and
12 family and intimate relationships can negatively impact the trajectory of women's lives and are
13 profound and far reaching.
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28 Examining the cumulative life-course impact of endometriosis may have an influence on a
29 physician's ability to understand a woman's complete experience with the disease, help identify
30 patients who are most vulnerable to its impacts, and inform options for management.^{18,20,23,24} A
31 fuller understanding of the life-course impact of endometriosis may also elucidate patterns of
32 patient needs and identify forms of supportive multidisciplinary care necessary, including the
33 need for early referral to specialists and other professionals who provide complementary
34 healthcare. These needs are likely to change over time, during different phases of each
35 patient's life. For example, teams that include gynecologists and pain specialists may help
36 patients manage endometriosis-associated pain symptoms; reproductive endocrinologists may
37 help manage infertility, if this occurs; sexual health counselors may collaborate with patients
38 who have dyspareunia; and counselors/psychologists may assist with chronic stress and mental
39 health issues.²⁵ Physicians who are responsive to patients' individual needs and values can
40 positively support overall quality of life in those patients who experience infertility^{26,27} and
41 endometriosis.²¹
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3 The objective of this multinational survey was to gain a better understanding of patient
4 perspectives on how endometriosis impacts their daily activities and identify how the disease
5 may influence women's major life decisions and attainment of their goals.
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10 11 **METHODS**

12 13 14 15 **Ethics approval**

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17 The Advarra Institutional Review Board (Columbia, MD, USA) reviewed the cross-sectional
18 survey for participants in the United States (exempt determination #Pro00029982,
19 26 September 2018). Informed consent was not obtained due to the exempt nature of this
20 survey; however, participants did consent to participate in a survey and email invitations were
21 provided to people who opted to receive communications.
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32 33 **Survey development**

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35 An online survey was created in a collaborative effort between AbbVie (North Chicago, IL, USA)
36 and MyHealthTeams (San Francisco, CA, USA), a company that creates social networks for
37 communities of individuals living with chronic conditions to foster discussion and provide support
38 among people facing similar circumstances. The survey was provided in English and was
39 available online from October 3 through October 25, 2018. The 14 survey questions about
40 women's experiences with endometriosis were based on our knowledge about the disease
41 state, existing publications, and online conversations participants were having (**see Patient and**
42 **public Involvement** for further details). In addition, the survey contained 4 screening questions
43 and 6 demographic questions (identified as Supporting Information). The primary goal of the
44 survey was to capture patients' perspectives on the negative impact of endometriosis on
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3 different aspects of their life course, including how endometriosis has affected their work,
4 education, relationships, overall life decisions, and attainment of goals. This portion of the
5 survey was modeled after a validated instrument created to measure life-course impact of
6 disease in patients with psoriasis.²² Survey questions were rotated to avoid any bias introduced
7 by order-of-answer selections. Most survey questions were closed-ended and provided multiple-
8 choice options to participants; two questions were open-ended and allowed participants to
9 provide written responses detailing any life accomplishments they believed were impeded by
10 endometriosis or to offer anything else they wanted to share about the impact endometriosis
11 had on their lives. The survey used in this study is included in the supplementary material.
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24 **Patient and public involvement**

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28 Survey questions were developed based on organic conversations members were having on
29 MyEndometriosisTeam.com to ensure both relevance of topics and patient-focused language,
30 and then piloted with several individuals for qualitative feedback. The social media network,
31 MyEndometriosisTeam.com was developed for women living with endometriosis and consists of
32 more than 108,000 members across 13 countries. Based on institutional review board
33 exemption requirements, people were asked at the beginning of the survey if they agreed to
34 participate, and email invitations were sent only to those people who opted into receiving
35 communications.
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47 **Participant eligibility and recruitment**

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51 Members of the social network MyEndometriosisTeam.com were recruited through 33,000 email
52 invitations. Invitations posted on the public Facebook page for MyEndometriosisTeam.com
53 recruited additional women to participate in the survey, which was live from October 3 to
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3 October 25, 2018. The English-language survey was conducted among an international
4 population of women who were at least 19 years of age and who self-identified as having
5 endometriosis. The survey was anonymous, and answers could not be linked to individual
6 members.
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11 12 13 **Survey analysis**

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17 Descriptive statistics were used to tabulate survey responses in this cross-sectional study. After
18 descriptive statistics were quantified for all respondents, a subanalysis was performed that
19 restricted the survey responder population to women who “somewhat agreed” or “strongly
20 agreed” that they were “less positive about the future” (LPAF) or that they “had not reached their
21 full potential” (NRFP) because of endometriosis. These two questions were selected for this
22 subanalysis to focus on the life-course impact attributed to endometriosis as identified by those
23 who reported low optimism or low goal attainment.
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34 **RESULTS**

35 36 37 **Survey response and demographics**

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42 A total of 743 women completed the survey (table 1), which was live from October 3 to October
43 25, 2018.
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49 Among respondents to the English-language survey, 474 (64%) were from the United States,
50 and 269 (36%) were from other countries, including one-fifth from the United Kingdom (17%),
51 and one-fifth summed from Canada, Australia, South Africa, Ireland, New Zealand, and The
52 Netherlands (table 1). Most women were younger than age 40 years. Almost half of the
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Missmer SA, *et al*

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3 respondents were unaware of their stage of endometriosis (according to the rASRM scoring
4 system), which was obtained at their most recent surgery (48%). Among the 52% respondents
5 who recalled knowing their rASRM score, most reported having stage 4 (table 1).
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Table 1 Demographics and burden of endometriosis

Characteristic	Respondents, n (%) (N=743)
Age at time of survey, years	
19–29	206 (28)
30–39	339 (46)
40–49	180 (24)
50 or older	18 (2)
Country	
United States (excluding Puerto Rico)	474 (64)
United Kingdom	128 (17)
Canada	38 (5)
Australia	37 (5)
South Africa	20 (3)
Ireland	17 (2)
Other	15 (2)
New Zealand	11 (1)
The Netherlands	3 (0.4)
Level of education	
Some high school or less	33 (4)
High school diploma	111 (15)
Some college	214 (29)
College degree	254 (34)
Graduate school/degree	111 (15)
Prefer not to answer	20 (3)
Endometriosis stage	
Stage 1	33 (4)
Stage 2	39 (5)
Stage 3	93 (13)
Stage 4	223 (30)
Not sure	355 (48)
Method of diagnosis	
Laparoscopic surgery	650 (87)
Clinical only	87 (12)
Not sure	6 (0.8)

Diagnosis and symptoms

Diagnosis

Women began experiencing symptoms of endometriosis at a young age, with many experiencing symptoms by age 15. Most women reported having a diagnosis of endometriosis made several years after the appearance of symptoms, on average approximately 9 years. Nearly half of women (42%) said it took 10 years or longer after the initial onset of their symptoms to receive a surgical or clinical diagnosis of endometriosis. The delay was longer the younger the woman's age at symptom onset; it took an average of 13 years to surgical diagnosis for women who began experiencing symptoms by age 13. Most women reported their diagnosis had been confirmed by laparoscopy (table 1).

Endometriosis-associated pain

Most women (56%) reported experiencing pain daily, and nearly an additional one-quarter of women reported feeling endometriosis-associated pain a few times per week. When asked to rate how severe their pain was in the last 12 months on a scale from 0 (no pain) to 10 (worst imaginable pain), more than half of the respondents (54%) rated their worst pain within the last 12 months as a 9 or 10. About two-thirds of women reported their endometriosis-associated pain had worsened over the years when asked if endometriosis-related pain had gotten better, worse, or stayed the same.

Life-course impairment

Education and employment potential

Many of the women surveyed (40%) said they “somewhat agreed” or “strongly agreed” that they had experienced difficulties achieving their educational goals or had missed school (55%) because of endometriosis-associated symptoms (figure 1A). Almost half of participants (45%) “somewhat agreed” or “strongly agreed” that they could not work full time, and a similar percentage (47%) reported not working at a job they would have preferred. Most reported that they had missed work (74%) or earned less money than they could have (54%) because of endometriosis-associated symptoms.

Relationships and social engagements

Most women (83%) “somewhat agreed” or “strongly agreed” that endometriosis-associated symptoms led to problems in their intimate relationships and/or created a barrier to starting a family (58%). Most women similarly believed that endometriosis-associated symptoms had led them to limit their social activities (82%), made them less outgoing (81%), and caused them to travel less (59%) (figure 1B).

Physical well-being

Most women “somewhat agreed” or “strongly agreed” endometriosis limited their ability to stay active (79%) and maintain a healthy diet (55%) (figure 1C). A high proportion of women (43%) perceived that endometriosis-associated symptoms resulted in use of alcohol, drugs, or cigarettes.

Life-course impairment overall

Overall, most women (80%) “somewhat agreed” or “strongly agreed” endometriosis-associated symptoms had caused them to lose time from their daily lives (figure 1D). A similar number of women reported that they were less positive about the future because of their endometriosis-associated symptoms (80%), and 75% “somewhat agreed” or “strongly agreed” that endometriosis-associated symptoms had kept them from reaching their full potential in life.

Experiences and emotions associated with endometriosis

Women reported that numerous experiences attributed to endometriosis had altered their life potential in a negative way (figure 2A) or negatively impacted their lives in other ways (figure 2B). The most frequent responses were common symptoms of endometriosis, including pelvic pain apart from menstruation, painful menstruation, pelvic pain during menstruation, and painful sexual intercourse.

Most women surveyed reported that endometriosis impacted their ability to perform daily tasks. However, many of the negative experiences attributed to endometriosis were related to the use of healthcare services and treatments. For example, women reported taking prescription pain medications, visiting emergency departments, having multiple surgeries, being hospitalized overnight, taking prescription medication for depression or anxiety, or seeing a mental health professional because of their endometriosis-associated symptoms. Around half the women surveyed reported that the experiences that had the most negative impact on their lives were their need to take prescription medication and the multiple surgeries for endometriosis. In addition, most women surveyed reported several negative emotions that they attributed to endometriosis, including feeling depressed, anxious, unsexy, or having low self-esteem (figure 2C).

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3 Women managed the impact of their endometriosis in different ways (figure 2D). Most
4 commonly this included talking to a spouse or partner about their condition, using non-medical
5 strategies such as diet or exercise to control their pain and seeking support from friends and
6 family.
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11 12 13 **Additional analysis of women who believed their future and life potential were more** 14 **impacted by endometriosis** 15

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18 Most of the sample included women who “somewhat agreed” or “strongly agreed” they were
19 LPAF (79%; n=589) or had NRFP in life (75%; n=556) because of endometriosis, and several
20 questions limited to these women were further analyzed (Supporting Information table 1).
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23 Overall, women who believed they were LPAF or had NRFP reported more negative
24 experiences compared with the fewer respondents who did not indicate they were LPAF (non-
25 LPAF, 21%; n=154) or had NRFP (non-NRFP, 25%; n=187). Daily pain was reported by a
26 higher proportion of women who believed they were LPAF or had NRPF because of
27 endometriosis compared with other women (62% LPAF vs 34% non-LPAF; 61% NRFP vs 40%
28 non-NRFP; Supporting Information table 1A). More women who believed they were LPAF or
29 had NRFP also reported negative experiences related to education and work they attributed to
30 endometriosis, including having earned less money (61% LPAF vs 29% non-LPAF; 66% NRFP
31 vs 21% non-NRFP), not working a preferred job (54% LPAF vs 25% non-LPAF; 58% NRFP vs
32 17% non-NRFP), or not achieving educational goals (44% LPAF vs 21% non-LPAF; 47% NRFP
33 vs 16% non-NRFP) (Supporting Information table 1B). A higher proportion of women who
34 believed their future and life potential were more impacted by their disease reported
35 endometriosis-related experiences altered their life potential in a negative way (Supporting
36 Information table 1C). Similarly, more of these women reported negative experiences and
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3 emotions they attributed to endometriosis (Supporting Information table 1D, E). All women used
4 similar strategies to cope with and mitigate the impact of endometriosis on their lives
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7 (Supporting Information table 1F).
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11 **DISCUSSION**

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16 A survey of women with endometriosis who self-reported pronounced symptoms also reported
17 experiences that were perceived by them to negatively impact their views of the future and
18 overall life potential. For many women, endometriosis-associated symptoms negatively affect
19 various areas of their lives, including education and employment, relationships and social
20 engagements, and physical well-being. Participants indicated that adverse experiences related
21 to management of their disease and its impact on everyday life also believed that their future
22 and life potential was negatively impacted by endometriosis.
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32 The severity of pain reported by women who completed the online survey indicates that
33 respondents in our study may have had a greater symptom burden than did women participating
34 in previous studies using similar pain scales.²⁸⁻³⁰ Women in our study also reported slightly
35 lengthier delays in diagnosis after the onset of their first symptoms. Findings in previous studies
36 have illustrated that delays are common in diagnosing endometriosis.^{13,31-39} Although some
37 recent literature suggests that the delay in diagnosis may be slowly improving,³⁷ the use of non-
38 invasive and accurate diagnostic tools could improve diagnosis times and reduce women's pain
39 and distress.^{39,40} The delays in diagnosis reported by our study participants and others indicate
40 many women experiencing troublesome symptoms of endometriosis may still wait extended
41 periods before receiving a definitive diagnosis and initiating treatment.
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3 The higher pain burden and longer diagnostic delay reported in our sample, which may include
4 higher numbers of women who sought social network support because they were more
5 frustrated with their disease experience, could conceivably be due in part to their longer
6 struggles with more challenging symptoms than would be observed in the general population of
7 women with diagnosed endometriosis. Results from a recent study using the same social
8 network to recruit participants found that the majority of respondents rated their worst pain
9 higher than 7 on a 10-point scale, only a little lower than the pain rating given by the women in
10 our study.⁴¹ Additionally, the previous study participants also experienced a diagnostic delay,
11 supporting the theory that recruitment from this member-centered network may draw more
12 women who have struggled longer with their disease.⁴¹ Interestingly, overall trends in diagnostic
13 delays observed between age groups in our study are consistent with reports in previous
14 research, that being women whose symptom onset was at a younger age experienced longer
15 times to diagnosis.^{13,33,37}

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33 Many respondents said they missed school and were generally unable to achieve their
34 educational goals because of endometriosis. There is a dearth of research on the impact of
35 endometriosis on women's educational aspirations and their ability to achieve goals due to
36 endometriosis-associated symptoms compared with the impact endometriosis has on
37 professional work or other areas of life.⁹ Findings from some existing studies suggest
38 endometriosis-associated symptoms may impact grades, attendance, or completion of
39 educational programs.^{19,20,42} Although informative, these studies were more qualitative in nature
40 and involved small sample sizes.^{19,20,42} A quantitative study examining the lives of 78 women
41 15 years after receiving a verified diagnosis of endometriosis found only a fraction of women
42 reported that their disease had a negative impact on their education.¹¹ However, the women
43 included in that study seemed to report less frequent pain and endometriosis-related effects like
44 depression compared with the reports made by women in our study. Furthermore, the small

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3 sample was collected at a single Norwegian hospital and the findings may not be representative
4 of women's experiences with endometriosis on a wider scale.¹¹ Regardless, any impact on
5 education is concerning, and our study results emphasize the need for additional research into
6 this overlooked area in women with endometriosis. Research on other medical conditions, like
7 adolescent fibromyalgia, supports that chronic pain can negatively impact education, reinforcing
8 the likelihood that endometriosis may have a similar impact.^{43,44}
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18 Respondents in the current study also reported endometriosis-associated symptoms caused
19 them to miss work, earn less money, prevented them from a job they would have preferred, or
20 impeded their working full time or part time. Many health conditions that can occur with
21 endometriosis can impact work productivity and potential, including depression, other chronic
22 pain conditions or disorders, and digestive disorders.⁴⁵ Endometriosis was self-reported by
23 respondents in this study, and it is possible that other chronic conditions (particularly, chronic
24 overlapping pain conditions) may also contribute to women's perceived interference with
25 productivity and employment opportunities. Indeed, more than half of women with symptomatic
26 endometriosis can present with comorbid pain syndromes,⁴⁶ and these may include conditions
27 associated with pelvic pain, like dysmenorrhea, irritable bowel syndrome, or painful bladder
28 syndrome.^{47,48} However, findings from previous studies have illustrated that endometriosis-
29 associated symptoms may lead to losses in productivity both at home and in the workplace,
30 potentially impacting professional achievement.^{12,36,49,50} In our study, higher proportions of
31 women who indicated that they were LPAF or had NRFP because of endometriosis reported
32 painful symptoms and negative experiences compared with other respondents. Also, women
33 who were LPAF or had NRFP more often believed it was harder for them to perform daily tasks
34 because of their disease.
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3 Our results further support that endometriosis symptoms are disruptive and may lead to loss of
4 productivity, ultimately influencing women's major life decisions or consequences, including
5 whether to work at reduced capacity or pursue preferred jobs. Results from a recent multicenter
6 study of women with confirmed endometriosis and a matched comparison group found the
7 disease forced some women to seek work outside desired professions, which, in turn, resulted
8 in health-related limitations in career choices.⁵⁰ These collective findings are concerning,
9 because satisfaction in a chosen profession—or at a minimum options available to make life
10 decisions regarding one's profession—is an important component of an overall satisfying quality
11 of life, and the decision to work less or pursue a less desirable job may have downstream
12 implications for women's finances, relationships, social lives, or travel decisions.^{17,50}
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26 Respondents to our survey reported endometriosis had a negative impact on their relationships;
27 social engagements; and ability to have children, when desired, which is consistent with findings
28 from a host of previous studies demonstrating the negative impact of endometriosis on social
29 well-being and health-related quality of life.^{9,12,36,49} Interestingly, 46% of women in our study who
30 reported experiencing infertility is slightly higher than the 14%–40% range reported in previous
31 studies, again hinting at our population's higher symptom burden.^{36,41,51} Other chronic pain
32 conditions have also impacted these life-course components, including conditions related to
33 musculoskeletal pain and chronic back pain.^{52,53}
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44 Similar to decisions involving education and professional achievement, life choices involving the
45 pursuit of intimate relationships or starting a family may have downstream implications in other
46 areas, like finance, psychological well-being, or employment, which may have their own
47 downstream impacts on additional aspects of a person's life course.¹⁷ Likewise, women
48 frequently reported not being physically active and having poorer diets because of their disease.
49 Although few studies have examined this aspect of endometriosis, findings from two smaller
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3 studies have suggested that pain associated with the disease may also have a negative impact
4 on exercise and nutrition.^{9,32,54}
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9 Of particular concern was the view of many women that their disease made them increase their
10 use of alcohol, drugs, or cigarettes. Research into whether pain and experiences related to
11 endometriosis may be associated with higher rates of substance abuse is severely lacking.
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13 However, there are demonstrated associations between other chronic pain conditions and
14 substance abuse that support our finding.^{55,56} Results from our study draw attention to this issue
15 and highlight substance abuse as an important avenue for additional investigations.
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24 Findings from our study indicate that women with endometriosis may experience many
25 healthcare-related side effects. Of particular concern, patients noted that treatments meant to
26 help reduce the burden of endometriosis may have their own negative impact. Many women
27 perceived that use of prescription medications and multiple surgeries to control the symptoms of
28 endometriosis had a negative impact on their life potential, and this response was stronger in
29 women who indicated they were LPAF or believed they had NRFP due to their disease. Results
30 from one recent study showed that medical treatment for a condition may increase a patient's
31 stress levels and potentially affect their psychological health.⁵⁷ Patients who were taking
32 prescription medications and who experienced more challenging adverse effects from their
33 therapies had higher perceived stress levels, and women undergoing multiple surgeries were
34 especially impacted. These reports underscore the potential value of supportive psychological
35 care for patients with endometriosis as part of effective long-term disease management.
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51 In general, women experienced a range of consequences that they attributed to living with and
52 managing the limitations imposed by endometriosis. While each woman experienced the impact
53 of endometriosis differently, the majority believed that they were living life less fully than they
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3 could have because of their endometriosis-associated symptoms. This belief was informed by
4 the symptoms and healthcare requirements they faced, and, in turn, may have influenced major
5 life decisions that could have their own deleterious effects on personal fulfillment and life
6 potential. The interconnectedness of effects triggered by major life decisions highlights the
7 importance of conducting further research into the cumulative burden of debilitating diseases
8 like endometriosis within the context of an individual's life course.
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CONCLUSIONS

Most women in our international survey experienced a high burden associated with the disease and reported that endometriosis-associated pain and associated experiences had a negative impact on their outlook about their future and overall life potential. Women believed endometriosis impacted life decisions surrounding education, their professional lives, their social lives, and their physical well-being. Our study of the impact of endometriosis on a woman's life course helps provide a clearer understanding of her complete experience with their disease. Our findings also suggest there is a need to develop early, effective treatments and to provide access to effective treatment to limit the impact of endometriosis on a woman's life course.

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Missmer SA, *et al*

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11
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30 **Data Sharing Statement**

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33 AbbVie is committed to responsible data sharing regarding the clinical trials and
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35 studies we sponsor. This includes access to anonymized, individual and trial-level data
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37 (analysis data sets), as well as other information (eg, protocols and clinical study
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39 reports), as long as the trials are not part of an ongoing or planned regulatory
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41 submission. This includes requests for clinical trial data for unlicensed products and
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43 indications.
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47 This study data can be requested by any qualified researchers who engage in rigorous,
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49 independent scientific research, and will be provided following review and approval of a
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51 research proposal and statistical analysis plan and execution of a data sharing
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53 agreement. Data requests can be submitted at any time and the data will be accessible
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55 for 12 months, with possible extensions considered. For more information on the
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FIGURE LEGENDS

Figure 1 Life course impact of endometriosis. Women were asked to indicate how much they agreed with statements involving the impact of endometriosis on (A) educational and professional achievements, (B) social life and relationships, (C) physical well-being, (D) overall life course.

Figure 2 Experiences and emotions attributed to endometriosis. Respondents were asked to select which experiences related to endometriosis had the most negative impact on their life potential (A). Women were also asked to indicate which general negative experiences (B) and emotions (C) they had undergone because of endometriosis and what kinds of approaches they had taken to manage the impact of endometriosis (D).

FIGURE 1

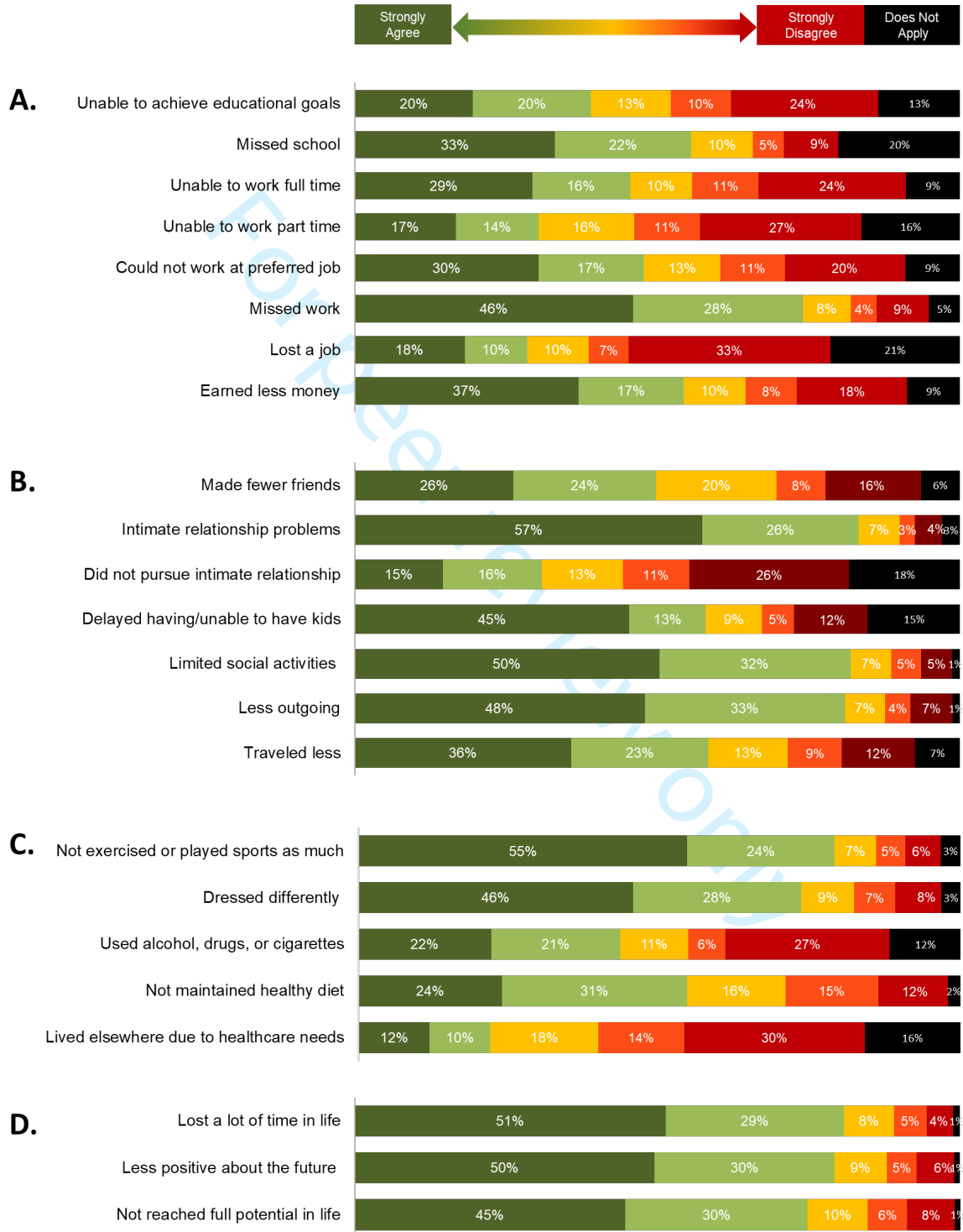
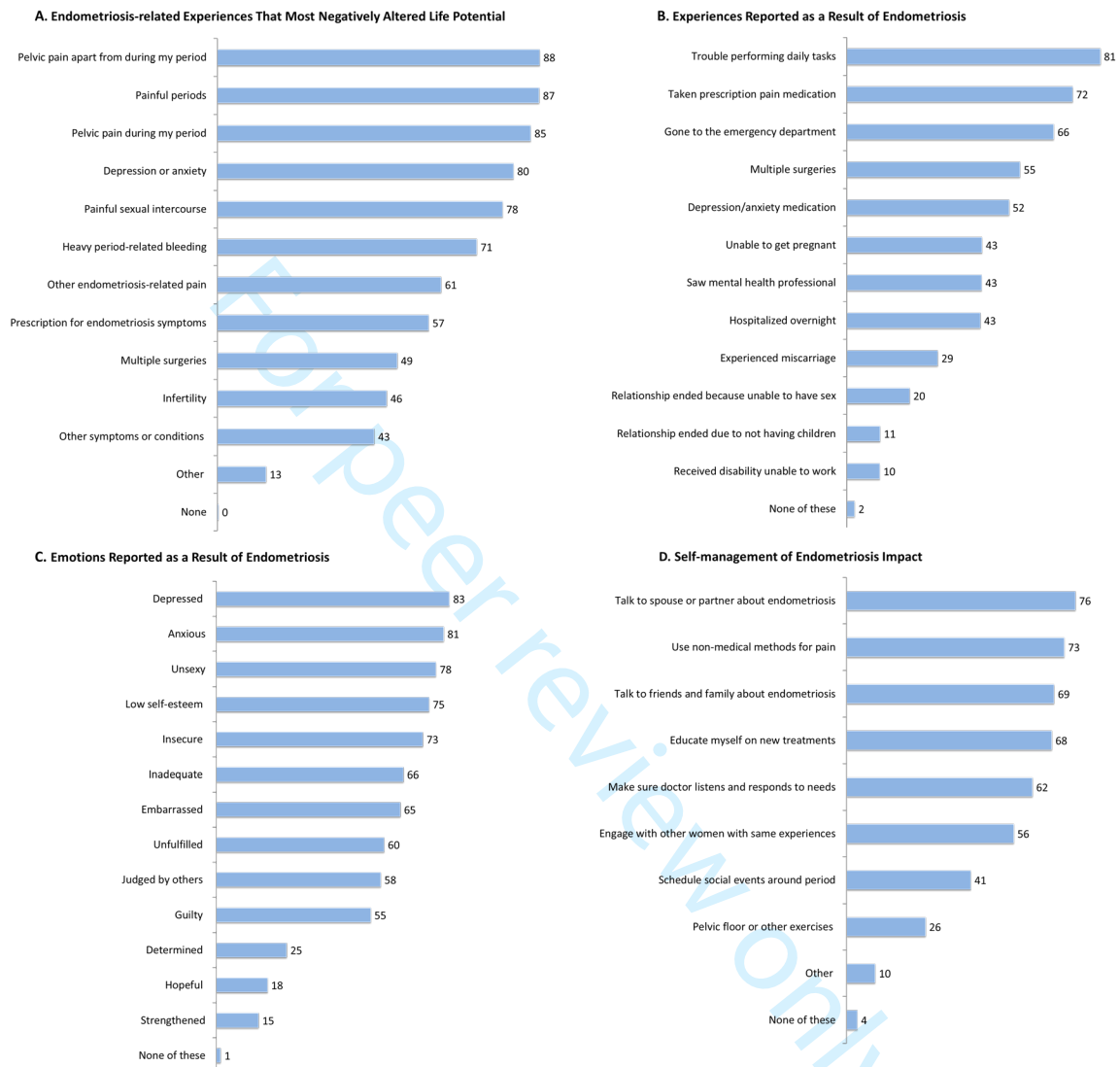


FIGURE 2



The impact of endometriosis on women's life decisions and goal attainment

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Samantha Eichner,³ Oscar Antunez Flores,³ Andrew W Horne,⁴ Beth Schneider,⁵ Sawsan As-
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SUPPORTING INFORMATION

Supporting Information Table 1. Women indicated how much they agreed or disagreed with the impact of endometriosis on the following: (A) pain, (B) work and education, (C) life experiences altered in a negative way, (D) impact on life, (E) feelings, (F) management of impact.

Survey. MyEndometriosisTeam Survey – Life Course Impact Survey

Supporting Information Table 1.

S1A	Daily	A few times a week	A few times a month	Weekly	Monthly	Every few months	Never	Once or twice a year
Total, n (%) (N = 743)	415 (55.9)	160 (21.5)	78 (10.5)	43 (5.8)	31 (4.2)	9 (1.2)	4 (0.5)	3 (0.4)
Less positive about future, n (%) (n = 589)	362 (61.5)	120 (20.4)	50 (8.5)	31 (5.3)	16 (2.7)	6 (1.0)	2 (0.3)	2 (0.3)
Remaining respondents (n = 154)	53 (34.4)	40 (26.0)	28 (18.2)	12 (7.8)	15 (9.7)	3 (1.9)	2 (1.3)	1 (0.6)
Did not reach full potential, n (%) (n = 556)	341 (61.3)	121 (21.8)	44 (7.9)	28 (5.0)	13 (2.3)	6 (1.1)	2 (0.4)	1 (0.2)
Remaining respondents (n = 187)	74 (39.6)	39 (20.9)	15 (8.0)	34 (18.2)	18 (9.6)	3 (1.6)	2 (1.1)	2 (1.1)

S1B	Missed days of work	Missed school	Earned less money	Could not work at preferred job	Unable to work full time	Unable to achieve educational goals	Unable to work part time	Lost a job
Total, n (%) (N = 743)	550 (74.9)	413 (56.3)	404 (55.0)	355 (48.4)	338 (46.0)	290 (39.5)	226 (30.8)	212 (28.9)
Less positive about future, n (%) (n = 589)	463 (78.6)	343 (58.2)	359 (61.0)	316 (53.7)	300 (50.9)	257 (43.6)	202 (34.3)	190 (32.3)
Remaining respondents (n = 154)	87 (56.5)	70 (45.5)	45 (29.2)	39 (25.3)	38 (24.7)	33 (21.4)	24 (15.6)	22 (14.3)
Did not reach full potential, n (%) (n = 556)	448 (80.6)	329 (59.2)	365 (65.6)	323 (58.1)	295 (53.1)	261 (46.9)	205 (36.9)	193 (34.7)
Remaining respondents (n = 187)	102 (54.5)	84 (44.9)	39 (20.9)	32 (17.1)	43 (23.0)	29 (15.5)	21 (11.2)	19 (10.2)

Missmer SA, *et al*

S1C

	Pelvic pain apart from period	Painful periods	Pelvic pain during period	Depression or anxiety	Painful sexual intercourse	Heavy period- related bleeding	Other endometriosi s-related pain	Taken prescription for symptoms	Multiple surgeries	Infertility	Other symptoms or conditions
Total, n (%) (N = 743)	651 (87.6)	650 (87.5)	633 (85.2)	598 (80.5)	576 (77.5)	524 (70.5)	452 (60.8)	427 (57.5)	363 (48.9)	342 (46.0)	317 (42.7)
Less positive about future, n (%) (n = 589)	528 (89.6)	517 (87.8)	506 (85.9)	505 (85.7)	461 (78.3)	413 (70.1)	382 (64.9)	353 (59.9)	297 (50.4)	272 (46.2)	268 (45.5)
Remaining respondents (n = 154)	123 (79.9)	133 (86.4)	127 (82.5)	93 (60.4)	115 (74.7)	111 (72.1)	70 (45.5)	74 (48.1)	66 (42.9)	70 (45.5)	49 (31.8)
Did not reach full potential, n (%) (n = 556)	500 (89.9)	491 (88.3)	482 (86.7)	476 (85.6)	430 (77.3)	400 (71.9)	366 (65.8)	332 (59.7)	284 (51.1)	261 (46.9)	259 (46.6)
Remaining respondents (n = 187)	151 (80.7)	159 (85.0)	151 (80.7)	122 (65.2)	146 (78.1)	124 (66.3)	86 (46.0)	95 (50.8)	79 (42.2)	81 (43.3)	58 (31.0)

S1D

	Trouble performing daily tasks	Taken Rx pain medication	Gone to ER	Multiple surgeries	Depression/ anxiety medication	Unable to get pregnant	Saw mental health professional	Hospitalized overnight	Experienced miscarriage	Relationship ended because unable to have sex
Total, n (%) (N = 743)	594 (80.9)	529 (72.1)	485 (66.1)	406 (55.3)	380 (51.8)	317 (43.2)	316 (43.1)	313 (42.6)	213 (29.0)	147 (20.0)
Less positive about future, n (%) (n = 589)	500 (84.9)	442 (75.0)	406 (68.9)	333 (56.5)	327 (55.5)	251 (42.6)	276 (46.9)	266 (45.2)	167 (28.4)	132 (22.4)
Remaining respondents (n = 154)	94 (61.0)	87 (56.5)	79 (51.3)	73 (47.4)	53 (34.4)	66 (42.9)	40 (26.0)	47 (30.5)	46 (29.9)	15 (9.7)
Did not reach full potential, n (%) (n = 556)	478 (86.0)	421 (75.7)	390 (70.1)	311 (55.9)	308 (55.4)	239 (43.0)	265 (47.7)	249 (44.8)	166 (29.9)	132 (23.7)
Remaining respondents (n = 187)	116 (62.0)	108 (57.8)	95 (50.8)	95 (50.8)	72 (38.5)	78 (41.7)	51 (27.3)	64 (34.2)	47 (25.1)	15 (8.0)

S1E		Depressed	Anxious	Unsexy	Low self-esteem	Insecure	Inadequate	Embarrassed	Unfulfilled	Judged by others	Guilty
Total, n (%) (N = 743)		607 (82.7)	592 (80.7)	572 (77.9)	554 (75.5)	538 (73.3)	487 (66.3)	479 (65.3)	437 (59.5)	428 (58.3)	402 (54.8)
Less positive about future, n (%) (n = 589)		517 (87.8)	491 (83.4)	468 (79.5)	478 (81.2)	469 (79.6)	421 (71.5)	415 (70.5)	387 (65.7)	380 (64.5)	350 (59.4)
Remaining respondents (n = 154)		90 (58.4)	101 (65.6)	104 (67.5)	76 (49.4)	69 (44.8)	66 (42.9)	64 (41.6)	50 (32.5)	48 (31.2)	52 (33.8)
Did not reach full potential, n (%) (n = 556)		487 (87.6)	462 (83.1)	441 (79.3)	443 (79.7)	434 (78.1)	401 (72.1)	393 (70.7)	375 (67.4)	352 (63.3)	330 (59.4)
Remaining respondents (n = 187)		120 (64.2)	130 (69.5)	131 (70.1)	111 (59.4)	104 (55.6)	86 (46.0)	86 (46.0)	62 (33.2)	76 (40.6)	72 (38.5)

S1F		Talk to spouse or partner	Use non-medical methods for pain	Talk to friends and family	Educate self on treatments	Make doctor listen and respond to needs	Engage with other women with same experiences	Schedule social events around period	Pelvic floor or other exercises	Other	None of these
Total, n (%) (N = 743)		560 (76.3)	533 (72.6)	508 (69.2)	502 (68.4)	455 (62.0)	409 (55.7)	304 (41.4)	193 (26.3)	70 (9.5)	26 (3.5)
Less positive about future, n (%) (n = 589)		445 (75.6)	425 (72.2)	409 (69.4)	409 (69.4)	369 (62.6)	337 (57.2)	257 (43.6)	162 (27.5)	61 (10.4)	19 (3.2)
Remaining respondents (n = 154)		115 (74.7)	108 (70.1)	99 (64.3)	93 (60.4)	86 (55.8)	72 (46.8)	47 (30.5)	31 (20.1)	9 (5.8)	7 (4.5)
Did not reach full potential, n (%) (n = 556)		418 (75.2)	405 (72.8)	383 (68.9)	394 (70.9)	345 (62.1)	325 (58.5)	246 (44.2)	153 (27.5)	59 (10.6)	20 (3.6)
Remaining respondents (n = 187)		142 (75.9)	128 (68.4)	125 (66.8)	108 (57.8)	110 (58.8)	84 (44.9)	58 (31.0)	40 (21.4)	11 (5.9)	6 (3.2)

Survey.

MyEndometriosisTeam Survey – Life Course Impact Survey

Introduction

Part of our mission at MyEndometriosisTeam is to help build awareness and understanding of the impact that endometriosis can have on daily life. Creating a better understanding of what other women with endometriosis go through is important to many members. The aim of this study is to understand real-life experiences of women living with chronic endometriosis. This includes how it may influence life choices and any long-lasting effect it has.

This survey should take approximately 8 minutes to complete. Your participation is completely voluntary, and your responses are anonymous. MyEndometriosisTeam never shares any personally identifying information. Highlights of the findings of this research survey will be shared back with the MyEndometriosisTeam community. We are conducting this survey in collaboration with one of our pharmaceutical partners. This is one of the ways we keep MyEndometriosisTeam free while making sure your voice is heard. If you have any questions regarding the survey, please contact support@myendometriosisteam.com.

If you are 19 years of age or older, live in the United States (excluding Puerto Rico), understand the statements above and freely consent to participate in this research, click on the “Yes, I agree” button to begin the survey.

Yes, I agree

No thanks, I'd rather not participate

Section 1: Screening Questions

S1. Which of the following describes you?

Male (**Terminate**)

Female

1
2
3 S2. What is your age?
4

5 Under 19 (**Terminate**)
6

7 19-29
8

9 30-39
10

11 40-49
12

13 50-59
14

15 60 or older
16
17

18
19 S3. Which one of the following best describes your condition?
20

21 Stage 1 endometriosis
22

23 Stage 2 endometriosis
24

25 Stage 3 endometriosis
26

27 Stage 4 endometriosis
28

29 Not sure what stage of endometriosis I have
30

31 I do not have endometriosis (**Terminate**)
32
33

34
35 S4. In which country do you currently live?
36

37 United States (excluding Puerto Rico) (**Continue**)
38

39 Australia
40

41 Canada
42

43 Ireland
44

45 Netherlands
46

47 New Zealand
48

49 South Africa
50

51 United Kingdom
52

53 Other
54
55

56 Section 1: Endometriosis Severity
57
58

1. At what age did your endometriosis symptoms begin? (drop down menu)
2. At approximately what age did you start your first period? (drop down menu)
3. Thinking about when you first started to experience endometriosis symptoms, approximately how many years did it take before you were diagnosed with endometriosis? (drop down menu)
4. Did you ever have a surgical procedure such as a laparoscopy or laparotomy to confirm you have endometriosis?
 - Yes
 - No
 - Not sure
5. Which one of the following best describes how often you typically feel some type of endometriosis-related pain?
 - Daily
 - A few times a week
 - Weekly
 - A few times a month
 - Monthly
 - Every few months
 - Once or twice a year
 - Never
6. Please rate how severe your endometriosis related pain has been at its worst in the last 12 months using a scale from 0 to 10 where 0=no pain and 10=worst imaginable pain. (Drop down menu).

7. Over the years, has your endometriosis related pain gotten better, gotten worse or stayed the same?

Gotten much better

Gotten somewhat better

Stayed the same

Gotten somewhat worse

Gotten much worse

Section 2: Impact on Quality of Life and Life Choices

8. Please indicate how much you agree or disagree with the following statements about the impact endometriosis has had **on your entire life up to now.**

(Rotate order)

Because of my endometriosis:

(Please select one box for each row)	Strongly disagree	Some-what Disagr	Neutral	Some-what Agree	Strongly agree	Not Applic-able
I was unable to achieve my educational goals	1	2	3	4	5	6
I missed many days of school	1	2	3	4	5	6
I was unable to work full time	1	2	3	4	5	6
I was unable to work part time	1	2	3	4	5	6
I could not work at the job I would have preferred	1	2	3	4	5	6
I missed many days of work	1	2	3	4	5	6
I lost a job	1	2	3	4	5	6

I earned less money than I could have	1	2	3	4	5	6
I made fewer friends	1	2	3	4	5	6
I have had problems with sexual or intimate relationships	1	2	3	4	5	6
I have not dated or pursued an intimate relationship	1	2	3	4	5	6
I have delayed having or have been unable to have children	1	2	3	4	5	6
I have limited my social activities	1	2	3	4	5	6
I have not exercised or played sports as much as I would have liked	1	2	3	4	5	6
I do not live where I would like due to my healthcare needs	1	2	3	4	5	6
I lost a lot of time in my life	1	2	3	4	5	6
I have travelled less than I would have liked	1	2	3	4	5	6
I have dressed differently than I would have liked	1	2	3	4	5	6
I have used alcohol, drugs or smoked cigarettes	1	2	3	4	5	6
I have not maintained a healthy diet	1	2	3	4	5	6
I have been less outgoing	1	2	3	4	5	6
I have been less positive about the future	1	2	3	4	5	6
I have not reached my full potential in life	1	2	3	4	5	6

- 1
2
3 9. What endometriosis-related experiences, if any, do you think have most contributed to
4 altering your life potential in a negative way? Select all that apply. (Rotate order)
5
6

7 Painful sexual intercourse

8 Pelvic pain during my period

9 Pelvic pain apart from during my period

10 Painful periods

11 Heavy period-related bleeding

12 Other endometriosis related pain

13 Infertility

14 Depression or anxiety

15 Multiple surgeries

16 Prescription treatment to control endometriosis symptoms

17 Other symptoms or conditions (please specify)

18 Other (please specify)

19 None
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3 10. Which, if any of these, have you experienced as a result of your endometriosis? Check
4 all that apply. (Rotate order)
5
6

7 Taken prescription medication for the pain (for example, opioids)

8 Taken prescription medication to treat depression or anxiety

9 Had multiple surgical procedures

10 Been hospitalized overnight

11 Gone to the emergency room

12 Received disability income due to being unable to work

13 Had a miscarriage (whether or not it was due to having endometriosis)

14 Had trouble performing daily tasks

15 Saw a mental health professional (e. g., psychiatrist, counselor)

16 Was unable to get pregnant

17 Had a relationship end because I was unable to have children

18 Had a relationship end because I was unable to have sex

19 None of these
20
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3 11. And which, if any of these emotions, have you experienced as a result of your
4 endometriosis? Check all that apply. (Rotate order)
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6

7 **I have felt...**
8

9 Low self esteem
10

11 Judged by others
12

13 Inadequate
14

15 Unsexy
16

17 Insecure
18

19 Guilty
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21 Determined
22

23 Strengthened
24

25 Hopeful
26

27 Embarrassed
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29 Unfulfilled
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31 Depressed
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33 Anxious
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35 None of these
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3 12. Which of the following, if any, have you done to help manage the impact of endometriosis?
4 Select all that apply. (rotate order)
5

6
7 Schedule social events around my period

8
9 Engage with other women going through the same experiences

10
11 Talk to my friends and family about endometriosis

12
13 Talk to my spouse or partner about my endometriosis

14
15 Pelvic floor or other exercises to lessen pain during sex

16
17 Make sure my doctor listens and responds to my needs

18
19 Educate myself on new treatments

20
21 Use non-medical methods for controlling pain (e.g., ice or heat, lubricants during sex)

22
23 Other (please describe)

24
25 None of these

- 26
27 13. Because of endometriosis, is there anything you feel you were unable to accomplish in
28 your life? (open end)

- 29
30 14. Is there anything else you would like us to know about the impact endometriosis has had
31 on your life? (open end)
32

33 Just a few last questions.
34
35
36

- 37 D1. Which of the following best describes the area where you live?
38
39
40

41 Urban

42 Suburban

43 Rural

44 Not sure / prefer not to say
45
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3 D2. What is the highest level of education you have achieved?
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7 Less than high school

8 Some high school

9 High school or equivalent (e. g., GED)

10 Some college, but no degree

11 Associate degree

12 College degree (e.g., B.A., B.S.)

13 Some graduate school, but no degree

14 Graduate school (e.g., M.S. M.D., Ph.D.)

15 Prefer not to answer
16
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25 D3. What is your current employment status?
26
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28 Working full time

29 Working part time

30 Unemployed, not looking for work

31 Unemployed, looking for work

32 Retired

33 Unable to work

34 Prefer not to answer
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3 D4. Which of the following best describes your marital status?
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5

6
7 Single/never married

8 Married

9 Widowed

10 Divorced or separated

11 Prefer not to answer

12
13
14
15
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18 (Skip D5 if “married” or “prefer not to answer” selected in D4)
19
20
21

22 D5. Are you currently in an intimate relationship?
23
24
25

26 Yes

27 No

28 Prefer not to answer
29
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32

33 D6. How many children, if any, do you have?
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35
36
37

38 None

39 1

40 2

41 3

42 4

43 5 or more

44 Prefer not to answer
45
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52 Thank you for answering these questions.
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BMJ Open

The impact of endometriosis on women's life decisions and goal attainment measured in a cross-sectional survey of members of an online patient community

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3 1 **The impact of endometriosis on women's life decisions and goal attainment measured in**
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5 2 **a cross-sectional survey of members of an online patient community**
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1 ABSTRACT

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8 **Objectives:** To examine women's perceptions of endometriosis-associated disease burden and
9
10 its impact on life decisions and goal attainment.

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15 **Design:** An anonymous online survey was distributed in October 2018 through the social media
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17 network MyEndometriosisTeam.com.

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22 **Participants:** Women aged 19 years and older living in several English-speaking countries who
23
24 self-identified as having endometriosis.

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32 **Outcome measures:** Patients' perspectives on how endometriosis has affected their work,
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34 education, relationships, overall life decisions, and attainment of goals. Subanalyses were
35
36 performed for women who identified as "less positive about the future" (LPAF) or had "not
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38 reached their full potential" (NRFP) due to endometriosis.

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Results: 743 women completed the survey. Women reported high levels of pain when pain was
at its worst (mean score, 8.9 on severity scale of 0 [no pain] to 10 [worst imaginable pain]) and
most (56%, n=415) experienced pain daily. Women reported other negative experiences
attributed to endometriosis, including emergency department visits (66%, n=485), multiple
surgeries (55%, n=406), and prescription treatments for symptoms of endometriosis (72%,
n=529). Women indicated that they believed endometriosis had a negative impact on their
educational and professional achievements, social lives/relationships, and overall physical
health. Most women "somewhat agreed"/"strongly agreed" that endometriosis caused them to
lose time in life (81%, n=601), feel LPAF (80%, n=589), and feel they had NRFP (75%, n=556).
Women who identified as LPAF or NRFP generally reported more negative experiences than
those who were non-LPAF or non-NRFP.

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2
3 1 **Conclusions:** Pain and negative experiences related to endometriosis were perceived to
4
5 2 negatively impact major life-course decisions and attainment of goals. Greater practitioner
6
7 3 awareness of the impact that endometriosis has on a woman's life course and the importance of
8
9 4 meaningful dialogue with patients may be important for improving long-term management of the
10
11 5 disease and help identify women who are most vulnerable.
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15 6 **Abstract Word Count:** 291 (300 word maximum)
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19 7 **Strengths and limitations of this study**
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- 22 8 • Strength: Quantitative survey with a meaningful sample size and sample population that
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24 9 spanned multiple countries
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26 10 • Strength: Targeted research questions developed based on existing conversations on a
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28 11 social network platform
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30 12 • Strength: Use of social network familiar to patients, facilitating honesty in responses to
31
32 13 sensitive topics
33
34 14 • Limitation: Possible self-selection bias due to voluntary participation in an online
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36 15 community and no targeted sampling; quantitative data may not be generalizable to all
37
38 16 women with endometriosis
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40 17 • Limitation: Self-reported patient responses that were not confirmed by medical records
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42 18 or other complementary data
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1 BACKGROUND

2 Endometriosis is an often chronic gynecologic disorder that impacts 10% of women of
3 reproductive age.¹ Endometrial-like tissue thriving outside the uterus leads to local and systemic
4 inflammation that can result in a wide range of life-impacting effects, including pelvic pain,
5 dysmenorrhea, dyspareunia, and infertility.²⁻⁴ These debilitating effects have an immense impact
6 on a patient's quality of life and overall well-being.^{5,6} For example, symptoms of endometriosis
7 may have a negative impact on women's psychological health,^{7,8} strain social and intimate
8 relationships,^{5,9-11} and lead to losses in productivity, both at home and in the workplace.¹² These
9 issues have been further exacerbated by the COVID-19 pandemic, which has led to reduced
10 access to medical care, delayed treatments, increased stress, loss of work productivity, and
11 mandated self-isolation.^{13,14}

12 Outside the physical and emotional toll, the collective symptoms of endometriosis are also
13 associated with direct and indirect costs that are burdensome to patients. Visits to physicians
14 and emergency departments, pharmacy claims, and other direct expenses are estimated to cost
15 between \$12,000 to \$15,000 per patient per year in the United States, and the loss of work and
16 productivity may amount to additional losses of thousands of dollars per patient.^{12,15-18}

17 Most studies examining chronic diseases like endometriosis focus on one or two specific areas
18 of the disease, such as its social, physical, or psychological impact at a specific point in
19 time.^{19,20} In contrast, few studies have examined the impact of endometriosis on a woman's life
20 course based on how symptoms and experiences resulting from the disease influence major life
21 events and decisions (such as whether to pursue educational opportunities, choose a career
22 path, establish intimate relationships, and plan for a family) and the overall ability of patients to
23 attain their life goals.^{19,20} The few existing studies have small sample sizes or are qualitative,

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3 1 relying on informational interviews to ascertain the life-course impact of the disease, but
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5 2 highlight the substantial impacts that endometriosis can have on social activities, intimate
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7 3 relationships, education, work productivity, and psychological well-being.^{11,21-23} Understanding
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9 4 life-course impairment, as opposed to focusing on the symptoms of the disease (such as pain or
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11 5 infertility, which are most often addressed individually not holistically), is vital because of the
12
13 6 complicated interrelationship among symptoms and their downstream effects. Individual
14
15 7 symptoms can influence critical life decisions (eg, work, education, or personal relationships) in
16
17 8 ways that are interrelated and can impact other areas of a patient's life. For example, chronic
18
19 9 pain may influence the type and amount of work performed or whether a patient decides to work
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21 10 at all, which, in turn, can have financial implications on the patient's lifestyle, family,
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23 11 relationships, or sense of personal fulfillment.^{19,20} Symptoms may determine where a patient
24
25 12 chooses to live because of financial considerations, healthcare access, or proximity to support
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27 13 networks. Similarly, dyspareunia related to endometriosis may lead some women to avoid
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29 14 intimate relationships, which may have downstream implications for marriage, family planning,
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31 15 and mental and emotional health.^{24,25} Cumulatively, persistent symptoms of endometriosis and
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33 16 their impact on daily activities and family and intimate relationships can negatively impact the
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35 17 trajectory of women's lives and are profound and far-reaching.
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1 The objective of this multinational survey was to gain a better understanding of patient
2 perspectives on how endometriosis impacts their daily activities and identify how the disease
3 may influence women's major life decisions and attainment of their goals. In addition, we sought
4 to understand the endometriosis-related life-course impacts specifically in women who reported
5 low optimism or low goal attainment. Insights into a patient's complete experience with
6 endometriosis are needed to develop and provide access to effective treatments to reduce the
7 negative impacts of endometriosis on a woman's life course. Greater awareness of the potential
8 negative life-course impacts of endometriosis is important for helping physicians to identify and
9 understand patients' needs and improve the long-term management of endometriosis.

10 **METHODS**

11 **Ethics approval**

12 The Advarra Institutional Review Board (Columbia, MD, USA) reviewed the cross-sectional
13 survey for participants in the United States and determined that informed consent was not
14 required (exempt determination #Pro00029982, 26 September 2018). However, participants did
15 consent to participate in a survey and email invitations were provided to people who opted to
16 receive communications.

17 **Survey development**

18 An online survey was created in a collaborative effort between AbbVie (North Chicago, IL, USA)
19 and MyHealthTeams (San Francisco, CA, USA), a company that creates social networks for
20 communities of individuals living with chronic conditions to foster discussion and provide support
21 among people facing similar circumstances. The survey was programmed and administered

1 through Qualtrics, an online survey tool that allows users to capture survey responses in an
2 anonymized manner. The survey was provided in English and was available online on the social
3 media network website MyEndometriosisTeam.com from October 3 through October 25, 2018.
4 The 14 survey questions about women's experiences with endometriosis were based on our
5 knowledge about the disease state, existing publications, and online conversations participants
6 were having (**see Patient and public involvement** for further detail). In addition, the survey
7 contained 4 screening questions and 6 demographic questions (identified as Supporting
8 Information). The primary goal of the survey was to capture patients' perspectives on the
9 negative impacts of endometriosis on different aspects of their life courses, including how
10 endometriosis has affected their work, education, relationships, overall life decisions, and
11 attainment of goals. This portion of the survey was modeled after a validated instrument created
12 to measure life-course impact of disease in patients with psoriasis.²⁵ Survey questions were
13 rotated to avoid any bias introduced by order of answer selections. Most survey questions were
14 closed-ended and provided multiple-choice options to participants; two questions were open-
15 ended and allowed participants to provide written responses detailing any life accomplishments
16 they believed were impeded by endometriosis or to offer anything else they wanted to share
17 about the impact of endometriosis on their lives. Responses were required for all closed-ended
18 questions; therefore, no imputations for missing data were required. The survey used in this
19 study is included in the supplementary material.

20 **Patient and public involvement**

21 Survey questions were developed based on reviewing conversations members were having on
22 MyEndometriosisTeam.com to ensure both relevance of topics and patient-focused language.
23 The social media network, MyEndometriosisTeam.com, was developed for women living with
24 endometriosis and consists of more than 108,000 members across 13 countries. Based on

1 institutional review board exemption requirements, people were asked at the beginning of the
2 survey if they agreed to participate, and email invitations were sent only to those people who
3 opted into receiving communications.

4 **Participant eligibility and recruitment**

5 Members of the social network MyEndometriosisTeam.com were recruited through 33,000 email
6 invitations. Invitations posted on the public Facebook page for MyEndometriosisTeam recruited
7 additional women to participate in the survey, which was live on the MyEndometriosisTeam.com
8 website from October 3 to October 25, 2018. The English-language survey was conducted
9 among an international population of women who were at least 19 years of age and who self-
10 identified as having endometriosis. The survey was anonymous and answers could not be
11 linked to individual members.

12 **Survey analysis**

13 Descriptive statistics were used to tabulate survey responses in this cross-sectional study. After
14 descriptive statistics were quantified for all respondents, a subanalysis was performed that
15 restricted the survey responder population to women who “somewhat agreed” or “strongly
16 agreed” that they were “less positive about the future” (LPAF) or that they “had not reached their
17 full potential” (NRFP) because of endometriosis. These two questions were selected for this
18 subanalysis to focus on the life-course impact attributed to endometriosis as identified by those
19 who reported low optimism or low goal attainment.

Table 1 Demographics and burden of endometriosis

Characteristic	Overall Respondents, n (%) (N=743)	LPAF Respondents, n (%) (N=589)	NRFP Respondents, n (%) (N=556)
Age at time of survey, years			
19–29	206 (28)	179 (30)	155 (28)
30–39	339 (46)	269 (46)	259 (47)
40–49	180 (24)	128 (22)	129 (23)
50 or older	18 (2)	13 (2)	13 (2)

RESULTS

Survey response and demographics

A total of 743 women completed the survey (table 1), which was live from October 3 to October 25, 2018.

Among respondents to the English-language survey, 474 (64%) were from the United States, and 269 (36%) were from other countries, including one-fifth from the United Kingdom (17%, n=128), and one-fifth summed from Canada, Australia, South Africa, Ireland, New Zealand, and The Netherlands (table 1). Most women (73%, n=542) were younger than 40 years of age.

Almost half of the respondents (48%, n=355) were unaware of their stage of endometriosis (according to the rASRM scoring system), which was obtained at their most recent surgery.

Among the 52% of respondents who recalled their rASRM score, most (57%, n=223) reported having stage 4 endometriosis (table 1). Baseline demographics were generally comparable between the overall study population and women who identified as LFAP or NRFP (table 1).

Country			
United States (excluding Puerto Rico ^a)	474 (64)	370 (63)	364 (65)
United Kingdom	128 (17)	102 (17)	92 (17)
Canada	38 (5)	32 (5)	30 (5)
Australia	37 (5)	31 (5)	27 (5)
South Africa	20 (3)	15 (3)	9 (2)
Ireland	17 (2)	15 (3)	12 (2)
Other	15 (2)	12 (2)	13 (2)
New Zealand	11 (1)	9 (2)	8 (1)
The Netherlands	3 (0.4)	3 (1)	1 (<0.1)
Level of education			
Some high school or less	33 (4)	21 (4)	20 (4)
High school diploma	111 (15)	80 (14)	76 (14)
Some college	214 (29)	164 (28)	176 (32)
College degree	254 (34)	129 (22)	113 (20)
Graduate school/degree	111 (15)	59 (10)	50 (9)
Prefer not to answer	20 (3)	15 (3)	10 (2)
Endometriosis stage			
Stage 1	33 (4)	24 (4)	22 (4)
Stage 2	39 (5)	28 (5)	29 (5)
Stage 3	93 (13)	70 (12)	73 (13)
Stage 4	223 (30)	191 (32)	171 (31)
Not sure	355 (48)	276 (47)	261 (47)
Method of diagnosis			
Laparoscopic surgery	650 (87)	518 (88)	494 (89)
Clinical only	87 (12)	66 (11)	57 (10)
Not sure	6 (0.8)	5 (1)	5 (1)

^aPatients from Puerto Rico were separated from the United States population into the "other" category due to IRB exemption qualifications that were different for residents of Puerto Rico versus residents of the 50 states of the United States.

1 Diagnosis and symptoms

2 Diagnosis

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3 1 Women began experiencing symptoms of endometriosis at a young age, with many
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5 2 experiencing symptoms by age 15. Most women (74%, n=549) reported having a diagnosis of
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7 3 endometriosis made more than 3 years after the appearance of symptoms (average delay of
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9 4 approximately 9 years). Nearly half of women (42%, n=313) said it took 10 years or longer after
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11 5 the initial onset of their symptoms to receive a surgical or clinical diagnosis of endometriosis.
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13 6 The younger the woman's age at symptom onset, the longer the delay; it took, on average, 13
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15 7 years to reach a surgical diagnosis for women who began experiencing symptoms by age 13.
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17 8 Most women (87%, n=650) reported their diagnosis had been confirmed by laparoscopy (table
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19 9 1).

10 *Endometriosis-associated pain*

11 Most women (56%, n=415) reported experiencing pain daily and nearly an additional one-
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13 12 quarter of them reported feeling endometriosis-associated pain a few times per week. When
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15 13 asked to rate how severe their pain was in the last 12 months on a scale from 0 (no pain) to 10
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17 14 (worst imaginable pain), more than half of the respondents (54%) rated their worst pain within
18
19 15 the last 12 months as a 9 or 10. About two-thirds of women reported their endometriosis-
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21 16 associated pain had worsened over the years when asked if endometriosis-related pain had
22
23 17 gotten better, worse, or stayed the same.

18 **Life-course impairment**

19 *Education and employment potential*

20 Many of the women surveyed said they "somewhat agreed" or "strongly agreed" that they had
21
22 21 experienced difficulties achieving their educational goals (40%, n=290) or had missed school
23
24 22 (55%, n=413) because of endometriosis-associated symptoms (figure 1A). Almost half of

1 participants (45%, n=338) “somewhat agreed” or “strongly agreed” that they could not work full
2 time, and a similar percentage (47%, n=355) reported not working at a job they would have
3 preferred. Most reported that they had missed work (74%, n=550) or earned less money than
4 they could have (54%, n=404) because of endometriosis-associated symptoms. These findings
5 were consistent among patients in the United States compared with the rest of the world
6 (supporting information figure 1).

7 *Relationships and social engagements*

8 Most women “somewhat agreed” or “strongly agreed” that endometriosis-associated symptoms
9 led to problems in their intimate relationships (83%, n=613) and/or created a barrier to starting a
10 family (58%, n=431). Most women similarly believed that endometriosis-associated symptoms
11 had led them to limit their social activities (82%, n=609), made them less outgoing (81%,
12 n=602), and caused them to travel less (59%, n=434) (figure 1B).

13 *Physical well-being*

14 Most women “somewhat agreed” or “strongly agreed” endometriosis limited their ability to stay
15 active (79%, n=588) and maintain a healthy diet (55%, n=406) (figure 1C). A high proportion of
16 women (43%, n=323) perceived that endometriosis-associated symptoms resulted in use of
17 alcohol, drugs, or cigarettes.

18 *Life-course impairment overall*

19 Overall, most women (80%, n=601) “somewhat agreed” or “strongly agreed” endometriosis-
20 associated symptoms had caused them to lose time from their daily lives (figure 1D). A similar
21 number of women reported that they were less positive about the future because of their
22 endometriosis-associated symptoms (80%, n=589), and 75% (n=556) “somewhat agreed” or

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3 1 “strongly agreed” that endometriosis-associated symptoms had kept them from reaching their
4
5 2 full potential in life.
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9 3 **Experiences and emotions associated with endometriosis**

10 4 Women reported that numerous experiences attributed to endometriosis had altered their life
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12 5 potential in a negative way (figure 2A) or negatively impacted their lives in other ways
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14 6 (figure 2B). The most frequent responses were common symptoms of endometriosis, including
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16 7 pelvic pain apart from menstruation, painful menstruation, pelvic pain during menstruation, and
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18 8 painful sexual intercourse.
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25 9 Most women surveyed reported that endometriosis impacted their ability to perform daily tasks
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27 10 (81%, n=594); however, many of the negative experiences attributed to endometriosis were
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29 11 related to the use of healthcare services and treatments. For example, women reported taking
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31 12 prescription pain medications (72%, n=529), visiting emergency departments (66%, n=485),
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33 13 having multiple surgeries (55%, n=406), being hospitalized overnight (43%, n=313), taking
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35 14 prescription medication for depression or anxiety (52%, n=380), or seeing a mental health
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37 15 professional because of their endometriosis-associated symptoms (43%, n=316). Around half of
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39 16 the women surveyed reported that the experiences that most negatively impacted their lives
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41 17 were their need to take prescription medication (57%, n=427) and the multiple surgeries for
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43 18 endometriosis (49%, n=363). In addition, most women surveyed reported several negative
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45 19 emotions that they attributed to endometriosis, including feeling depressed (83%, n=607),
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47 20 anxious (81%, n=592), unsexy (78%, n=572), or having low self-esteem (75%, n=554; figure
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49 21 2C).
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3 1 Women managed the impact of their endometriosis in different ways (figure 2D). Most
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5 2 commonly, this included talking to a spouse or partner about their condition, using non-medical
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7 3 strategies (such as diet or exercise) to control their pain, and seeking support from friends and
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9 4 family.
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14 5 **Additional analysis of women who believed their future and life potential were more**
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16 6 **impacted by endometriosis**
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19 7 Most of the sample included women who “somewhat agreed” or “strongly agreed” that they were
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21 8 LPAF (80%; n=589) or had NRFP in life (75%; n=556) because of endometriosis, and several
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23 9 questions limited to these women were further analyzed (Supporting Information table 1).
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25 10 Overall, the observational data in this study suggested women who believed they were LPAF or
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27 11 had NRFP generally reported more negative experiences than the fewer respondents who did
28
29 12 not indicate they were LPAF (non-LPAF, 21%; n=154) or had NRFP (non-NRFP, 25%; n=187).
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31 13 Daily pain was reported by a higher proportion of women who believed they were LPAF or had
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33 14 NRPF because of endometriosis, compared with other women (62% LPAF vs 34% non-LPAF;
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35 15 61% NRFP vs 40% non-NRFP; Supporting Information table 1A). More women who believed
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37 16 they were LPAF or had NRFP also reported negative experiences related to education and work
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39 17 they attributed to endometriosis, including having earned less money (61% LPAF vs 29% non-
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41 18 LPAF; 66% NRFP vs 21% non-NRFP), not working a preferred job (54% LPAF vs 25% non-
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43 19 LPAF; 58% NRFP vs 17% non-NRFP), or not achieving educational goals (44% LPAF vs 21%
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45 20 non-LPAF; 47% NRFP vs 16% non-NRFP) (Supporting Information table 1B). A higher
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47 21 proportion of women who believed their future and life potential were more impacted by their
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49 22 disease reported endometriosis-related experiences altered their life potential in a negative way
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51 23 (Supporting Information table 1C). Similarly, more of these women reported negative
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53 24 experiences and emotions they attributed to endometriosis (Supporting Information table 1D, E).
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3 1 All women used similar strategies to cope with and mitigate the impact of endometriosis on their
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5 2 lives (Supporting Information table 1F).
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9 4 **DISCUSSION**

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14 5 A survey of women with endometriosis who self-reported pronounced symptoms also reported
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16 6 experiences that were perceived by them to negatively impact their views of the future and
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18 7 overall life potential. For many women, endometriosis-associated symptoms negatively affect
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20 8 various areas of their lives, including education and employment, relationships and social
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22 9 engagements, and physical well-being. Participants indicated that adverse experiences related
23
24 10 to management of their disease and its impact on everyday life also believed that their future
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26 11 and life potential were negatively impacted by endometriosis.
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30 12 Examining the cumulative life-course impact of endometriosis may influence a physician's ability
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32 13 to understand a woman's complete experience with the disease, help identify patients who are
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34 14 most vulnerable to its impacts, and inform options for management.^{9,20,22,26} A fuller
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36 15 understanding of the life-course impact of endometriosis may also elucidate patterns of patient
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38 16 needs and identify which forms of supportive multidisciplinary care are necessary, including the
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40 17 need for early referral to specialists and other professionals who provide complementary
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42 18 healthcare. These needs are likely to change over time, during the different phases of each
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44 19 patient's life. For example, teams that include gynecologists and pain specialists may help
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46 20 patients manage endometriosis-associated pain symptoms; reproductive endocrinologists may
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48 21 help manage infertility, if this occurs; sexual health counselors may collaborate with patients
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50 22 who have dyspareunia; and counselors/psychologists may assist with chronic stress and mental
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52 23 health issues.²⁷ Physicians who are responsive to patients' individual needs and values can
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54 24 positively support overall quality of life in those patients who experience infertility^{28,29} and other
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3 1 negative symptoms of endometriosis, such as chronic abdominal pain, dysmenorrhea, and
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5 2 dyspareunia.²⁴ Endometriosis may also contribute to social inequalities; further research is
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7 3 needed to explore this topic and develop social policies to address these inequalities.
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11 4 The severity of pain reported by women who completed the online survey indicates that
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13 5 respondents in our study may have had a greater symptom burden than did women participating
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15 6 in previous studies using similar pain scales.³⁰⁻³² Women in our study also reported slightly
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17 7 lengthier delays in diagnosis after the onset of their first symptoms. Findings in previous studies
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19 8 have illustrated that delays are common in diagnosing endometriosis.^{15,33-41} Although some
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21 9 recent literature suggests that the delay in diagnosis may be slowly improving,³⁹ the use of non-
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23 10 invasive and accurate diagnostic tools could improve diagnosis times and reduce women's pain
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25 11 and distress.^{41,42} The delays in diagnosis reported by our study participants and others indicate
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27 12 many women experiencing troublesome symptoms of endometriosis may still wait extended
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29 13 periods before receiving a definitive diagnosis and initiating treatment.
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35 14 The higher pain burden and longer diagnostic delay reported in our sample, which may include
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37 15 higher numbers of women who sought social network support because they were more
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39 16 frustrated with their disease experience, could conceivably be due in part to their longer
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41 17 struggles with more challenging symptoms than would be observed in the general population of
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43 18 women with diagnosed endometriosis. Results from a recent study using the same social
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45 19 network to recruit participants found that the majority of respondents rated their worst pain
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47 20 higher than 7 on a 10-point scale, only a little lower than the pain rating given by the women in
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49 21 our study.⁴³ Additionally, the previous study participants also experienced a diagnostic delay,
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51 22 supporting the theory that recruitment from this member-centered network may draw more
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53 23 women who have struggled longer with their disease.⁴³ Interestingly, overall trends in diagnostic
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55 24 delays observed between age groups in our study are consistent with reports in previous
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3 1 research, ie, women whose symptom onset occurred at a younger age experienced longer
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5 2 times to diagnosis.^{15,35,39}
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9 3 Many respondents said they missed school and were generally unable to achieve their
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11 4 educational goals because of endometriosis. There is a dearth of research on the impact of
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13 5 endometriosis on women's educational aspirations and their ability to achieve goals due to
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15 6 endometriosis-associated symptoms, compared with the impact endometriosis has on
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17 7 professional work or other areas of life.⁹ Findings from some existing studies suggest
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19 8 endometriosis-associated symptoms may impact grades, attendance, or completion of
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21 9 educational programs.^{21,22,44} Although informative, these studies were more qualitative in nature
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23 10 and involved small sample sizes.^{21,22,44} A quantitative study examining the lives of 78 women
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25 11 15 years after receiving a verified diagnosis of endometriosis found only a fraction of women
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27 12 reported that their disease had a negative impact on their education.¹¹ However, the women
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29 13 included in that study seemed to report less frequent pain and endometriosis-related effects, like
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31 14 depression, compared with the reports made by women in our study. Furthermore, the small
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33 15 sample was collected at a single Norwegian hospital and the findings may not be representative
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35 16 of women's experiences with endometriosis on a wider scale.¹¹ Regardless, any impact on
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37 17 education is concerning, and our study results emphasize the need for additional research into
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39 18 this overlooked area in women with endometriosis. Research on other medical conditions, like
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41 19 adolescent fibromyalgia, supports that chronic pain can negatively impact education, reinforcing
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43 20 the likelihood that endometriosis may have a similar impact.^{45,46}
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49 21 Respondents in the current study also reported endometriosis-associated symptoms caused
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51 22 them to miss work, earn less money, prevented them from a job they would have preferred, or
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53 23 impeded their working full time or part time. Many health conditions that can occur with
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55 24 endometriosis can impact work productivity and potential, including depression, other chronic

1 pain conditions or disorders, and digestive disorders.⁴⁷ Endometriosis was self-reported by
2 respondents in this study, and it is possible that other chronic conditions (particularly, chronic
3 overlapping pain conditions) may also contribute to women's perceived interference with
4 productivity and employment opportunities. Indeed, more than half of women with symptomatic
5 endometriosis can present with comorbid pain syndromes,⁴⁸ and these may include conditions
6 associated with pelvic pain, like dysmenorrhea, irritable bowel syndrome, or painful bladder
7 syndrome.^{49,50} Findings from previous studies have also illustrated that endometriosis-
8 associated symptoms may lead to losses in productivity both at home and in the workplace,
9 potentially impacting professional achievement.^{12,38,51,52} In our study, higher proportions of
10 women who indicated that they were LPAF or had NRFP because of endometriosis reported
11 painful symptoms and negative experiences compared with other respondents. Also, women
12 who were LPAF or had NRFP more often believed it was harder to perform daily tasks because
13 of their disease.

14 Our results further support that endometriosis symptoms are disruptive and may lead to loss of
15 productivity, ultimately influencing women's major life decisions or consequences, including
16 whether to work at reduced capacity or pursue preferred jobs. Results from a recent multicenter
17 study of women with confirmed endometriosis and a matched comparison group found the
18 disease forced some women to seek work outside desired professions, which, in turn, resulted
19 in health-related limitations in career choices.⁵² These collective findings are concerning
20 because satisfaction in a chosen profession—or, at a minimum, the options available to make
21 life decisions regarding one's profession—is an important component of an overall satisfying
22 quality of life, and the decision to work less or pursue a less desirable job may have
23 downstream implications for women's finances, relationships, social lives, or travel
24 decisions.^{19,52}

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3 1 Respondents to our survey reported endometriosis had a negative impact on their relationships,
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5 2 social engagements, and ability to have children (when desired), which is consistent with
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7 3 findings from a host of previous studies that demonstrated the negative impacts of
8
9 4 endometriosis on social well-being and health-related quality of life.^{9,12,38,51} Interestingly, 46% of
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11 5 women in our study reported experiencing infertility, which is slightly higher than the 14%–40%
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13 6 range reported in previous studies, again hinting at our population's higher symptom
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15 7 burden.^{38,43,53} Other chronic pain conditions have also impacted these life-course components,
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17 8 including conditions related to musculoskeletal pain and chronic back pain.^{54,55}
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21 9 Similar to decisions involving education and professional achievement, life choices involving the
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23 10 pursuit of intimate relationships or starting a family may have downstream implications in other
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25 11 areas, like finance, psychological well-being, or employment, which may have their own
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27 12 downstream impacts on additional aspects of a person's life course.¹⁹ Likewise, women
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29 13 frequently reported not being physically active and having poorer diets because of their disease.
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31 14 Although few studies have examined this aspect of endometriosis, findings from two smaller
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33 15 studies have suggested that pain associated with the disease may also have a negative impact
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35 16 on exercise and nutrition.^{9,34,56}
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40 17 Of particular concern was the view of many women that their disease made them increase their
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42 18 use of alcohol, drugs, or cigarettes. Research into whether pain and experiences related to
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44 19 endometriosis may be associated with higher rates of substance abuse is severely lacking.
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46 20 However, there are demonstrated associations between other chronic pain conditions and
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48 21 substance abuse that support our finding.^{57,58} The results from our study draw attention to this
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50 22 issue and highlight substance abuse as an important avenue for additional investigation.
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1 The findings from our study indicate that women with endometriosis may experience many
2 healthcare-related side effects. Of particular concern, patients noted that treatments meant to
3 help reduce the burden of endometriosis may have their own negative impact. Many women
4 perceived that use of prescription medications and multiple surgeries to control the symptoms of
5 endometriosis had a negative impact on their life potential, and this response was stronger in
6 women who indicated they were LPAF or believed they had NRFP due to their disease. Results
7 from one recent study showed that medical treatment for a condition may increase a patient's
8 stress levels and potentially affect their psychological health.⁵⁹ Patients who were taking
9 prescription medications and who experienced more challenging adverse effects from their
10 therapies had higher perceived stress levels, and women undergoing multiple surgeries were
11 especially impacted. These reports underscore the potential value of supportive psychological
12 care for patients with endometriosis as part of effective long-term disease management.

13 Limitations of this study include the selection of participants from an online community with
14 voluntary participation, no targeted sampling, and no way to calculate a response rate. The
15 participants were generally well educated, had access to health care, and participated in an
16 online social network. Data on race, ethnicity, or socioeconomic status were not collected.
17 Patients who experienced the most significant psychosocial impacts of endometriosis or lacked
18 the resources to access the online community may not have been represented in the sample
19 population, whereas the patients who were most affected by severe pelvic pain may have been
20 more likely to participate in the study. These factors may have led to self-selection bias;
21 therefore, the results of this study may not be generalizable to the overall population of patients
22 with endometriosis.

23 In general, women experienced a range of consequences that they attributed to living with and
24 managing the limitations imposed by endometriosis. In addition to pain, women reported that the

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3 1 endometriosis-related experiences that most impacted their lives in a negative way included
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5 2 depression or anxiety (80%), heavy menstrual bleeding (71%), the need to take prescription
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7 3 treatments (57%) or undergo multiple surgeries (49%), or infertility (46%). In other studies,
8
9 4 women have reported not feeling “normal” or feminine, experiencing a range of negative
10
11 5 emotions (eg, anger, depression, hopelessness, disappointment, and exhaustion), having
12
13 6 limited physical or sexual activity, struggling to find appropriate treatments, feeling guilt over
14
15 7 disrupted relationships, and suffering in silence due to endometriosis-related
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17 8 symptoms.^{22,23} While each woman experienced the impact of endometriosis differently, the
18
19 9 majority believed that they were living life less fully than they could have because of their
20
21 10 endometriosis-associated symptoms. This belief was informed by the symptoms and healthcare
22
23 11 requirements they faced, and, in turn, may have influenced major life decisions that could have
24
25 12 their own deleterious effects on personal fulfillment and life potential. The interconnectedness of
26
27 13 effects triggered by major life decisions highlights the importance of conducting further research
28
29 14 into the cumulative burden of debilitating diseases like endometriosis within the context of an
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31 15 individual’s life course.
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37 **CONCLUSIONS**

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41 17 Most women in our international survey experienced a high burden associated with the disease
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43 18 and reported that endometriosis-associated pain and associated experiences had a negative
44
45 19 impact on their outlook about their future and overall life potential. Women believed
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47 20 endometriosis impacted life decisions surrounding education, their professional lives, their social
48
49 21 lives, and their physical well-being. Our study of the impact of endometriosis on a woman’s life
50
51 22 course helps provide a clearer understanding of her complete experience with their disease.
52
53 23 Our findings also suggest there is a need to develop early, effective treatments and to provide
54
55 24 access to effective treatment to limit the impact of endometriosis on a woman’s life course.
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2
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14 6 author revisions.
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16
17 7 Board Member and Ambassador, SEUD Board Member, Trustee and Medical Advisor to
18
19 8 Endometriosis UK, and Medical Advisor to Pelvic Pain Support Network.
20
21

22
23
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28

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31
32 12 Myovant, and Eximis.
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35 36 13 **Data Sharing Statement**

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39 14 AbbVie is committed to responsible data sharing regarding the clinical trials and
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41 15 studies we sponsor. This includes access to anonymized, individual and trial-level data
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43 16 (analysis data sets), as well as other information (eg, protocols and clinical study
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45 17 reports), as long as the trials are not part of an ongoing or planned regulatory
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47 18 submission. This includes requests for clinical trial data for unlicensed products and
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49 19 indications.
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53 20 This study data can be requested by any qualified researchers who engage in rigorous,
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55 21 independent scientific research, and will be provided following review and approval of a
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3 1 research proposal and statistical analysis plan and execution of a data sharing
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5 2 agreement. Data requests can be submitted at any time and the data will be accessible
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7 3 for 12 months, with possible extensions considered. For more information on the
8
9 4 process, or to submit a request, visit the following link: [https://www.abbvie.com/our-](https://www.abbvie.com/our-science/clinical-trials/clinical-trials-data-and-information-sharing/data-and-information-sharing-with-qualified-researchers.html)
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11 science/clinical-trials/clinical-trials-data-and-information-sharing/data-and-information-
12 5 sharing-with-qualified-researchers.html.
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3 1 **FIGURE LEGENDS**
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7 2 **Figure 1** Life-course impact of endometriosis. Women were asked to indicate how much they
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9 3 agreed with statements involving the impact of endometriosis on (A) educational and
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11 4 professional achievements, (B) social life and relationships, (C) physical well-being, and (D)
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13 5 overall life course.
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18 6 **Figure 2** Experiences and emotions attributed to endometriosis. Respondents were asked to
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20 7 select which experiences related to endometriosis had the most negative impacts on their life
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22 8 potential (A). Women were also asked to indicate which general negative experiences (B) and
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24 9 emotions (C) they had undergone because of endometriosis and what kinds of approaches they
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26 10 had taken to manage the impact of endometriosis (D).
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FIGURE 1

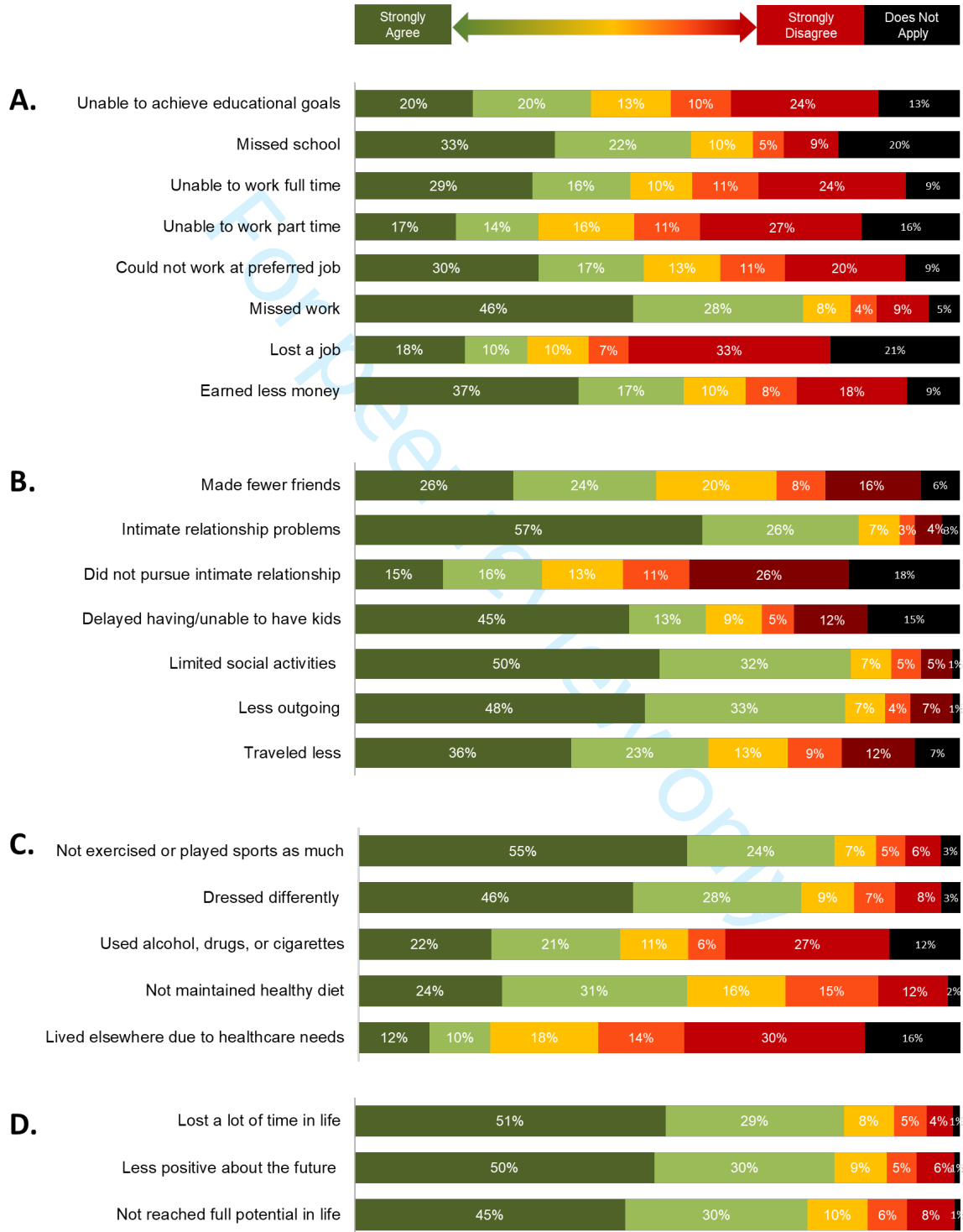
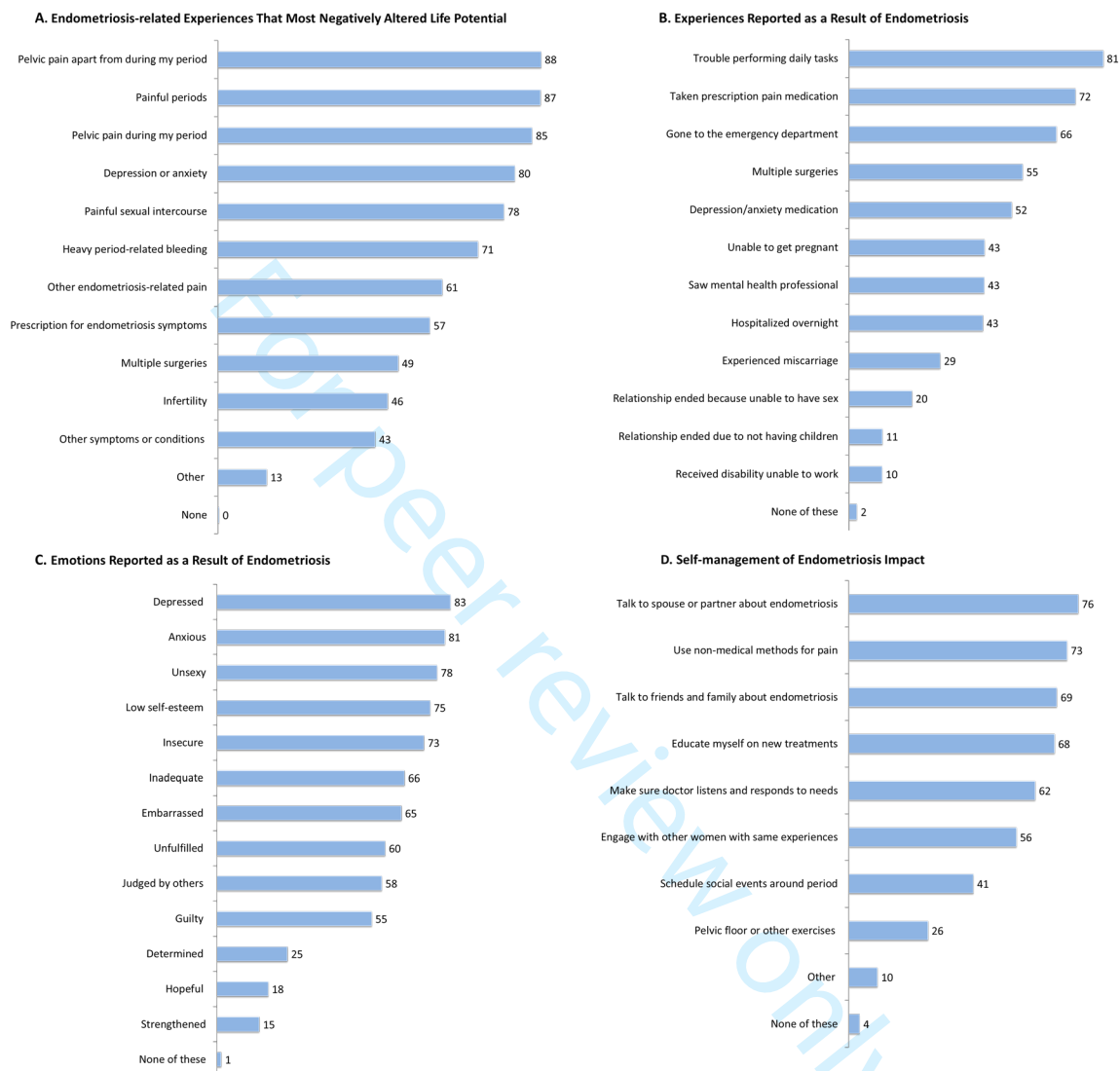


FIGURE 2



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3 **The impact of endometriosis on women's life decisions and goal attainment measured in**
4 **a cross-sectional survey of members of an online patient community**
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9 Stacey A Missmer,¹ Frank F Tu,² Ahmed M Soliman,³ Stephanie E Chiuve,³ Sarah Cross,³
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SUPPORTING INFORMATION

Supporting Information Table 1. Women indicated how much they agreed or disagreed with the impact of endometriosis on the following: (A) pain, (B) work and education, (C) life experiences altered in a negative way, (D) impact on life, (E) feelings, and (F) management of impact.

Supporting Information Figure 1. Impact of endometriosis on educational and professional achievements in the United States (A) and in the rest of the world (B).

Survey. MyEndometriosisTeam Survey – Life Course Impact Survey

Supporting Information Table 1.

S1A	Daily	A few times a week	A few times a month	Weekly	Monthly	Every few months	Never	Once or twice a year
Total, n (%) (N = 743)	415 (55.9)	160 (21.5)	78 (10.5)	43 (5.8)	31 (4.2)	9 (1.2)	4 (0.5)	3 (0.4)
Less positive about future, n (%) (n = 589)	362 (61.5)	120 (20.4)	50 (8.5)	31 (5.3)	16 (2.7)	6 (1.0)	2 (0.3)	2 (0.3)
Remaining respondents (n = 154)	53 (34.4)	40 (26.0)	28 (18.2)	12 (7.8)	15 (9.7)	3 (1.9)	2 (1.3)	1 (0.6)
Did not reach full potential, n (%) (n = 556)	341 (61.3)	121 (21.8)	44 (7.9)	28 (5.0)	13 (2.3)	6 (1.1)	2 (0.4)	1 (0.2)
Remaining respondents (n = 187)	74 (39.6)	39 (20.9)	15 (8.0)	34 (18.2)	18 (9.6)	3 (1.6)	2 (1.1)	2 (1.1)

S1B	Missed days of work	Missed school	Earned less money	Could not work at preferred job	Unable to work full time	Unable to achieve educational goals	Unable to work part time	Lost a job
Total, n (%) (N = 743)	550 (74.9)	413 (56.3)	404 (55.0)	355 (48.4)	338 (46.0)	290 (39.5)	226 (30.8)	212 (28.9)
Less positive about future, n (%) (n = 589)	463 (78.6)	343 (58.2)	359 (61.0)	316 (53.7)	300 (50.9)	257 (43.6)	202 (34.3)	190 (32.3)
Remaining respondents (n = 154)	87 (56.5)	70 (45.5)	45 (29.2)	39 (25.3)	38 (24.7)	33 (21.4)	24 (15.6)	22 (14.3)
Did not reach full potential, n (%) (n = 556)	448 (80.6)	329 (59.2)	365 (65.6)	323 (58.1)	295 (53.1)	261 (46.9)	205 (36.9)	193 (34.7)
Remaining respondents (n = 187)	102 (54.5)	84 (44.9)	39 (20.9)	32 (17.1)	43 (23.0)	29 (15.5)	21 (11.2)	19 (10.2)

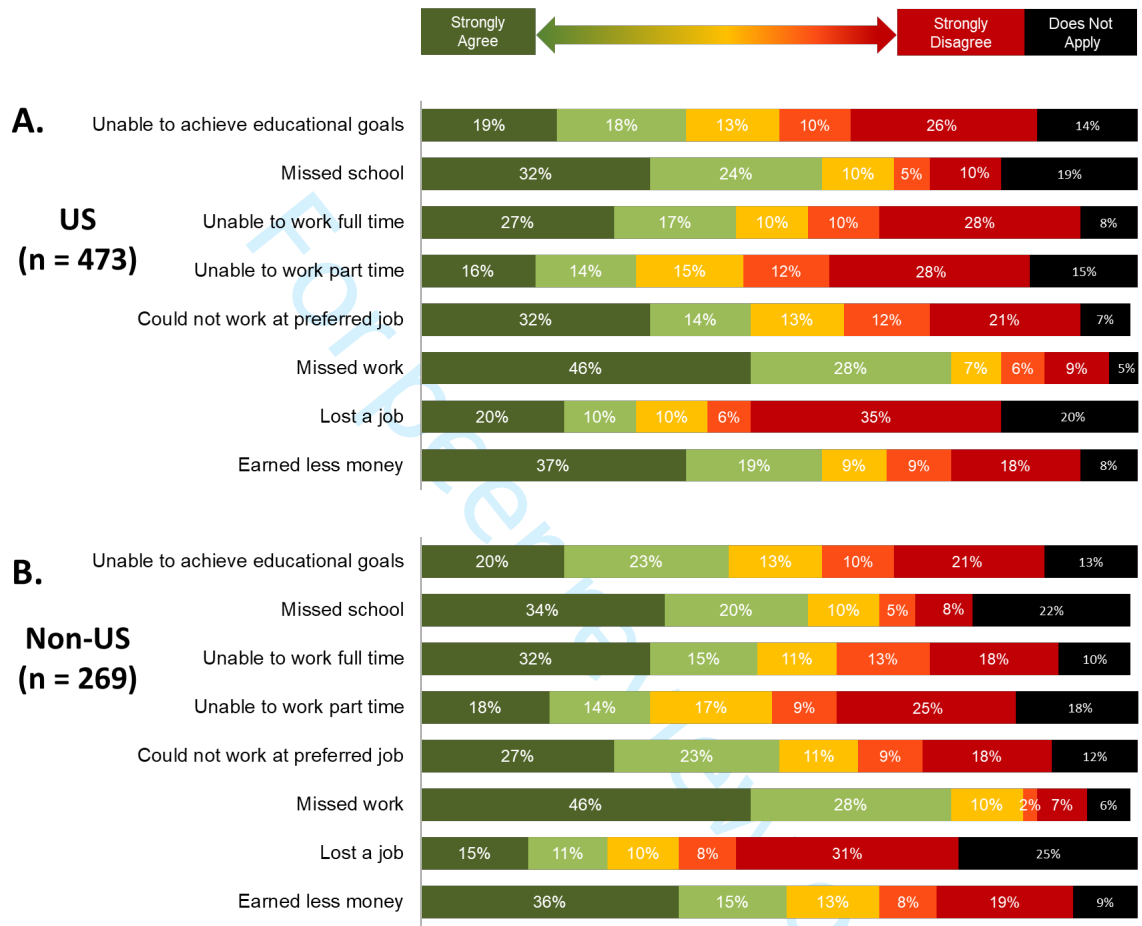
S1C	Pelvic pain apart from period	Painful periods	Pelvic pain during period	Depression or anxiety	Painful sexual intercourse	Heavy period- related bleeding	Other endometriosi s-related pain	Taken prescription for symptoms	Multiple surgeries	Infertility	Other symptoms or conditions
Total, n (%) (N = 743)	651 (87.6)	650 (87.5)	633 (85.2)	598 (80.5)	576 (77.5)	524 (70.5)	452 (60.8)	427 (57.5)	363 (48.9)	342 (46.0)	317 (42.7)
Less positive about future, n (%) (n = 589)	528 (89.6)	517 (87.8)	506 (85.9)	505 (85.7)	461 (78.3)	413 (70.1)	382 (64.9)	353 (59.9)	297 (50.4)	272 (46.2)	268 (45.5)
Remaining respondents (n = 154)	123 (79.9)	133 (86.4)	127 (82.5)	93 (60.4)	115 (74.7)	111 (72.1)	70 (45.5)	74 (48.1)	66 (42.9)	70 (45.5)	49 (31.8)
Did not reach full potential, n (%) (n = 556)	500 (89.9)	491 (88.3)	482 (86.7)	476 (85.6)	430 (77.3)	400 (71.9)	366 (65.8)	332 (59.7)	284 (51.1)	261 (46.9)	259 (46.6)
Remaining respondents (n = 187)	151 (80.7)	159 (85.0)	151 (80.7)	122 (65.2)	146 (78.1)	124 (66.3)	86 (46.0)	95 (50.8)	79 (42.2)	81 (43.3)	58 (31.0)

S1D	Trouble performing daily tasks	Taken Rx pain medication	Gone to ER	Multiple surgeries	Depression/ anxiety medication	Unable to get pregnant	Saw mental health professional	Hospitalized overnight	Experienced miscarriage	Relationship ended because unable to have sex
Total, n (%) (N = 743)	594 (80.9)	529 (72.1)	485 (66.1)	406 (55.3)	380 (51.8)	317 (43.2)	316 (43.1)	313 (42.6)	213 (29.0)	147 (20.0)
Less positive about future, n (%) (n = 589)	500 (84.9)	442 (75.0)	406 (68.9)	333 (56.5)	327 (55.5)	251 (42.6)	276 (46.9)	266 (45.2)	167 (28.4)	132 (22.4)
Remaining respondents (n = 154)	94 (61.0)	87 (56.5)	79 (51.3)	73 (47.4)	53 (34.4)	66 (42.9)	40 (26.0)	47 (30.5)	46 (29.9)	15 (9.7)
Did not reach full potential, n (%) (n = 556)	478 (86.0)	421 (75.7)	390 (70.1)	311 (55.9)	308 (55.4)	239 (43.0)	265 (47.7)	249 (44.8)	166 (29.9)	132 (23.7)
Remaining respondents (n = 187)	116 (62.0)	108 (57.8)	95 (50.8)	95 (50.8)	72 (38.5)	78 (41.7)	51 (27.3)	64 (34.2)	47 (25.1)	15 (8.0)

S1E	Depressed	Anxious	Unsexy	Low self-esteem	Insecure	Inadequate	Embarrassed	Unfulfilled	Judged by others	Guilty
Total, n (%) (N = 743)	607 (82.7)	592 (80.7)	572 (77.9)	554 (75.5)	538 (73.3)	487 (66.3)	479 (65.3)	437 (59.5)	428 (58.3)	402 (54.8)
Less positive about future, n (%) (n = 589)	517 (87.8)	491 (83.4)	468 (79.5)	478 (81.2)	469 (79.6)	421 (71.5)	415 (70.5)	387 (65.7)	380 (64.5)	350 (59.4)
Remaining respondents (n = 154)	90 (58.4)	101 (65.6)	104 (67.5)	76 (49.4)	69 (44.8)	66 (42.9)	64 (41.6)	50 (32.5)	48 (31.2)	52 (33.8)
Did not reach full potential, n (%) (n = 556)	487 (87.6)	462 (83.1)	441 (79.3)	443 (79.7)	434 (78.1)	401 (72.1)	393 (70.7)	375 (67.4)	352 (63.3)	330 (59.4)
Remaining respondents (n = 187)	120 (64.2)	130 (69.5)	131 (70.1)	111 (59.4)	104 (55.6)	86 (46.0)	86 (46.0)	62 (33.2)	76 (40.6)	72 (38.5)

S1F	Talk to spouse or partner	Use non-medical methods for pain	Talk to friends and family	Educate self on treatments	Make doctor listen and respond to needs	Engage with other women with same experiences	Schedule social events around period	Pelvic floor or other exercises	Other	None of these
Total, n (%) (N = 743)	560 (76.3)	533 (72.6)	508 (69.2)	502 (68.4)	455 (62.0)	409 (55.7)	304 (41.4)	193 (26.3)	70 (9.5)	26 (3.5)
Less positive about future, n (%) (n = 589)	445 (75.6)	425 (72.2)	409 (69.4)	409 (69.4)	369 (62.6)	337 (57.2)	257 (43.6)	162 (27.5)	61 (10.4)	19 (3.2)
Remaining respondents (n = 154)	115 (74.7)	108 (70.1)	99 (64.3)	93 (60.4)	86 (55.8)	72 (46.8)	47 (30.5)	31 (20.1)	9 (5.8)	7 (4.5)
Did not reach full potential, n (%) (n = 556)	418 (75.2)	405 (72.8)	383 (68.9)	394 (70.9)	345 (62.1)	325 (58.5)	246 (44.2)	153 (27.5)	59 (10.6)	20 (3.6)
Remaining respondents (n = 187)	142 (75.9)	128 (68.4)	125 (66.8)	108 (57.8)	110 (58.8)	84 (44.9)	58 (31.0)	40 (21.4)	11 (5.9)	6 (3.2)

Supporting Information Figure 1.



Survey.

MyEndometriosisTeam Survey – Life Course Impact Survey

Introduction

Part of our mission at MyEndometriosisTeam is to help build awareness and understanding of the impact that endometriosis can have on daily life. Creating a better understanding of what other women with endometriosis go through is important to many members. The aim of this study is to understand real-life experiences of women living with chronic endometriosis. This includes how it may influence life choices and any long-lasting effect it has.

This survey should take approximately 8 minutes to complete. Your participation is completely voluntary, and your responses are anonymous. MyEndometriosisTeam never shares any personally identifying information. Highlights of the findings of this research survey will be shared back with the MyEndometriosisTeam community. We are conducting this survey in collaboration with one of our pharmaceutical partners. This is one of the ways we keep MyEndometriosisTeam free while making sure your voice is heard. If you have any questions regarding the survey, please contact support@myendometriosisteam.com.

If you are 19 years of age or older, live in the United States (excluding Puerto Rico), understand the statements above and freely consent to participate in this research, click on the “Yes, I agree” button to begin the survey.

Yes, I agree

No thanks, I'd rather not participate

Section 1: Screening Questions

S1. Which of the following describes you?

Male (**Terminate**)

Female

1
2
3 S2. What is your age?
4

5 Under 19 (**Terminate**)
6

7 19-29
8

9 30-39
10

11 40-49
12

13 50-59
14

15 60 or older
16
17

18
19 S3. Which one of the following best describes your condition?
20

21 Stage 1 endometriosis
22

23 Stage 2 endometriosis
24

25 Stage 3 endometriosis
26

27 Stage 4 endometriosis
28

29 Not sure what stage of endometriosis I have
30

31 I do not have endometriosis (**Terminate**)
32
33

34 S4. In which country do you currently live?
35

36 United States (excluding Puerto Rico) (**Continue**)
37

38 Australia
39

40 Canada
41

42 Ireland
43

44 Netherlands
45

46 New Zealand
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48 South Africa
49

50 United Kingdom
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52 Other
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Section 1: Endometriosis Severity

1. At what age did your endometriosis symptoms begin? (drop-down menu)
2. At approximately what age did you start your first period? (drop-down menu)
3. Thinking about when you first started to experience endometriosis symptoms, approximately how many years did it take before you were diagnosed with endometriosis? (drop-down menu)
4. Did you ever have a surgical procedure, such as a laparoscopy or laparotomy, to confirm you have endometriosis?
 - Yes
 - No
 - Not sure
5. Which one of the following best describes how often you typically feel some type of endometriosis-related pain?
 - Daily
 - A few times a week
 - Weekly
 - A few times a month
 - Monthly
 - Every few months
 - Once or twice a year
 - Never

6. Please rate how severe your endometriosis related pain has been at its worst in the last 12 months using a scale from 0 to 10, where 0=no pain and 10=worst imaginable pain. (Drop down menu).

7. Over the years, has your endometriosis related pain gotten better, gotten worse, or stayed the same?

Gotten much better

Gotten somewhat better

Stayed the same

Gotten somewhat worse

Gotten much worse

Section 2: Impact on Quality of Life and Life Choices

8. Please indicate how much you agree or disagree with the following statements about the impact endometriosis has had **on your entire life up to now**.

(Rotate order)

Because of my endometriosis:

(Please select one box for each row)	Strongly disagree	Some-what Disagr	Neutral	Some-what Agree	Strongly agree	Not Applic-able
I was unable to achieve my educational goals	1	2	3	4	5	6
I missed many days of school	1	2	3	4	5	6
I was unable to work full time	1	2	3	4	5	6
I was unable to work part time	1	2	3	4	5	6
I could not work at the job I would have preferred	1	2	3	4	5	6

I missed many days of work	1	2	3	4	5	6
I lost a job	1	2	3	4	5	6
I earned less money than I could have	1	2	3	4	5	6
I made fewer friends	1	2	3	4	5	6
I have had problems with sexual or intimate relationships	1	2	3	4	5	6
I have not dated or pursued an intimate relationship	1	2	3	4	5	6
I have delayed having or have been unable to have children	1	2	3	4	5	6
I have limited my social activities	1	2	3	4	5	6
I have not exercised or played sports as much as I would have liked	1	2	3	4	5	6
I do not live where I would like due to my healthcare needs	1	2	3	4	5	6
I lost a lot of time in my life	1	2	3	4	5	6
I have travelled less than I would have liked	1	2	3	4	5	6
I have dressed differently than I would have liked	1	2	3	4	5	6
I have used alcohol, drugs or smoked cigarettes	1	2	3	4	5	6
I have not maintained a healthy diet	1	2	3	4	5	6
I have been less outgoing	1	2	3	4	5	6
I have been less positive about the future	1	2	3	4	5	6
I have not reached my full potential in life	1	2	3	4	5	6

- 1
2
3 9. What endometriosis-related experiences, if any, do you think have most contributed to
4 altering your life potential in a negative way? Select all that apply. (Rotate order)
5
6

7 Painful sexual intercourse

8 Pelvic pain during my period

9 Pelvic pain apart from during my period

10 Painful periods

11 Heavy period-related bleeding

12 Other endometriosis related pain

13 Infertility

14 Depression or anxiety

15 Multiple surgeries

16 Prescription treatment to control endometriosis symptoms

17 Other symptoms or conditions (please specify)

18 Other (please specify)

19 None
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3 10. Which, if any, of these, have you experienced as a result of your endometriosis? Check
4 all that apply. (Rotate order)
5
6

7 Taken prescription medication for the pain (for example, opioids)

8 Taken prescription medication to treat depression or anxiety

9 Had multiple surgical procedures

10 Been hospitalized overnight

11 Gone to the emergency room

12 Received disability income due to being unable to work

13 Had a miscarriage (whether or not it was due to having endometriosis)

14 Had trouble performing daily tasks

15 Saw a mental health professional (eg., psychiatrist, counselor)

16 Was unable to get pregnant

17 Had a relationship end because I was unable to have children

18 Had a relationship end because I was unable to have sex

19 None of these
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3 11. And which, if any, of these emotions, have you experienced as a result of your
4 endometriosis? Check all that apply. (Rotate order)
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6

7 **I have felt...**
8

9 Low self esteem
10

11 Judged by others
12

13 Inadequate
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15 Unsexy
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17 Insecure
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19 Guilty
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21 Determined
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23 Strengthened
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25 Hopeful
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27 Embarrassed
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29 Unfulfilled
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31 Depressed
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33 Anxious
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35 None of these
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3 12. Which of the following, if any, have you done to help manage the impact of endometriosis?
4 Select all that apply. (rotate order)
5

6 Schedule social events around my period
7

8 Engage with other women going through the same experiences
9

10 Talk to my friends and family about endometriosis
11

12 Talk to my spouse or partner about my endometriosis
13

14 Pelvic floor or other exercises to lessen pain during sex
15

16 Make sure my doctor listens and responds to my needs
17

18 Educate myself on new treatments
19

20 Use non-medical methods for controlling pain (e.g., ice or heat, lubricants during sex)
21

22 Other (please describe)
23

24 None of these

- 25 13. Because of endometriosis, is there anything you feel you were unable to accomplish in
26 your life? (open end)
27
28

- 29 14. Is there anything else you would like us to know about the impact endometriosis has had
30 on your life? (open end)
31
32

33 Just a few last questions.
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36

- 37 D1. Which of the following best describes the area where you live?
38
39
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41 Urban
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43 Suburban
44

45 Rural
46

47 Not sure / prefer not to say
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3 D2. What is the highest level of education you have achieved?
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7 Less than high school

8 Some high school

9 High school or equivalent (e. g., GED)

10 Some college, but no degree

11 Associate degree

12 College degree (e.g., B.A., B.S.)

13 Some graduate school, but no degree

14 Graduate school (e.g., M.S., M.D., Ph.D.)

15 Prefer not to answer
16
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25 D3. What is your current employment status?
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28 Working full time

29 Working part time

30 Unemployed, not looking for work

31 Unemployed, looking for work

32 Retired

33 Unable to work

34 Prefer not to answer
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3 D4. Which of the following best describes your marital status?
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6

7 Single/never married

8 Married

9 Widowed

10 Divorced or separated

11 Prefer not to answer

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18 (Skip D5 if “married” or “prefer not to answer” selected in D4)
19
20
21

22 D5. Are you currently in an intimate relationship?
23
24
25

26 Yes

27 No

28 Prefer not to answer
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33 D6. How many children, if any, do you have?
34
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36
37

38 None

39 1

40 2

41 3

42 4

43 5 or more

44 Prefer not to answer
45
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52 Thank you for answering these questions.
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STROBE Statement—Checklist of items that should be included in reports of *cross-sectional studies*

	Item No	Recommendation	Location in Manuscript
Title and abstract	1	(a) Indicate the study’s design with a commonly used term in the title or the abstract (b) Provide in the abstract an informative and balanced summary of what was done and what was found	Page 1, lines 1-2 Page 3, lines 2-22; page 4, lines 1-5
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	Page 5, lines 1-23; page 6, lines 1-17
Objectives	3	State specific objectives, including any prespecified hypotheses	Page 7, lines 1-9
Methods			
Study design	4	Present key elements of study design early in the paper	Page 7, lines 18-21; page 8, lines 1-24; page 9, lines 1-19
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	Page 7, line 12; page 8, lines 1-3 and 23-24; page 9, lines 5-10
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants	Page 8, lines 20-24; page 9, lines 1-11
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	N/A
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	Page 7, line 21; page 8, lines 1-19; supporting information pages 7-17
Bias	9	Describe any efforts to address potential sources of bias	Page 8, lines 12-13; page 9, lines 10-11
Study size	10	Explain how the study size was arrived at	Page 8, lines 23-24; page 9, lines 1-10
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	N/A
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	Page 9, lines 12-19
		(b) Describe any methods used to examine subgroups and interactions	Page 9, lines 12-19
		(c) Explain how missing data were addressed	Page 8, lines 17-18

		(d) If applicable, describe analytical methods taking account of sampling strategy	N/A
		(e) Describe any sensitivity analyses	N/A
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	Page 10, lines 3-4
		(b) Give reasons for non-participation at each stage	N/A
		(c) Consider use of a flow diagram	N/A
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	Page 11, Table 1
		(b) Indicate number of participants with missing data for each variable of interest	N/A (no missing data; see page 8, lines 17-18)
Outcome data	15*	Report numbers of outcome events or summary measures	Pages 12-14; page 15, lines 1-7; Figures 1-2
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	N/A
		(b) Report category boundaries when continuous variables were categorized	N/A
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	N/A
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	Page 15, lines 8-23; page 16, lines 1-6; supporting information pages 2-6
Discussion			
Key results	18	Summarise key results with reference to study objectives	Page 16, lines 9-24; page 17, lines 1-7; page 22, lines 19-24
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	Page 4, lines 14-18; page 21, lines 15-24
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	Page 16, lines 9-24; pages 17-22
Generalisability	21	Discuss the generalisability (external validity) of the study results	Page 16, lines 16-24; page 19, lines 1-7; page 22, lines 14-17; page 23, lines 1-2
Other information			

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Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	Page 24, lines 11-12
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*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.

For peer review only

BMJ Open

The impact of endometriosis on women's life decisions and goal attainment measured in a cross-sectional survey of members of an online patient community

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Complete List of Authors:	Missmer, Stacey A.; Michigan State University College of Human Medicine; Harvard University T H Chan School of Public Health Tu, Frank; NorthShore University HealthSystem; University of Chicago Pritzker School of Medicine Soliman, Ahmed M.; AbbVie Inc Chiuve, Stephanie; AbbVie Inc Cross, Sarah; AbbVie Inc Eichner, Samantha; AbbVie Inc Antunez Flores, Oscar; AbbVie Inc Horne, Andrew; The University of Edinburgh MRC Centre for Reproductive Health, Schneider, Beth; MyHealthTeams As-Sanie, Sawsan; University of Michigan, Obstetrics and Gynaecology
Primary Subject Heading:	Obstetrics and gynaecology
Secondary Subject Heading:	Obstetrics and gynaecology, Qualitative research
Keywords:	GYNAECOLOGY, Community gynaecology < GYNAECOLOGY, QUALITATIVE RESEARCH

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Manuscripts



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3 1 **The impact of endometriosis on women's life decisions and goal attainment measured in**
4
5 2 **a cross-sectional survey of members of an online patient community**
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9 3 Stacey A Missmer,¹ Frank F Tu,² Ahmed M Soliman,³ Stephanie E Chiuve,³ Sarah Cross,³
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40 15 **Key Words:** Qualitative Research; Gynaecology; Community Gynaecology
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1 **ABSTRACT**

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8 **Objectives:** To examine women's perceptions of endometriosis-associated disease burden and
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10 its impact on life decisions and goal attainment.

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15 **Design:** An anonymous online survey was distributed in October 2018 through the social media
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17 network MyEndometriosisTeam.com.

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22 **Participants:** Women aged 19 years and older living in several English-speaking countries who
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24 self-identified as having endometriosis.

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32 **Outcome measures:** Patients' perspectives on how endometriosis has affected their work,
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34 education, relationships, overall life decisions, and attainment of goals. Subanalyses were
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36 performed for women who identified as "less positive about the future" (LPAF) or had "not
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38 reached their full potential" (NRFP) due to endometriosis.

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Results: 743 women completed the survey. Women reported high levels of pain when pain was
at its worst (mean score, 8.9 on severity scale of 0 [no pain] to 10 [worst imaginable pain]) and
most (56%, n=415) experienced pain daily. Women reported other negative experiences
attributed to endometriosis, including emergency department visits (66%, n=485), multiple
surgeries (55%, n=406), and prescription treatments for symptoms of endometriosis (72%,
n=529). Women indicated that they believed endometriosis had a negative impact on their
educational and professional achievements, social lives/relationships, and overall physical
health. Most women "somewhat agreed"/"strongly agreed" that endometriosis caused them to
lose time in life (81%, n=601), feel LPAF (80%, n=589), and feel they had NRFP (75%, n=556).
Women who identified as LPAF or NRFP generally reported more negative experiences than
those who were non-LPAF or non-NRFP.

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3 1 **Conclusions:** Pain and negative experiences related to endometriosis were perceived to
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5 2 negatively impact major life-course decisions and attainment of goals. Greater practitioner
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7 3 awareness of the impact that endometriosis has on a woman's life course and the importance of
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9 4 meaningful dialogue with patients may be important for improving long-term management of the
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11 5 disease and help identify women who are most vulnerable.
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15 6 **Abstract Word Count:** 291 (300 word maximum)
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19 7 **Strengths and limitations of this study**
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- 22 8 • Strength: Quantitative survey with a meaningful sample size and sample population that
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24 9 spanned multiple countries
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26 10 • Strength: Targeted research questions developed based on existing conversations on a
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28 11 social network platform
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30 12 • Strength: Use of social network familiar to patients, facilitating honesty in responses to
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32 13 sensitive topics
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34 14 • Limitation: Possible self-selection bias due to voluntary participation in an online
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36 15 community and no targeted sampling; quantitative data may not be generalizable to all
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38 16 women with endometriosis
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40 17 • Limitation: Self-reported patient responses that were not confirmed by medical records
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42 18 or other complementary data
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1 BACKGROUND

2 Endometriosis is an often chronic gynecologic disorder that impacts 10% of women of
3 reproductive age.¹ Endometrial-like tissue thriving outside the uterus leads to local and systemic
4 inflammation that can result in a wide range of life-impacting effects, including pelvic pain,
5 dysmenorrhea, dyspareunia, and infertility.²⁻⁴ These debilitating effects have an immense impact
6 on a patient's quality of life and overall well-being.^{5,6} For example, symptoms of endometriosis
7 may have a negative impact on women's psychological health,^{7,8} strain social and intimate
8 relationships,^{5,9-11} and lead to losses in productivity, both at home and in the workplace.¹² These
9 issues have been further exacerbated by the COVID-19 pandemic, which has led to reduced
10 access to medical care, delayed treatments, increased stress, loss of work productivity, and
11 mandated self-isolation.^{13,14}

12 Outside the physical and emotional toll, the collective symptoms of endometriosis are also
13 associated with direct and indirect costs that are burdensome to patients. Visits to physicians
14 and emergency departments, pharmacy claims, and other direct expenses are estimated to cost
15 between \$12,000 to \$15,000 per patient per year in the United States, and the loss of work and
16 productivity may amount to additional losses of thousands of dollars per patient.^{12,15-18}

17 Most studies examining chronic diseases like endometriosis focus on one or two specific areas
18 of the disease, such as its social, physical, or psychological impact at a specific point in
19 time.^{19,20} In contrast, few studies have examined the impact of endometriosis on a woman's life
20 course (ie, "life-course impairment") based on how symptoms and experiences resulting from
21 the disease influence major life events and decisions (such as whether to pursue educational
22 opportunities, choose a career path, establish intimate relationships, and plan for a family) and
23 the overall ability of patients to attain their life goals.^{19,20} The few existing studies have small

1 sample sizes or are qualitative, relying on informational interviews to ascertain the life-course
2 impact of the disease, but highlight the substantial impacts that endometriosis can have on
3 social activities, intimate relationships, education, work productivity, and psychological well-
4 being.^{11,21-23} Understanding life-course impairment, as opposed to focusing on the symptoms of
5 the disease (such as pain or infertility, which are most often addressed individually not
6 holistically), is vital because of the complicated interrelationship among symptoms and their
7 downstream effects. Individual symptoms can influence critical life decisions (eg, work,
8 education, or personal relationships) in ways that are interrelated and can impact other areas of
9 a patient's life. For example, chronic pain may influence the type and amount of work performed
10 or whether a patient decides to work at all, which, in turn, can have financial implications on the
11 patient's lifestyle, family, relationships, or sense of personal fulfillment.^{19,20} Symptoms may
12 determine where a patient chooses to live because of financial considerations, healthcare
13 access, or proximity to support networks. Similarly, dyspareunia related to endometriosis may
14 lead some women to avoid intimate relationships, which may have downstream implications for
15 marriage, family planning, and mental and emotional health.^{24,25} Cumulatively, persistent
16 symptoms of endometriosis and their impact on daily activities and family and intimate
17 relationships can negatively impact the trajectory of women's lives and are profound and far-
18 reaching.

1 The objective of this multinational survey was to gain a better understanding of patient
2 perspectives on how endometriosis impacts their daily activities and identify how the disease
3 may influence women's major life decisions and attainment of their goals. In addition, we sought
4 to understand the endometriosis-related life-course impacts specifically in women who reported
5 low optimism or low goal attainment by investigating the specific reasons for life-course
6 impairment among the subset of women who felt their lives were most negatively impacted by
7 endometriosis. Insights into a patient's complete experience with endometriosis are needed to
8 develop and provide access to effective treatments to reduce the negative impacts of
9 endometriosis on a woman's life course. Greater awareness of the potential negative life-course
10 impacts of endometriosis is important for helping physicians to identify and understand patients'
11 needs and improve the long-term management of endometriosis.

12 **METHODS**

13 **Ethics approval**

14 The Advarra Institutional Review Board (Columbia, MD, USA) reviewed the cross-sectional
15 survey for participants in the United States and determined that informed consent was not
16 required (exempt determination #Pro00029982, 26 September 2018). However, participants did
17 consent to participate in a survey and email invitations were provided to people who opted to
18 receive communications.

19 **Survey development**

20 An online survey was created in a collaborative effort between AbbVie (North Chicago, IL, USA)
21 and MyHealthTeams (San Francisco, CA, USA), a company that creates social networks for

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3 1 communities of individuals living with chronic conditions to foster discussion and provide support
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5 2 among people facing similar circumstances. The survey was programmed and administered
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7 3 through Qualtrics, an online survey tool that allows users to capture survey responses in an
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9 4 anonymized manner. The survey was provided in English and was available online on the social
10
11 5 media network website MyEndometriosisTeam.com from October 3 through October 25, 2018.
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13 6 The 14 survey questions about women's experiences with endometriosis were based on our
14
15 7 knowledge about the disease state, existing publications, and online conversations participants
16
17 8 were having (**see Patient and public involvement** for further detail). In addition, the survey
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19 9 contained 4 screening questions and 6 demographic questions (identified as Supporting
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21 10 Information). The primary goal of the survey was to capture patients' perspectives on the
22
23 11 negative impacts of endometriosis on different aspects of their life courses, including how
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25 12 endometriosis has affected their work, education, relationships, overall life decisions, and
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27 13 attainment of goals. This portion of the survey was modeled after a validated instrument created
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29 14 to measure life-course impact of disease in patients with psoriasis.²⁵ This tool was used as a
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31 15 starting point for model development as it has been validated for another chronic disease with
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33 16 excess psychological and psychosocial burden, has been used clinically, and was published in
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35 17 the scientific literature. Survey questions were rotated to avoid any bias introduced by order of
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37 18 answer selections. Most survey questions were closed-ended and provided multiple-choice
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39 19 options to participants; two questions were open-ended and allowed participants to provide
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41 20 written responses detailing any life accomplishments they believed were impeded by
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43 21 endometriosis or to offer anything else they wanted to share about the impact of endometriosis
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45 22 on their lives. Responses were required for all closed-ended questions; therefore, no
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47 23 imputations for missing data were required. The survey used in this study is included in the
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49 24 supplementary material.
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56 **Patient and public involvement**

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1 Survey questions were developed based on reviewing conversations members were having on
2 MyEndometriosisTeam.com to ensure both relevance of topics and patient-focused language.
3 The social media network, MyEndometriosisTeam.com, was developed for women living with
4 endometriosis and consists of more than 108,000 members across 13 countries. Based on
5 institutional review board exemption requirements, people were asked at the beginning of the
6 survey if they agreed to participate, and email invitations were sent only to those people who
7 opted into receiving communications.

8 **Participant eligibility and recruitment**

9 Members of the social network MyEndometriosisTeam.com were recruited through 33,000 email
10 invitations. Invitations posted on the public Facebook page for MyEndometriosisTeam recruited
11 additional women to participate in the survey, which was live on the MyEndometriosisTeam.com
12 website from October 3 to October 25, 2018. The English-language survey was conducted
13 among an international population of women who were at least 19 years of age and who self-
14 identified as having endometriosis. The survey was anonymous and answers could not be
15 linked to individual members.

16 **Survey analysis**

17 Descriptive statistics were used to tabulate survey responses in this cross-sectional study. After
18 descriptive statistics were quantified for all respondents, a subanalysis was performed that
19 restricted the survey responder population to women who “somewhat agreed” or “strongly
20 agreed” that they were “less positive about the future” (LPAF) or that they “had not reached their
21 full potential” (NRFP) because of endometriosis. These two questions were selected for this
22 subanalysis to focus on the life-course impact attributed to endometriosis as identified by those

Table 1 Demographics and burden of endometriosis

Characteristic	Overall Respondents, n (%)	LPAF Respondents, n (%)	NRFP Respondents, n (%)
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1 who reported low optimism or low goal attainment. For this analysis, life-course impairment was
 2 defined as respondents who “somewhat agreed” or “strongly agreed” that endometriosis had
 3 negatively impacted their education, employment, relationships, social activities, and physical
 4 and emotional well-being.

5 RESULTS

6 Survey response and demographics

7 A total of 743 women completed the survey (table 1), which was live from October 3 to October
 8 25, 2018.

9 Among respondents to the English-language survey, 474 (64%) were from the United States,
 10 and 269 (36%) were from other countries, including one-fifth from the United Kingdom (17%,
 11 n=128), and one-fifth summed from Canada, Australia, South Africa, Ireland, New Zealand, and
 12 The Netherlands (table 1). Most women (73%, n=542) were younger than 40 years of age.
 13 Almost half of the respondents (48%, n=355) were unaware of their stage of endometriosis
 14 (according to the rASRM scoring system), which was obtained at their most recent surgery.
 15 Among the 52% of respondents who recalled their rASRM score, most (57%, n=223) reported
 16 having stage 4 endometriosis (table 1). Baseline demographics were generally comparable
 17 between the overall study population and women who identified as LFAP or NRFP (table 1).

	(N=743)	(N=589)	(N=556)
Age at time of survey, years			
19–29	206 (28)	179 (30)	155 (28)
30–39	339 (46)	269 (46)	259 (47)
40–49	180 (24)	128 (22)	129 (23)
50 or older	18 (2)	13 (2)	13 (2)
Country			
United States (excluding Puerto Rico ^a)	474 (64)	370 (63)	364 (65)
United Kingdom	128 (17)	102 (17)	92 (17)
Canada	38 (5)	32 (5)	30 (5)
Australia	37 (5)	31 (5)	27 (5)
South Africa	20 (3)	15 (3)	9 (2)
Ireland	17 (2)	15 (3)	12 (2)
Other	15 (2)	12 (2)	13 (2)
New Zealand	11 (1)	9 (2)	8 (1)
The Netherlands	3 (0.4)	3 (1)	1 (<0.1)
Level of education			
Some high school or less	33 (4)	21 (4)	20 (4)
High school diploma	111 (15)	80 (14)	76 (14)
Some college	214 (29)	164 (28)	176 (32)
College degree	254 (34)	129 (22)	113 (20)
Graduate school/degree	111 (15)	59 (10)	50 (9)
Prefer not to answer	20 (3)	15 (3)	10 (2)
Endometriosis stage			
Stage 1	33 (4)	24 (4)	22 (4)
Stage 2	39 (5)	28 (5)	29 (5)
Stage 3	93 (13)	70 (12)	73 (13)
Stage 4	223 (30)	191 (32)	171 (31)
Not sure	355 (48)	276 (47)	261 (47)
Method of diagnosis			
Laparoscopic surgery	650 (87)	518 (88)	494 (89)
Clinical only	87 (12)	66 (11)	57 (10)
Not sure	6 (0.8)	5 (1)	5 (1)

^aPatients from Puerto Rico were separated from the United States population into the “other” category due to IRB exemption qualifications that were different for residents of Puerto Rico versus residents of the 50 states of the United States.

1 **Diagnosis and symptoms**

2 *Diagnosis*

3 Women began experiencing symptoms of endometriosis at a young age, with many
4 experiencing symptoms by age 15. Most women (74%, n=549) reported having a diagnosis of
5 endometriosis made more than 3 years after the appearance of symptoms (average delay of
6 approximately 9 years). Nearly half of women (42%, n=313) said it took 10 years or longer after
7 the initial onset of their symptoms to receive a surgical or clinical diagnosis of endometriosis.
8 The younger the woman's age at symptom onset, the longer the delay; it took, on average, 13
9 years to reach a surgical diagnosis for women who began experiencing symptoms by age 13.
10 Most women (87%, n=650) reported their diagnosis had been confirmed by laparoscopy
11 (table 1).

12 *Endometriosis-associated pain*

13 Most women (56%, n=415) reported experiencing pain daily and nearly an additional one-
14 quarter of them reported feeling endometriosis-associated pain a few times per week. When
15 asked to rate how severe their pain was in the last 12 months on a scale from 0 (no pain) to 10
16 (worst imaginable pain), more than half of the respondents (54%) rated their worst pain within
17 the last 12 months as a 9 or 10. About two-thirds of women reported their endometriosis-
18 associated pain had worsened over the years when asked if endometriosis-related pain had
19 gotten better, worse, or stayed the same.

20 **Life-course impairment**

21 *Education and employment potential*

1 Many of the women surveyed said they “somewhat agreed” or “strongly agreed” that they had
2 experienced difficulties achieving their educational goals (40%, n=290) or had missed school
3 (55%, n=413) because of endometriosis-associated symptoms (figure 1A). Almost half of
4 participants (45%, n=338) “somewhat agreed” or “strongly agreed” that they could not work full
5 time, and a similar percentage (47%, n=355) reported not working at a job they would have
6 preferred. Most reported that they had missed work (74%, n=550) or earned less money than
7 they could have (54%, n=404) because of endometriosis-associated symptoms. These findings
8 were consistent among patients in the United States compared with the rest of the world
9 (supporting information figure 1).

10 *Relationships and social engagements*

11 Most women “somewhat agreed” or “strongly agreed” that endometriosis-associated symptoms
12 led to problems in their intimate relationships (83%, n=613) and/or created a barrier to starting a
13 family (58%, n=431). Most women similarly believed that endometriosis-associated symptoms
14 had led them to limit their social activities (82%, n=609), made them less outgoing (81%,
15 n=602), and caused them to travel less (59%, n=434) (figure 1B).

16 *Physical well-being*

17 Most women “somewhat agreed” or “strongly agreed” endometriosis limited their ability to stay
18 active (79%, n=588) and maintain a healthy diet (55%, n=406) (figure 1C). A high proportion of
19 women (43%, n=323) perceived that endometriosis-associated symptoms resulted in use of
20 alcohol, drugs, or cigarettes.

21 *Life-course impairment overall*

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3 1 Overall, most women (80%, n=601) “somewhat agreed” or “strongly agreed” endometriosis-
4 associated symptoms had caused them to lose time from their daily lives (figure 1D). A similar
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6 2 associated symptoms had caused them to lose time from their daily lives (figure 1D). A similar
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8 3 number of women reported that they were less positive about the future because of their
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10 4 endometriosis-associated symptoms (80%, n=589), and 75% (n=556) “somewhat agreed” or
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12 5 “strongly agreed” that endometriosis-associated symptoms had kept them from reaching their
13
14 6 full potential in life.

7 **Experiences and emotions associated with endometriosis**

8 Women reported that numerous experiences attributed to endometriosis had altered their life
9 potential in a negative way (figure 2A) or negatively impacted their lives in other ways
10 (figure 2B). The most frequent responses were common symptoms of endometriosis, including
11 pelvic pain apart from menstruation, painful menstruation, pelvic pain during menstruation, and
12 painful sexual intercourse.

13 Most women surveyed reported that endometriosis impacted their ability to perform daily tasks
14 (81%, n=594); however, many of the negative experiences attributed to endometriosis were
15 related to the use of healthcare services and treatments. For example, women reported taking
16 prescription pain medications (72%, n=529), visiting emergency departments (66%, n=485),
17 having multiple surgeries (55%, n=406), being hospitalized overnight (43%, n=313), taking
18 prescription medication for depression or anxiety (52%, n=380), or seeing a mental health
19 professional because of their endometriosis-associated symptoms (43%, n=316). Around half of
20 the women surveyed reported that the experiences that most negatively impacted their lives
21 were their need to take prescription medication (57%, n=427) and the multiple surgeries for
22 endometriosis (49%, n=363). In addition, most women surveyed reported several negative
23 emotions that they attributed to endometriosis, including feeling depressed (83%, n=607),

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3 1 anxious (81%, n=592), unsexy (78%, n=572), or having low self-esteem (75%, n=554; figure
4 2C).

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9 3 Women managed the impact of their endometriosis in different ways (figure 2D). Most
10 4 commonly, this included talking to a spouse or partner about their condition, using non-medical
11 5 strategies (such as diet or exercise) to control their pain, and seeking support from friends and
12 6 family.

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19 7 **Additional analysis of women who believed their future and life potential were more**
20 8 **impacted by endometriosis**

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25 9 Most of the sample included women who “somewhat agreed” or “strongly agreed” that they were
26 10 LPAF (80%; n=589) or had NRFP in life (75%; n=556) because of endometriosis, and several
27 11 questions limited to these women were further analyzed (Supporting Information table 1).
28
29 12 Overall, the observational data in this study suggested women who believed they were LPAF or
30 13 had NRFP generally reported more negative experiences than the fewer respondents who did
31 14 not indicate they were LPAF (non-LPAF, 21%; n=154) or had NRFP (non-NRFP, 25%; n=187).
32
33 15 Daily pain was reported by 62% of women who believed they were LPAF and 61% of women
34 16 who had NRFP because of endometriosis (34% non-LPAF and 40% non-NRFP; Supporting
35 17 Information table 1A). Women who believed they were LPAF or had NRFP also reported
36 18 negative experiences related to education and work they attributed to endometriosis, including
37 19 having earned less money (61% LPAF, 29% non-LPAF, 66% NRFP, and 21% non-NRFP), not
38 20 working a preferred job (54% LPAF, 25% non-LPAF, 58% NRFP, 17% non-NRFP), or not
39 21 achieving educational goals (44% LPAF, 21% non-LPAF, 47% NRFP, 16% non-NRFP)
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41 22 (Supporting Information table 1B). Most women who believed their future and life potential were
42 23 more impacted by their disease reported endometriosis-related experiences altered their life

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3 1 potential in a negative way (Supporting Information table 1C). Similarly, many of these women
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5 2 reported negative experiences and emotions they attributed to endometriosis (Supporting
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7 3 Information table 1D, E). All women used similar strategies to cope with and mitigate the impact
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9 4 of endometriosis on their lives (Supporting Information table 1F).
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13 6 **DISCUSSION**

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18 7 This survey found that women with endometriosis who self-reported pronounced symptoms
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20 8 reported experiences that negatively impacted their perspective of the future and overall life
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22 9 potential. For many women, endometriosis-associated symptoms negatively affect various
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24 10 areas of their lives, including education and employment, relationships and social engagements,
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26 11 and physical well-being. Participants indicated that adverse experiences related to management
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28 12 of their disease and its impact on everyday life also believed that their future and life potential
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30 13 were negatively impacted by endometriosis.
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34 14 **Study implications**

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38 15 The severity of pain reported by women who completed the online survey indicates that
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40 16 respondents in our study may have had a greater symptom burden than did women participating
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42 17 in previous studies using similar pain scales.²⁶⁻²⁸ Women in our study also reported slightly
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44 18 lengthier delays in diagnosis after the onset of their first symptoms. Findings in previous studies
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46 19 have illustrated that delays are common in diagnosing endometriosis.^{15,29-37} Although some
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48 20 recent literature suggests that the delay in diagnosis may be slowly improving,³⁵ the use of non-
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50 21 invasive and accurate diagnostic tools could improve diagnosis times and reduce women's pain
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52 22 and distress.^{37,38} The delays in diagnosis reported by our study participants and others indicate
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1 many women experiencing troublesome symptoms of endometriosis may still wait extended
2 periods before receiving a definitive diagnosis and initiating treatment.

3 The higher pain burden and longer diagnostic delay reported in our sample, which may include
4 higher numbers of women who sought social network support because they were more
5 frustrated with their disease experience, could conceivably be due in part to their longer
6 struggles with more challenging symptoms than would be observed in the general population of
7 women with diagnosed endometriosis. Results from a recent study using the same social
8 network to recruit participants found that the majority of respondents rated their worst pain
9 higher than 7 on a 10-point scale, only a little lower than the pain rating given by the women in
10 our study.³⁹ Additionally, the previous study participants also experienced a diagnostic delay,
11 supporting the theory that recruitment from this member-centered network may draw more
12 women who have struggled longer with their disease.³⁹ Interestingly, overall trends in diagnostic
13 delays observed between age groups in our study are consistent with reports in previous
14 research, ie, women whose symptom onset occurred at a younger age experienced longer
15 times to diagnosis.^{15,31,35}

16 Many respondents said they missed school and were generally unable to achieve their
17 educational goals because of endometriosis. There is a dearth of research on the impact of
18 endometriosis on women's educational aspirations and their ability to achieve goals due to
19 endometriosis-associated symptoms, compared with the impact endometriosis has on
20 professional work or other areas of life.⁹ Findings from some existing studies suggest
21 endometriosis-associated symptoms may impact grades, attendance, or completion of
22 educational programs.^{21,22,40} Although informative, these studies were more qualitative in nature
23 and involved small sample sizes.^{21,22,40} A quantitative study examining the lives of 78 women
24 15 years after receiving a verified diagnosis of endometriosis found only a fraction of women

1 reported that their disease had a negative impact on their education.¹¹ However, the women
2 included in that study seemed to report less frequent pain and endometriosis-related effects, like
3 depression, compared with the reports made by women in our study. Furthermore, the small
4 sample was collected at a single Norwegian hospital and the findings may not be representative
5 of women's experiences with endometriosis on a wider scale.¹¹ Regardless, any impact on
6 education is concerning, and our study results emphasize the need for additional research into
7 this overlooked area in women with endometriosis. Research on other medical conditions, like
8 adolescent fibromyalgia, supports that chronic pain can negatively impact education, reinforcing
9 the likelihood that endometriosis may have a similar impact.^{41,42}

10 Respondents in the current study also reported endometriosis-associated symptoms caused
11 them to miss work, earn less money, prevented them from a job they would have preferred, or
12 impeded their working full time or part time. Many health conditions that can occur with
13 endometriosis can impact work productivity and potential, including depression, other chronic
14 pain conditions or disorders, and digestive disorders.⁴³ Endometriosis was self-reported by
15 respondents in this study, and it is possible that other chronic conditions (particularly, chronic
16 overlapping pain conditions) may also contribute to women's perceived interference with
17 productivity and employment opportunities. Indeed, more than half of women with symptomatic
18 endometriosis can present with comorbid pain syndromes,⁴⁴ and these may include conditions
19 associated with pelvic pain, like dysmenorrhea, irritable bowel syndrome, or painful bladder
20 syndrome.^{45,46} Findings from previous studies have also illustrated that endometriosis-
21 associated symptoms may lead to losses in productivity both at home and in the workplace,
22 potentially impacting professional achievement.^{12,34,47,48} In our study, most women who indicated
23 that they were LPAF or had NRFP because of endometriosis reported painful symptoms and
24 negative experiences. Also, women who were LPAF or had NRFP often believed it was harder
25 to perform daily tasks because of their disease.

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3 1 Our results further support that endometriosis symptoms are disruptive and may lead to loss of
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5 2 productivity, ultimately influencing women's major life decisions or consequences, including
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7 3 whether to work at reduced capacity or pursue preferred jobs. Results from a recent multicenter
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9 4 study of women with confirmed endometriosis and a matched comparison group found the
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11 5 disease forced some women to seek work outside desired professions, which, in turn, resulted
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13 6 in health-related limitations in career choices.⁴⁸ These collective findings are concerning
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15 7 because satisfaction in a chosen profession—or, at a minimum, the options available to make
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17 8 life decisions regarding one's profession—is an important component of an overall satisfying
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19 9 quality of life, and the decision to work less or pursue a less desirable job may have
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21 10 downstream implications for women's finances, relationships, social lives, or travel
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24 11 decisions.^{19,48}

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28 12 Respondents to our survey reported endometriosis had a negative impact on their relationships,
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30 13 social engagements, and ability to have children (when desired), which is consistent with
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32 14 findings from a host of previous studies that demonstrated the negative impacts of
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34 15 endometriosis on social well-being and health-related quality of life.^{9,12,34,47} Interestingly, 46% of
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36 16 women in our study reported experiencing infertility, which is slightly higher than the 14%–40%
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38 17 range reported in previous studies, again hinting at our population's higher symptom
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40 18 burden.^{34,39,49} Other chronic pain conditions have also impacted these life-course components,
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42 19 including conditions related to musculoskeletal pain and chronic back pain.^{50,51}

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46 20 Similar to decisions involving education and professional achievement, life choices involving the
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48 21 pursuit of intimate relationships or starting a family may have downstream implications in other
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50 22 areas, like finance, psychological well-being, or employment, which may have their own
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52 23 downstream impacts on additional aspects of a person's life course.¹⁹ Likewise, women
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54 24 frequently reported not being physically active and having poorer diets because of their disease.

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3 1 Although few studies have examined this aspect of endometriosis, findings from two smaller
4
5 2 studies have suggested that pain associated with the disease may also have a negative impact
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7 3 on exercise and nutrition.^{9,30,52}
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11 4 Of particular concern was the view of many women that their disease made them increase their
12
13 5 use of alcohol, drugs, or cigarettes. Research into whether pain and experiences related to
14
15 6 endometriosis may be associated with higher rates of substance abuse is severely lacking.
16
17 7 However, there are demonstrated associations between other chronic pain conditions and
18
19 8 substance abuse that support our finding.^{53,54} The results from our study draw attention to this
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21 9 issue and highlight substance abuse as an important avenue for additional investigation.
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26 10 The findings from our study indicate that women with endometriosis may experience many
27
28 11 healthcare-related side effects. Of particular concern, patients noted that treatments meant to
29
30 12 help reduce the burden of endometriosis may have their own negative impact. Many women
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32 13 perceived that use of prescription medications and multiple surgeries to control the symptoms of
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34 14 endometriosis had a negative impact on their life potential, and this response was also observed
35
36 15 in women who indicated they were LPAF or believed they had NRFP due to their disease.
37
38 16 Results from one recent study showed that medical treatment for a condition may increase a
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40 17 patient's stress levels and potentially affect their psychological health.⁵⁵ Patients who were
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42 18 taking prescription medications and who experienced more challenging adverse effects from
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44 19 their therapies had higher perceived stress levels, and women undergoing multiple surgeries
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46 20 were especially impacted. These reports underscore the potential value of supportive
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48 21 psychological care for patients with endometriosis as part of effective long-term disease
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50 22 management.
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3 1 In general, women experienced a range of consequences that they attributed to living with and
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5 2 managing the limitations imposed by endometriosis. In addition to pain, women reported that the
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7 3 endometriosis-related experiences that most impacted their lives in a negative way included
8
9 4 depression or anxiety (80%), heavy menstrual bleeding (71%), the need to take prescription
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11 5 treatments (57%) or undergo multiple surgeries (49%), or infertility (46%). In other studies,
12
13 6 women have reported not feeling “normal” or feminine, experiencing a range of negative
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15 7 emotions (eg, anger, depression, hopelessness, disappointment, and exhaustion), having
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17 8 limited physical or sexual activity, struggling to find appropriate treatments, feeling guilt over
18
19 9 disrupted relationships, and suffering in silence due to endometriosis-related
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21 10 symptoms.^{22,23} While each woman experienced the impact of endometriosis differently, the
22
23 11 majority believed that they were living life less fully than they could have because of their
24
25 12 endometriosis-associated symptoms. This belief was informed by the symptoms and healthcare
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27 13 requirements they faced, and, in turn, may have influenced major life decisions that could have
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29 14 their own deleterious effects on personal fulfillment and life potential. The interconnectedness of
30
31 15 effects triggered by major life decisions highlights the importance of conducting further research
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33 16 into the cumulative burden of debilitating diseases like endometriosis within the context of an
34
35 17 individual’s life course.

18 **Strengths and limitations**

19 Limitations of this study include the selection of participants from an online community with
20
21 20 voluntary participation, no targeted sampling, and no way to calculate a response rate. The
22
23 21 participants were generally well educated, had access to health care, and participated in an
24
25 22 online social network. Data on race, ethnicity, or socioeconomic status were not collected.
26
27 23 Patients who experienced the most significant psychosocial impacts of endometriosis or lacked
28
29 24 the resources to access the online community may not have been represented in the sample

1 population, whereas the patients who were most affected by severe pelvic pain may have been
2 more likely to participate in the study. These factors may have led to self-selection bias;
3 therefore, the results of this study may not be generalizable to the overall population of patients
4 with endometriosis. Any between-group comparisons are observational in nature and no
5 definitive conclusions can be made in the absence of formal statistical analysis.

6 **Future implications**

7 Examining the cumulative life-course impact of endometriosis may influence a physician's ability
8 to understand a woman's complete experience with the disease, help identify patients who are
9 most vulnerable to its impacts, and inform options for management.^{9,20,22,56} A fuller
10 understanding of the life-course impact of endometriosis may also elucidate patterns of patient
11 needs and identify which forms of supportive multidisciplinary care are necessary, including the
12 need for early referral to specialists and other professionals who provide complementary
13 healthcare. These needs are likely to change over time, during the different phases of each
14 patient's life. For example, teams that include gynecologists and pain specialists may help
15 patients manage endometriosis-associated pain symptoms; reproductive endocrinologists may
16 help manage infertility, if this occurs; sexual health counselors may collaborate with patients
17 who have dyspareunia; and counselors/psychologists may assist with chronic stress and mental
18 health issues.⁵⁷ Physicians who are responsive to patients' individual needs and values can
19 positively support overall quality of life in those patients who experience infertility^{58,59} and other
20 negative symptoms of endometriosis, such as chronic abdominal pain, dysmenorrhea, and
21 dyspareunia.²⁴ Endometriosis may also contribute to social inequalities; further research is
22 needed to explore this topic and develop social policies to address these inequalities.

1 Conclusion

2 Our international study of the impact of endometriosis on a woman's life course helps provide a
3 clearer understanding of her complete experience with the disease and shows that most women
4 experience a high burden associated with endometriosis that affects overall life potential in
5 many different ways.

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16 7

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25
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27

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16
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18
19 8 Endometriosis UK, and Medical Advisor to Pelvic Pain Support Network.
20
21

22
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27
28

29
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35 36 13 **Data Sharing Statement** 37

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39 14 AbbVie is committed to responsible data sharing regarding the clinical trials and
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41 15 studies we sponsor. This includes access to anonymized, individual and trial-level data
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43 16 (analysis data sets), as well as other information (eg, protocols and clinical study
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45 17 reports), as long as the trials are not part of an ongoing or planned regulatory
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47 18 submission. This includes requests for clinical trial data for unlicensed products and
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49 19 indications.
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53 20 This study data can be requested by any qualified researchers who engage in rigorous,
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55 21 independent scientific research, and will be provided following review and approval of a
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3 1 research proposal and statistical analysis plan and execution of a data sharing
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5 2 agreement. Data requests can be submitted at any time and the data will be accessible
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7 3 for 12 months, with possible extensions considered. For more information on the
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9 4 process, or to submit a request, visit the following link: [https://www.abbvie.com/our-](https://www.abbvie.com/our-science/clinical-trials/clinical-trials-data-and-information-sharing/data-and-information-sharing-with-qualified-researchers.html)
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11 science/clinical-trials/clinical-trials-data-and-information-sharing/data-and-information-
12 5 sharing-with-qualified-researchers.html.
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3 **1 FIGURE LEGENDS**
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7 **2 Figure 1** Life-course impact of endometriosis. Women were asked to indicate how much they
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10 **3** agreed with statements involving the impact of endometriosis on (A) educational and
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12 **4** professional achievements, (B) social life and relationships, (C) physical well-being, and (D)
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14 **5** overall life course.
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18 **6 Figure 2** Experiences and emotions attributed to endometriosis. Respondents were asked to
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20 **7** select which experiences related to endometriosis had the most negative impacts on their life
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22 **8** potential (A). Women were also asked to indicate which general negative experiences (B) and
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24 **9** emotions (C) they had undergone because of endometriosis and what kinds of approaches they
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26 **10** had taken to manage the impact of endometriosis (D).
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FIGURE 1

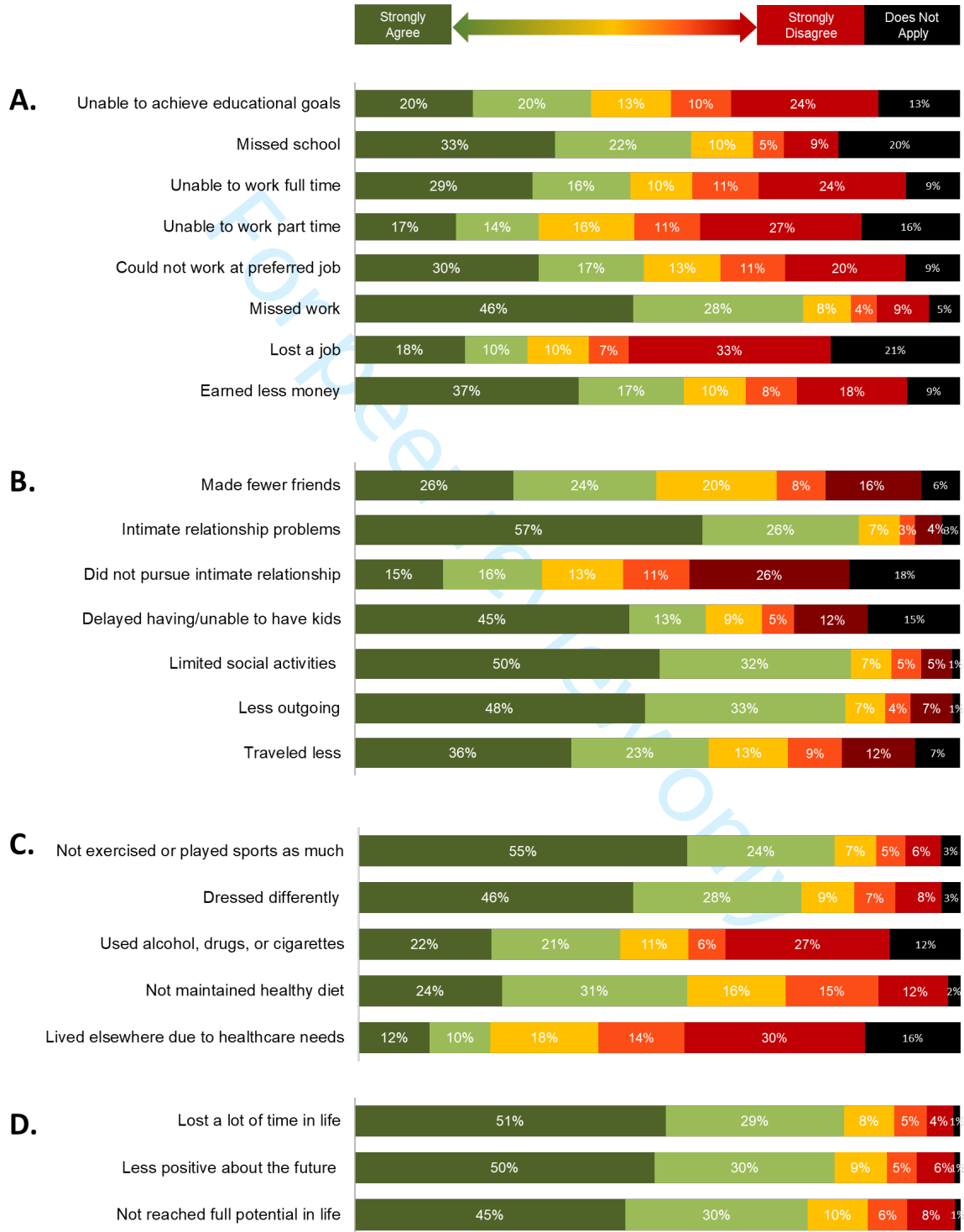
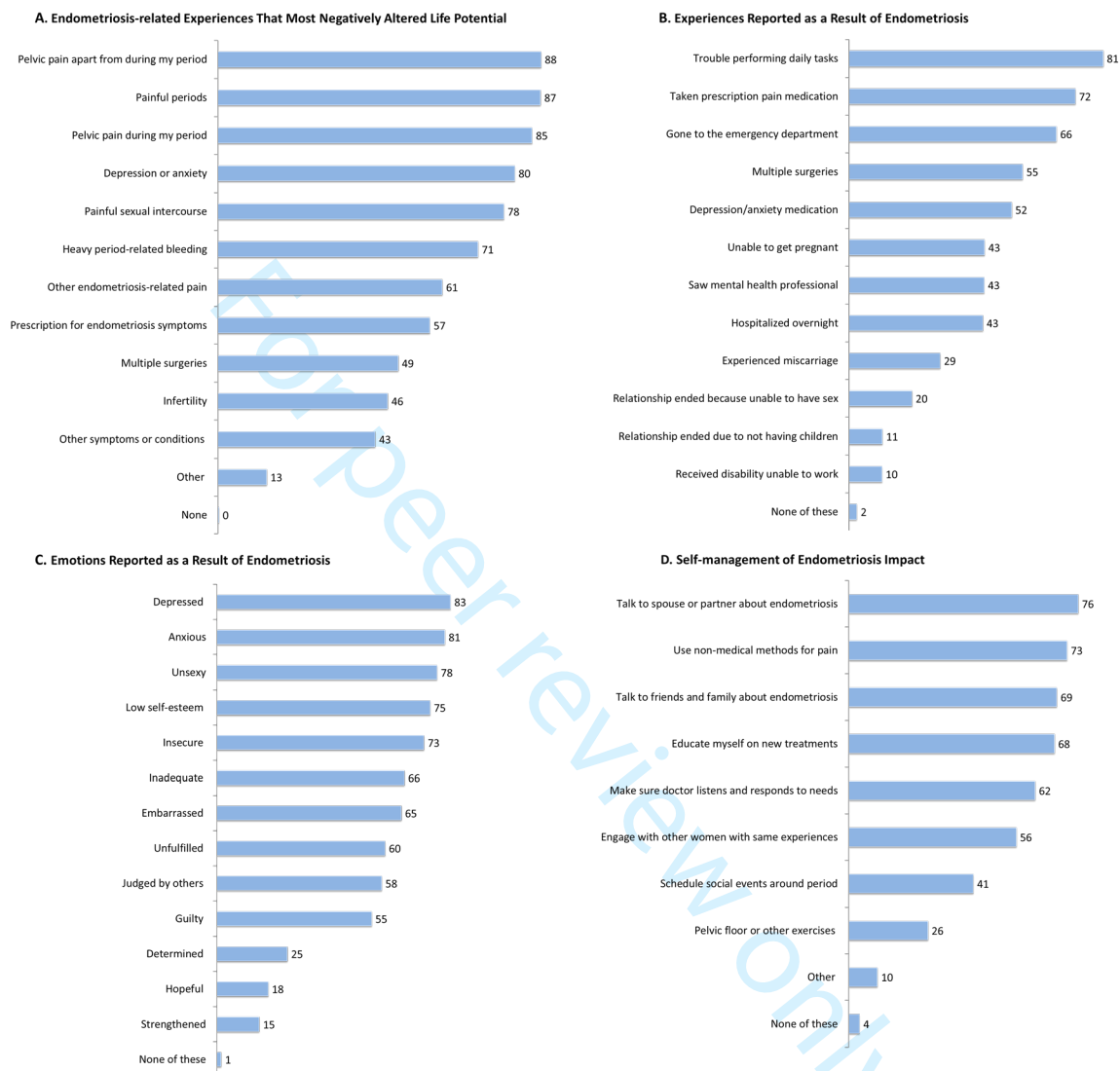


FIGURE 2



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3 **1 The impact of endometriosis on women's life decisions and goal attainment measured in**
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5 **2 a cross-sectional survey of members of an online patient community**
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9 3 Stacey A Missmer,¹ Frank F Tu,² Ahmed M Soliman,³ Stephanie E Chiuve,³ Sarah Cross,³
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11 4 Samantha Eichner,³ Oscar Antunez Flores,³ Andrew W Horne,⁴ Beth Schneider,⁵ Sawsan As-
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3 **1 SUPPORTING INFORMATION**
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7 **2 Supporting Information Table 1.** Women indicated how much they agreed or disagreed with
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10 **3** the impact of endometriosis on the following: (A) pain, (B) work and education, (C) life
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12 **4** experiences altered in a negative way, (D) impact on life, (E) feelings, and (F) management of
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14 **5** impact.
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18 **6 Supporting Information Figure 1.** Impact of endometriosis on educational and professional
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20 **7** achievements in the United States (A) and in the rest of the world (B).
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24 **8 Survey.** MyEndometriosisTeam Survey – Life Course Impact Survey
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Supporting Information Table 1.

S1A	Daily	A few times a week	A few times a month	Weekly	Monthly	Every few months	Never	Once or twice a year
Total, n (%) (N = 743)	415 (55.9)	160 (21.5)	78 (10.5)	43 (5.8)	31 (4.2)	9 (1.2)	4 (0.5)	3 (0.4)
Less positive about future, n (%) (n = 589)	362 (61.5)	120 (20.4)	50 (8.5)	31 (5.3)	16 (2.7)	6 (1.0)	2 (0.3)	2 (0.3)
Remaining respondents (n = 154)	53 (34.4)	40 (26.0)	28 (18.2)	12 (7.8)	15 (9.7)	3 (1.9)	2 (1.3)	1 (0.6)
Did not reach full potential, n (%) (n = 556)	341 (61.3)	121 (21.8)	44 (7.9)	28 (5.0)	13 (2.3)	6 (1.1)	2 (0.4)	1 (0.2)
Remaining respondents (n = 187)	74 (39.6)	39 (20.9)	15 (8.0)	34 (18.2)	18 (9.6)	3 (1.6)	2 (1.1)	2 (1.1)

S1B	Missed days of work	Missed school	Earned less money	Could not work at preferred job	Unable to work full time	Unable to achieve educational goals	Unable to work part time	Lost a job
Total, n (%) (N = 743)	550 (74.9)	413 (56.3)	404 (55.0)	355 (48.4)	338 (46.0)	290 (39.5)	226 (30.8)	212 (28.9)
Less positive about future, n (%) (n = 589)	463 (78.6)	343 (58.2)	359 (61.0)	316 (53.7)	300 (50.9)	257 (43.6)	202 (34.3)	190 (32.3)
Remaining respondents (n = 154)	87 (56.5)	70 (45.5)	45 (29.2)	39 (25.3)	38 (24.7)	33 (21.4)	24 (15.6)	22 (14.3)
Did not reach full potential, n (%) (n = 556)	448 (80.6)	329 (59.2)	365 (65.6)	323 (58.1)	295 (53.1)	261 (46.9)	205 (36.9)	193 (34.7)
Remaining respondents (n = 187)	102 (54.5)	84 (44.9)	39 (20.9)	32 (17.1)	43 (23.0)	29 (15.5)	21 (11.2)	19 (10.2)

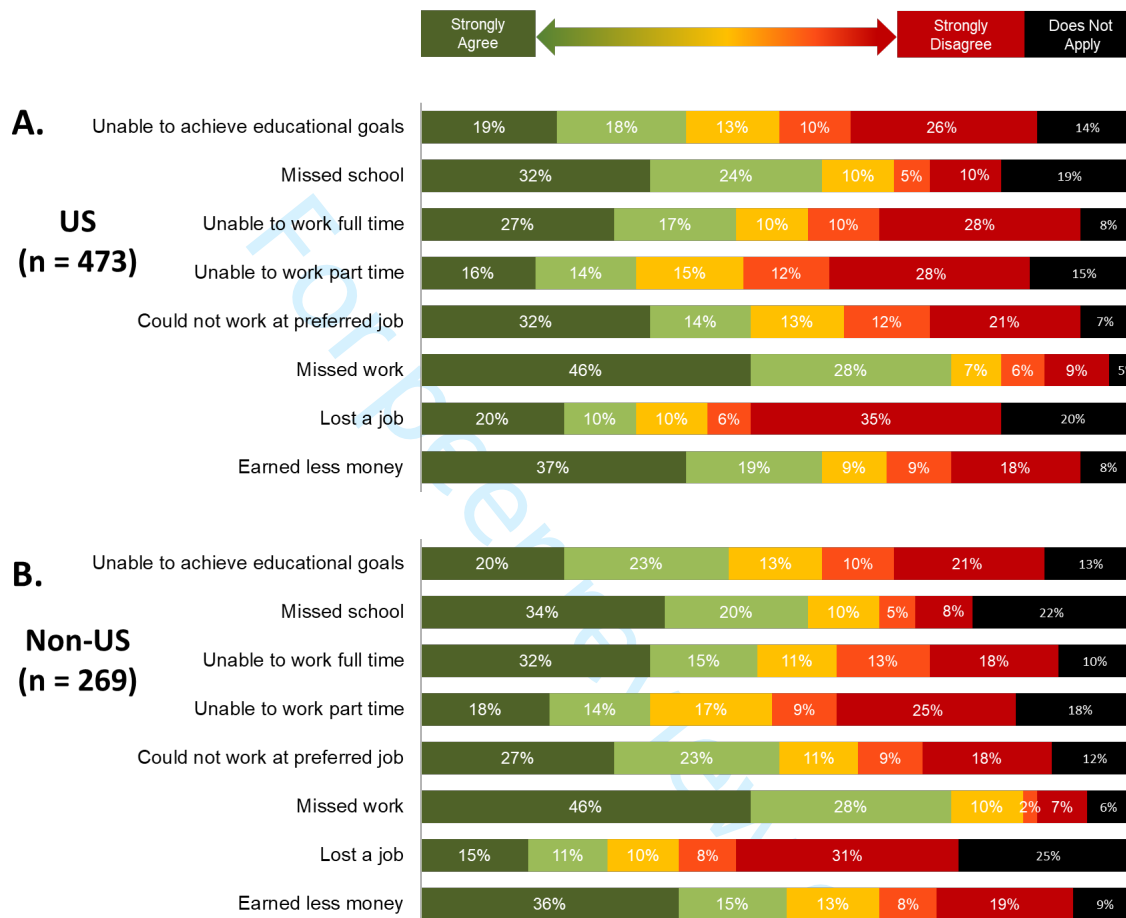
S1C	Pelvic pain apart from period	Painful periods	Pelvic pain during period	Depression or anxiety	Painful sexual intercourse	Heavy period- related bleeding	Other endometriosis- related pain	Taken prescription for symptoms	Multiple surgeries	Infertility	Other symptoms or conditions
Total, n (%) (N = 743)	651 (87.6)	650 (87.5)	633 (85.2)	598 (80.5)	576 (77.5)	524 (70.5)	452 (60.8)	427 (57.5)	363 (48.9)	342 (46.0)	317 (42.7)
Less positive about future, n (%) (n = 589)	528 (89.6)	517 (87.8)	506 (85.9)	505 (85.7)	461 (78.3)	413 (70.1)	382 (64.9)	353 (59.9)	297 (50.4)	272 (46.2)	268 (45.5)
Remaining respondents (n = 154)	123 (79.9)	133 (86.4)	127 (82.5)	93 (60.4)	115 (74.7)	111 (72.1)	70 (45.5)	74 (48.1)	66 (42.9)	70 (45.5)	49 (31.8)
Did not reach full potential, n (%) (n = 556)	500 (89.9)	491 (88.3)	482 (86.7)	476 (85.6)	430 (77.3)	400 (71.9)	366 (65.8)	332 (59.7)	284 (51.1)	261 (46.9)	259 (46.6)
Remaining respondents (n = 187)	151 (80.7)	159 (85.0)	151 (80.7)	122 (65.2)	146 (78.1)	124 (66.3)	86 (46.0)	95 (50.8)	79 (42.2)	81 (43.3)	58 (31.0)

S1D	Trouble performing daily tasks	Taken Rx pain medication	Gone to ER	Multiple surgeries	Depression/ anxiety medication	Unable to get pregnant	Saw mental health professional	Hospitalized overnight	Experienced miscarriage	Relationship ended because unable to have sex
Total, n (%) (N = 743)	594 (80.9)	529 (72.1)	485 (66.1)	406 (55.3)	380 (51.8)	317 (43.2)	316 (43.1)	313 (42.6)	213 (29.0)	147 (20.0)
Less positive about future, n (%) (n = 589)	500 (84.9)	442 (75.0)	406 (68.9)	333 (56.5)	327 (55.5)	251 (42.6)	276 (46.9)	266 (45.2)	167 (28.4)	132 (22.4)
Remaining respondents (n = 154)	94 (61.0)	87 (56.5)	79 (51.3)	73 (47.4)	53 (34.4)	66 (42.9)	40 (26.0)	47 (30.5)	46 (29.9)	15 (9.7)
Did not reach full potential, n (%) (n = 556)	478 (86.0)	421 (75.7)	390 (70.1)	311 (55.9)	308 (55.4)	239 (43.0)	265 (47.7)	249 (44.8)	166 (29.9)	132 (23.7)
Remaining respondents (n = 187)	116 (62.0)	108 (57.8)	95 (50.8)	95 (50.8)	72 (38.5)	78 (41.7)	51 (27.3)	64 (34.2)	47 (25.1)	15 (8.0)

S1E	Depressed	Anxious	Unsexy	Low self-esteem	Insecure	Inadequate	Embarrassed	Unfulfilled	Judged by others	Guilty
	Total, n (%) (N = 743)	607 (82.7)	592 (80.7)	572 (77.9)	554 (75.5)	538 (73.3)	487 (66.3)	479 (65.3)	437 (59.5)	428 (58.3)
Less positive about future, n (%) (n = 589)	517 (87.8)	491 (83.4)	468 (79.5)	478 (81.2)	469 (79.6)	421 (71.5)	415 (70.5)	387 (65.7)	380 (64.5)	350 (59.4)
Remaining respondents (n = 154)	90 (58.4)	101 (65.6)	104 (67.5)	76 (49.4)	69 (44.8)	66 (42.9)	64 (41.6)	50 (32.5)	48 (31.2)	52 (33.8)
Did not reach full potential, n (%) (n = 556)	487 (87.6)	462 (83.1)	441 (79.3)	443 (79.7)	434 (78.1)	401 (72.1)	393 (70.7)	375 (67.4)	352 (63.3)	330 (59.4)
Remaining respondents (n = 187)	120 (64.2)	130 (69.5)	131 (70.1)	111 (59.4)	104 (55.6)	86 (46.0)	86 (46.0)	62 (33.2)	76 (40.6)	72 (38.5)

S1F	Talk to spouse or partner	Use non-medical methods for pain	Talk to friends and family	Educate self on treatments	Make doctor listen and respond to needs	Engage with other women with same experiences	Schedule social events around period	Pelvic floor or other exercises	Other	None of these
	Total, n (%) (N = 743)	560 (76.3)	533 (72.6)	508 (69.2)	502 (68.4)	455 (62.0)	409 (55.7)	304 (41.4)	193 (26.3)	70 (9.5)
Less positive about future, n (%) (n = 589)	445 (75.6)	425 (72.2)	409 (69.4)	409 (69.4)	369 (62.6)	337 (57.2)	257 (43.6)	162 (27.5)	61 (10.4)	19 (3.2)
Remaining respondents (n = 154)	115 (74.7)	108 (70.1)	99 (64.3)	93 (60.4)	86 (55.8)	72 (46.8)	47 (30.5)	31 (20.1)	9 (5.8)	7 (4.5)
Did not reach full potential, n (%) (n = 556)	418 (75.2)	405 (72.8)	383 (68.9)	394 (70.9)	345 (62.1)	325 (58.5)	246 (44.2)	153 (27.5)	59 (10.6)	20 (3.6)
Remaining respondents (n = 187)	142 (75.9)	128 (68.4)	125 (66.8)	108 (57.8)	110 (58.8)	84 (44.9)	58 (31.0)	40 (21.4)	11 (5.9)	6 (3.2)

Supporting Information Figure 1.



Survey.

MyEndometriosisTeam Survey – Life Course Impact Survey

Introduction

Part of our mission at MyEndometriosisTeam is to help build awareness and understanding of the impact that endometriosis can have on daily life. Creating a better understanding of what other women with endometriosis go through is important to many members. The aim of this study is to understand real-life experiences of women living with chronic endometriosis. This includes how it may influence life choices and any long-lasting effect it has.

This survey should take approximately 8 minutes to complete. Your participation is completely voluntary, and your responses are anonymous. MyEndometriosisTeam never shares any personally identifying information. Highlights of the findings of this research survey will be shared back with the MyEndometriosisTeam community. We are conducting this survey in collaboration with one of our pharmaceutical partners. This is one of the ways we keep MyEndometriosisTeam free while making sure your voice is heard. If you have any questions regarding the survey, please contact support@myendometriosisteam.com.

If you are 19 years of age or older, live in the United States (excluding Puerto Rico), understand the statements above and freely consent to participate in this research, click on the “Yes, I agree” button to begin the survey.

Yes, I agree

No thanks, I'd rather not participate

Section 1: Screening Questions

S1. Which of the following describes you?

Male (**Terminate**)

Female

1
2
3 S2. What is your age?
4

5 Under 19 (**Terminate**)
6

7 19-29
8

9 30-39
10

11 40-49
12

13 50-59
14

15 60 or older
16
17

18
19 S3. Which one of the following best describes your condition?
20

21 Stage 1 endometriosis
22

23 Stage 2 endometriosis
24

25 Stage 3 endometriosis
26

27 Stage 4 endometriosis
28

29 Not sure what stage of endometriosis I have
30

31 I do not have endometriosis (**Terminate**)
32
33

34 S4. In which country do you currently live?
35

36 United States (excluding Puerto Rico) (**Continue**)
37

38 Australia
39

40 Canada
41

42 Ireland
43

44 Netherlands
45

46 New Zealand
47

48 South Africa
49

50 United Kingdom
51

52 Other
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56 Section 1: Endometriosis Severity
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1. At what age did your endometriosis symptoms begin? (drop-down menu)
2. At approximately what age did you start your first period? (drop-down menu)
3. Thinking about when you first started to experience endometriosis symptoms, approximately how many years did it take before you were diagnosed with endometriosis? (drop-down menu)
4. Did you ever have a surgical procedure, such as a laparoscopy or laparotomy, to confirm you have endometriosis?
 - Yes
 - No
 - Not sure
5. Which one of the following best describes how often you typically feel some type of endometriosis-related pain?
 - Daily
 - A few times a week
 - Weekly
 - A few times a month
 - Monthly
 - Every few months
 - Once or twice a year
 - Never
6. Please rate how severe your endometriosis related pain has been at its worst in the last 12 months using a scale from 0 to 10, where 0=no pain and 10=worst imaginable pain. (Drop down menu).

- 1
2
3 7. Over the years, has your endometriosis related pain gotten better, gotten worse, or stayed
4 the same?
5
6

7 Gotten much better

8 Gotten somewhat better

9 Stayed the same

10 Gotten somewhat worse

11 Gotten much worse
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20 Section 2: Impact on Quality of Life and Life Choices

- 21
22 8. Please indicate how much you agree or disagree with the following statements about the
23 impact endometriosis has had **on your entire life up to now.**
24
25

26 (Rotate order)
27
28

29 **Because of my endometriosis:**
30
31
32

(Please select one box for each row)	Strongly disagree	Some-what Disagr	Neutral	Some-what Agree	Strongly agree	Not Applic-able
I was unable to achieve my educational goals	1	2	3	4	5	6
I missed many days of school	1	2	3	4	5	6
I was unable to work full time	1	2	3	4	5	6
I was unable to work part time	1	2	3	4	5	6
I could not work at the job I would have preferred	1	2	3	4	5	6
I missed many days of work	1	2	3	4	5	6
I lost a job	1	2	3	4	5	6

I earned less money than I could have	1	2	3	4	5	6
I made fewer friends	1	2	3	4	5	6
I have had problems with sexual or intimate relationships	1	2	3	4	5	6
I have not dated or pursued an intimate relationship	1	2	3	4	5	6
I have delayed having or have been unable to have children	1	2	3	4	5	6
I have limited my social activities	1	2	3	4	5	6
I have not exercised or played sports as much as I would have liked	1	2	3	4	5	6
I do not live where I would like due to my healthcare needs	1	2	3	4	5	6
I lost a lot of time in my life	1	2	3	4	5	6
I have travelled less than I would have liked	1	2	3	4	5	6
I have dressed differently than I would have liked	1	2	3	4	5	6
I have used alcohol, drugs or smoked cigarettes	1	2	3	4	5	6
I have not maintained a healthy diet	1	2	3	4	5	6
I have been less outgoing	1	2	3	4	5	6
I have been less positive about the future	1	2	3	4	5	6
I have not reached my full potential in life	1	2	3	4	5	6

9. What endometriosis-related experiences, if any, do you think have most contributed to altering your life potential in a negative way? Select all that apply. (Rotate order)

- 1
- 2
- 3
- 4 Painful sexual intercourse
- 5
- 6 Pelvic pain during my period
- 7
- 8 Pelvic pain apart from during my period
- 9
- 10 Painful periods
- 11
- 12 Heavy period-related bleeding
- 13
- 14 Other endometriosis related pain
- 15
- 16 Infertility
- 17
- 18 Depression or anxiety
- 19
- 20 Multiple surgeries
- 21
- 22 Prescription treatment to control endometriosis symptoms
- 23
- 24 Other symptoms or conditions (please specify)
- 25
- 26 Other (please specify)
- 27
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- 1
2
3 10. Which, if any, of these, have you experienced as a result of your endometriosis? Check
4 all that apply. (Rotate order)
5
6

7 Taken prescription medication for the pain (for example, opioids)

8 Taken prescription medication to treat depression or anxiety

9 Had multiple surgical procedures

10 Been hospitalized overnight

11 Gone to the emergency room

12 Received disability income due to being unable to work

13 Had a miscarriage (whether or not it was due to having endometriosis)

14 Had trouble performing daily tasks

15 Saw a mental health professional (eg., psychiatrist, counselor)

16 Was unable to get pregnant

17 Had a relationship end because I was unable to have children

18 Had a relationship end because I was unable to have sex

19 None of these
20
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11. And which, if any, of these emotions, have you experienced as a result of your endometriosis? Check all that apply. (Rotate order)

I have felt...

Low self esteem

Judged by others

Inadequate

Unsexy

Insecure

Guilty

Determined

Strengthened

Hopeful

Embarrassed

Unfulfilled

Depressed

Anxious

None of these

For peer review only

- 1
2
3 12. Which of the following, if any, have you done to help manage the impact of endometriosis?
4 Select all that apply. (rotate order)
5

6
7 Schedule social events around my period

8
9 Engage with other women going through the same experiences

10
11 Talk to my friends and family about endometriosis

12
13 Talk to my spouse or partner about my endometriosis

14
15 Pelvic floor or other exercises to lessen pain during sex

16
17 Make sure my doctor listens and responds to my needs

18
19 Educate myself on new treatments

20
21 Use non-medical methods for controlling pain (e.g., ice or heat, lubricants during sex)

22
23 Other (please describe)

24
25 None of these

- 26
27 13. Because of endometriosis, is there anything you feel you were unable to accomplish in
28 your life? (open end)

- 29
30 14. Is there anything else you would like us to know about the impact endometriosis has had
31 on your life? (open end)
32

33 Just a few last questions.
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35
36

- 37 D1. Which of the following best describes the area where you live?
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41 Urban

42 Suburban

43 Rural

44 Not sure / prefer not to say
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3 D2. What is the highest level of education you have achieved?
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7 Less than high school

8 Some high school

9 High school or equivalent (e. g., GED)

10 Some college, but no degree

11 Associate degree

12 College degree (e.g., B.A., B.S.)

13 Some graduate school, but no degree

14 Graduate school (e.g., M.S., M.D., Ph.D.)

15 Prefer not to answer
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25 D3. What is your current employment status?
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28 Working full time

29 Working part time

30 Unemployed, not looking for work

31 Unemployed, looking for work

32 Retired

33 Unable to work

34 Prefer not to answer
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3 D4. Which of the following best describes your marital status?
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7 Single/never married

8 Married

9 Widowed

10 Divorced or separated

11 Prefer not to answer

12
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14
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18 (Skip D5 if “married” or “prefer not to answer” selected in D4)
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20
21

22 D5. Are you currently in an intimate relationship?
23
24
25

26 Yes

27 No

28 Prefer not to answer
29
30
31
32

33 D6. How many children, if any, do you have?
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35
36
37

38 None

39 1

40 2

41 3

42 4

43 5 or more

44 Prefer not to answer
45
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52 Thank you for answering these questions.
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STROBE Statement—Checklist of items that should be included in reports of ***cross-sectional studies***

	Item No	Recommendation	Location in Manuscript
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	Page 1, lines 1-2
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	Page 3, lines 1-22; page 4, lines 1-5
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	Page 5, lines 1-23; page 6, lines 1-18
Objectives	3	State specific objectives, including any prespecified hypotheses	Page 7, lines 1-11
Methods			
Study design	4	Present key elements of study design early in the paper	Page 7, lines 19-21; page 8, lines 1-23; page 9, lines 1-17
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	Page 8, lines 4-5; page 9, lines 11-17
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants	Page 9, lines 11-17
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	N/A
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	Page 7, lines 20-21; page 8, lines 1-23; supporting information pages 7-17
Bias	9	Describe any efforts to address potential sources of bias	Page 8, lines 17-18; page 9, lines 16-17
Study size	10	Explain how the study size was arrived at	Page 9, lines 5-6 and 11-16
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	Page 9, lines 19-20; page 10, lines 1-8

1				
2	Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	Page 9, lines 19-20
3			(b) Describe any methods used to examine subgroups and interactions	Page 9, lines 19-20; page 10, lines 1-8
4			(c) Explain how missing data were addressed	Page 8, lines 22-23
5			(d) If applicable, describe analytical methods taking account of sampling strategy	N/A
6			(e) Describe any sensitivity analyses	N/A
7				
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12	Results			
13				
14	Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	Page 10, lines 11-12
15			(b) Give reasons for non-participation at each stage	N/A
16			(c) Consider use of a flow diagram	N/A
17				
18				
19				
20				
21	Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	Page 10, lines 13-21; page 11, Table 1
22			(b) Indicate number of participants with missing data for each variable of interest	N/A (no missing data; see page 8, lines 22-23)
23				
24				
25				
26				
27	Outcome data	15*	Report numbers of outcome events or summary measures	Pages 12-14; page 15, lines 1-7; Figures 1-2
28				
29				
30	Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	N/A
31			(b) Report category boundaries when continuous variables were categorized	N/A
32			(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	N/A
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38	Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	Page 15, lines 8-23; page 16, lines 1-5; supporting information pages 2-6
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Discussion

Key results	18	Summarise key results with reference to study objectives	Page 16, lines 8-14; page 23, lines 1-5
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	Page 4, lines 14-18; page 21, lines 19-24; page 22, lines 1-5
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	Page 16, lines 16-23; pages 17-22
Generalisability	21	Discuss the generalisability (external validity) of the study results	Page 21, lines 1-17; page 22, lines 7-22; page 23, lines 1-5

Other information

Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	Page 24, lines 11-12
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*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.

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The impact of endometriosis on women's life decisions and goal attainment: a cross-sectional survey of members of an online patient community

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3 1 **The impact of endometriosis on women's life decisions and goal attainment: a cross-**
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5 2 **sectional survey of members of an online patient community**
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1 ABSTRACT

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8 **Objectives:** To examine women's perceptions of endometriosis-associated disease burden and
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10 its impact on life decisions and goal attainment.

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15 **Design:** An anonymous online survey was distributed in October 2018 through the social media
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17 network MyEndometriosisTeam.com.

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22 **Participants:** Women aged 19 years and older living in several English-speaking countries who
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24 self-identified as having endometriosis.

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32 **Outcome measures:** Patients' perspectives on how endometriosis has affected their work,
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34 education, relationships, overall life decisions, and attainment of goals. Subanalyses were
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36 performed for women who identified as "less positive about the future" (LPAF) or had "not
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38 reached their full potential" (NRFP) due to endometriosis.

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Results: 743 women completed the survey. Women reported high levels of pain when pain was
at its worst (mean score, 8.9 on severity scale of 0 [no pain] to 10 [worst imaginable pain]) and
most (56%, n=415) experienced pain daily. Women reported other negative experiences
attributed to endometriosis, including emergency department visits (66%, n=485), multiple
surgeries (55%, n=406), and prescription treatments for symptoms of endometriosis (72%,
n=529). Women indicated that they believed endometriosis had a negative impact on their
educational and professional achievements, social lives/relationships, and overall physical
health. Most women "somewhat agreed"/"strongly agreed" that endometriosis caused them to
lose time in life (81%, n=601), feel LPAF (80%, n=589), and feel they had NRFP (75%, n=556).
Women who identified as LPAF or NRFP generally reported more negative experiences than
those who were non-LPAF or non-NRFP.

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3 1 **Conclusions:** Women who completed this survey reported pain and negative experiences
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5 2 related to endometriosis that were perceived to negatively impact major life-course decisions
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7 3 and attainment of goals. Greater practitioner awareness of the impact that endometriosis has on
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9 4 a woman's life course and the importance of meaningful dialogue with patients may be
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11 5 important for improving long-term management of the disease and help identify women who are
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13 6 most vulnerable.

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17 7 **Abstract Word Count:** 298 (300 word maximum)

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21 8 **Strengths and limitations of this study**

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24 9 • A strength of our study is use of a quantitative survey with a meaningful sample size and
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26 10 sample population that spanned multiple countries.
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28 11 • This study is strengthened by targeted research questions developed based on existing
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30 12 conversations on a social network platform.
- 31
32 13 • Another strength of this study is the use of a social network familiar to patients,
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34 14 facilitating honesty in responses to sensitive topics.
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36 15 • An important limitation of our study is possible self-selection bias due to voluntary
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38 16 participation in an online community and no targeted sampling; quantitative data may
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40 17 therefore not be generalizable to all women with endometriosis.
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42 18 • The study is limited by self-reported patient responses that were not confirmed by
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44 19 medical records or other complementary data.
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1 INTRODUCTION

2 Endometriosis is an often chronic gynecologic disorder that impacts 10% of women of
3 reproductive age.¹ Endometrial-like tissue thriving outside the uterus leads to local and systemic
4 inflammation that can result in a wide range of life-impacting effects, including pelvic pain,
5 dysmenorrhea, dyspareunia, and infertility.²⁻⁴ These debilitating effects have an immense impact
6 on a patient's quality of life and overall well-being.^{5,6} For example, symptoms of endometriosis
7 may have a negative impact on women's psychological health,^{7,8} strain social and intimate
8 relationships,^{5,9-11} and lead to losses in productivity, both at home and in the workplace.¹² These
9 issues have been further exacerbated by the COVID-19 pandemic, which has led to reduced
10 access to medical care, delayed treatments, increased stress, loss of work productivity, and
11 mandated self-isolation.^{13,14}

12 Outside the physical and emotional toll, the collective symptoms of endometriosis are also
13 associated with direct and indirect costs that are burdensome to patients. Visits to physicians
14 and emergency departments, pharmacy claims, and other direct expenses are estimated to cost
15 between \$12,000 to \$15,000 per patient per year in the United States, and the loss of work and
16 productivity may amount to additional losses of thousands of dollars per patient.^{12,15-18}

17 Most studies examining chronic diseases like endometriosis focus on one or two specific areas
18 of the disease, such as its social, physical, or psychological impact at a specific point in
19 time.^{19,20} In contrast, few studies have examined the impact of endometriosis on a woman's life
20 course (ie, "life-course impairment") based on how symptoms and experiences resulting from
21 the disease influence major life events and decisions (such as whether to pursue educational
22 opportunities, choose a career path, establish intimate relationships, and plan for a family) and
23 the overall ability of patients to attain their life goals.^{19,20} The few existing studies have small

1 sample sizes or are qualitative, relying on informational interviews to ascertain the life-course
2 impact of the disease, but highlight the substantial impacts that endometriosis can have on
3 social activities, intimate relationships, education, work productivity, and psychological well-
4 being.^{11,21-23} Understanding life-course impairment, as opposed to focusing on the symptoms of
5 the disease (such as pain or infertility, which are most often addressed individually not
6 holistically), is vital because of the complicated interrelationship among symptoms and their
7 downstream effects. Individual symptoms can influence critical life decisions (eg, work,
8 education, or personal relationships) in ways that are interrelated and can impact other areas of
9 a patient's life. For example, chronic pain may influence the type and amount of work performed
10 or whether a patient decides to work at all, which, in turn, can have financial implications on the
11 patient's lifestyle, family, relationships, or sense of personal fulfillment.^{19,20} Symptoms may
12 determine where a patient chooses to live because of financial considerations, healthcare
13 access, or proximity to support networks. Similarly, dyspareunia related to endometriosis may
14 lead some women to avoid intimate relationships, which may have downstream implications for
15 marriage, family planning, and mental and emotional health.^{24,25} Cumulatively, persistent
16 symptoms of endometriosis and their impact on daily activities and family and intimate
17 relationships can negatively impact the trajectory of women's lives and are profound and far-
18 reaching.

1 The objective of this multinational survey was to gain a better understanding of patient
2 perspectives on how endometriosis impacts their daily activities and identify how the disease
3 may influence women's major life decisions and attainment of their goals. In addition, we sought
4 to understand the endometriosis-related life-course impacts specifically in women who reported
5 low optimism or low goal attainment by investigating the specific reasons for life-course
6 impairment among the subset of women who felt their lives were most negatively impacted by
7 endometriosis. Insights into a patient's complete experience with endometriosis are needed to
8 develop and provide access to effective treatments to reduce the negative impacts of
9 endometriosis on a woman's life course. Greater awareness of the potential negative life-course
10 impacts of endometriosis is important for helping physicians to identify and understand patients'
11 needs and improve the long-term management of endometriosis.

12 **METHODS**

13 **Ethics approval**

14 The Advarra Institutional Review Board (Columbia, MD, USA) reviewed the cross-sectional
15 survey for participants in the United States and determined that informed consent was not
16 required (exempt determination #Pro00029982, 26 September 2018). However, participants did
17 consent to participate in a survey and email invitations were provided to people who opted to
18 receive communications.

19 **Survey development**

20 An online survey was created in a collaborative effort between AbbVie (North Chicago, IL, USA)
21 and MyHealthTeams (San Francisco, CA, USA), a company that creates social networks for

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3 1 communities of individuals living with chronic conditions to foster discussion and provide support
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5 2 among people facing similar circumstances. The survey was programmed and administered
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7 3 through Qualtrics, an online survey tool that allows users to capture survey responses in an
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9 4 anonymized manner. The survey was provided in English and was available online on the social
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11 5 media network website MyEndometriosisTeam.com from October 3 through October 25, 2018.
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13 6 The 14 survey questions about women's experiences with endometriosis were based on our
14
15 7 knowledge about the disease state, existing publications, and online conversations participants
16
17 8 were having (see 'Patient and public involvement' for further detail). In addition, the survey
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19 9 contained 4 screening questions and 6 demographic questions (identified as Supporting
20
21 10 Information). The primary goal of the survey was to capture patients' perspectives on the
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23 11 negative impacts of endometriosis on different aspects of their life courses, including how
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25 12 endometriosis has affected their work, education, relationships, overall life decisions, and
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27 13 attainment of goals. This portion of the survey was modeled after a validated instrument created
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29 14 to measure life-course impact of disease in patients with psoriasis.²⁵ This tool was used as a
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31 15 starting point for model development as it has been validated for another chronic disease with
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33 16 excess psychological and psychosocial burden, has been used clinically, and was published in
34
35 17 the scientific literature. Survey questions were rotated to avoid any bias introduced by order of
36
37 18 answer selections. Most survey questions were closed-ended and provided multiple-choice
38
39 19 options to participants; two questions were open-ended and allowed participants to provide
40
41 20 written responses detailing any life accomplishments they believed were impeded by
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43 21 endometriosis or to offer anything else they wanted to share about the impact of endometriosis
44
45 22 on their lives. Responses were required for all closed-ended questions; therefore, no
46
47 23 imputations for missing data were required. The survey used in this study is included in the
48
49 24 supplementary material.

55 56 **Patient and public involvement**

1 Survey questions were developed based on reviewing conversations members were having on
2 MyEndometriosisTeam.com to ensure both relevance of topics and patient-focused language.
3 The social media network, MyEndometriosisTeam.com, was developed for women living with
4 endometriosis and consists of more than 108,000 members across 13 countries. Based on
5 institutional review board exemption requirements, people were asked at the beginning of the
6 survey if they agreed to participate, and email invitations were sent only to those people who
7 opted into receiving communications.

8 **Participant eligibility and recruitment**

9 Members of the social network MyEndometriosisTeam.com were recruited through 33,000 email
10 invitations. Invitations posted on the public Facebook page for MyEndometriosisTeam recruited
11 additional women to participate in the survey, which was live on the MyEndometriosisTeam.com
12 website from October 3 to October 25, 2018. The English-language survey was conducted
13 among an international population of women who were at least 19 years of age and who self-
14 identified as having endometriosis. The survey was anonymous, and answers could not be
15 linked to individual members.

16 **Survey analysis**

17 Descriptive statistics were used to tabulate survey responses in this cross-sectional study. After
18 descriptive statistics were quantified for all respondents, a subanalysis was performed that
19 restricted the survey responder population to women who “somewhat agreed” or “strongly
20 agreed” that they were “less positive about the future” (LPAF) or that they “had not reached their
21 full potential” (NRFP) because of endometriosis. These two questions were selected for this
22 subanalysis to focus on the life-course impact attributed to endometriosis as identified by those

Table 1 Demographics and burden of endometriosis

Characteristic	Overall Respondents, n (%) (N=743)	LPAF Respondents, n (%) (N=589)	NRFP Respondents, n (%) (N=556)
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1 who reported low optimism or low goal attainment. For this analysis, life-course impairment was
 2 defined as respondents who “somewhat agreed” or “strongly agreed” that endometriosis had
 3 negatively impacted their education, employment, relationships, social activities, and physical
 4 and emotional well-being.

5 RESULTS

6 Survey response and demographics

7 A total of 743 women completed the survey (table 1), which was live from October 3 to October
 8 25, 2018.

9 Among respondents to the English-language survey, 474 (64%) were from the United States,
 10 and 269 (36%) were from other countries, including one-fifth from the United Kingdom (17%,
 11 n=128), and one-fifth summed from Canada, Australia, South Africa, Ireland, New Zealand, and
 12 The Netherlands (table 1). Most women (73%, n=542) were younger than 40 years of age.
 13 Almost half of the respondents (48%, n=355) were unaware of their stage of endometriosis
 14 (according to the rASRM scoring system), which was obtained at their most recent surgery.
 15 Among the 52% of respondents who recalled their rASRM score, most (57%, n=223) reported
 16 having stage 4 endometriosis (table 1). Baseline demographics were generally comparable
 17 between the overall study population and women who identified as LFAP or NRFP (table 1).

Age at time of survey, years			
19–29	206 (28)	179 (30)	155 (28)
30–39	339 (46)	269 (46)	259 (47)
40–49	180 (24)	128 (22)	129 (23)
50 or older	18 (2)	13 (2)	13 (2)
Country			
United States (excluding Puerto Rico ^a)	474 (64)	370 (63)	364 (65)
United Kingdom	128 (17)	102 (17)	92 (17)
Canada	38 (5)	32 (5)	30 (5)
Australia	37 (5)	31 (5)	27 (5)
South Africa	20 (3)	15 (3)	9 (2)
Ireland	17 (2)	15 (3)	12 (2)
Other	15 (2)	12 (2)	13 (2)
New Zealand	11 (1)	9 (2)	8 (1)
The Netherlands	3 (0.4)	3 (1)	1 (<0.1)
Level of education			
Some high school or less	33 (4)	21 (4)	20 (4)
High school diploma	111 (15)	80 (14)	76 (14)
Some college	214 (29)	164 (28)	176 (32)
College degree	254 (34)	129 (22)	113 (20)
Graduate school/degree	111 (15)	59 (10)	50 (9)
Prefer not to answer	20 (3)	15 (3)	10 (2)
Endometriosis stage			
Stage 1	33 (4)	24 (4)	22 (4)
Stage 2	39 (5)	28 (5)	29 (5)
Stage 3	93 (13)	70 (12)	73 (13)
Stage 4	223 (30)	191 (32)	171 (31)
Not sure	355 (48)	276 (47)	261 (47)
Method of diagnosis			
Laparoscopic surgery	650 (87)	518 (88)	494 (89)
Clinical only	87 (12)	66 (11)	57 (10)
Not sure	6 (0.8)	5 (1)	5 (1)

^aPatients from Puerto Rico were separated from the United States population into the “other” category due to IRB exemption qualifications that were different for residents of Puerto Rico versus residents of the 50 states of the United States.

1 **Diagnosis and symptoms**

2 *Diagnosis*

3 Women began experiencing symptoms of endometriosis at a young age, with many
4 experiencing symptoms by age 15. Most women (74%, n=549) reported having a diagnosis of
5 endometriosis made more than 3 years after the appearance of symptoms (average delay of
6 approximately 9 years). Nearly half of women (42%, n=313) said it took 10 years or longer after
7 the initial onset of their symptoms to receive a surgical or clinical diagnosis of endometriosis.
8 The younger the woman's age at symptom onset, the longer the delay; it took, on average, 13
9 years to reach a surgical diagnosis for women who began experiencing symptoms by age 13.
10 Most women (87%, n=650) reported their diagnosis had been confirmed by laparoscopy
11 (table 1).

12 *Endometriosis-associated pain*

13 Most women (56%, n=415) reported experiencing pain daily and nearly an additional one-
14 quarter of them reported feeling endometriosis-associated pain a few times per week. When
15 asked to rate how severe their pain was in the last 12 months on a scale from 0 (no pain) to 10
16 (worst imaginable pain), more than half of the respondents (54%) rated their worst pain within
17 the last 12 months as a 9 or 10. About two-thirds of women reported their endometriosis-
18 associated pain had worsened over the years when asked if endometriosis-related pain had
19 gotten better, worse, or stayed the same.

20 **Life-course impairment**

21 *Education and employment potential*

1 Many of the women surveyed said they “somewhat agreed” or “strongly agreed” that they had
2 experienced difficulties achieving their educational goals (40%, n=290) or had missed school
3 (55%, n=413) because of endometriosis-associated symptoms (figure 1A). Almost half of
4 participants (45%, n=338) “somewhat agreed” or “strongly agreed” that they could not work full
5 time, and a similar percentage (47%, n=355) reported not working at a job they would have
6 preferred. Most reported that they had missed work (74%, n=550) or earned less money than
7 they could have (54%, n=404) because of endometriosis-associated symptoms. These findings
8 were consistent among patients in the United States compared with the rest of the world
9 (supporting information figure 1).

10 *Relationships and social engagements*

11 Most women “somewhat agreed” or “strongly agreed” that endometriosis-associated symptoms
12 led to problems in their intimate relationships (83%, n=613) and/or created a barrier to starting a
13 family (58%, n=431). Most women similarly believed that endometriosis-associated symptoms
14 had led them to limit their social activities (82%, n=609), made them less outgoing (81%,
15 n=602), and caused them to travel less (59%, n=434) (figure 1B).

16 *Physical well-being*

17 Most women “somewhat agreed” or “strongly agreed” endometriosis limited their ability to stay
18 active (79%, n=588) and maintain a healthy diet (55%, n=406) (figure 1C). A high proportion of
19 women (43%, n=323) perceived that endometriosis-associated symptoms resulted in use of
20 alcohol, drugs, or cigarettes.

21 *Life-course impairment overall*

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2
3 1 Overall, most women (80%, n=601) “somewhat agreed” or “strongly agreed” endometriosis-
4 associated symptoms had caused them to lose time from their daily lives (figure 1D). A similar
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6 2 associated symptoms had caused them to lose time from their daily lives (figure 1D). A similar
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8 3 number of women reported that they were less positive about the future because of their
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10 4 endometriosis-associated symptoms (80%, n=589), and 75% (n=556) “somewhat agreed” or
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12 5 “strongly agreed” that endometriosis-associated symptoms had kept them from reaching their
13
14 6 full potential in life.

7 **Experiences and emotions associated with endometriosis**

8 Women reported that numerous experiences attributed to endometriosis had altered their life
9 potential in a negative way (figure 2A) or negatively impacted their lives in other ways
10 (figure 2B). The most frequent responses were common symptoms of endometriosis, including
11 pelvic pain apart from menstruation, painful menstruation, pelvic pain during menstruation, and
12 painful sexual intercourse.

13 Most women surveyed reported that endometriosis impacted their ability to perform daily tasks
14 (81%, n=594); however, many of the negative experiences attributed to endometriosis were
15 related to the use of healthcare services and treatments. For example, women reported taking
16 prescription pain medications (72%, n=529), visiting emergency departments (66%, n=485),
17 having multiple surgeries (55%, n=406), being hospitalized overnight (43%, n=313), taking
18 prescription medication for depression or anxiety (52%, n=380), or seeing a mental health
19 professional because of their endometriosis-associated symptoms (43%, n=316). Around half of
20 the women surveyed reported that the experiences that most negatively impacted their lives
21 were their need to take prescription medication (57%, n=427) and the multiple surgeries for
22 endometriosis (49%, n=363). In addition, most women surveyed reported several negative
23 emotions that they attributed to endometriosis, including feeling depressed (83%, n=607),

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3 1 anxious (81%, n=592), unsexy (78%, n=572), or having low self-esteem (75%, n=554; figure
4 2C).

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9 3 Women managed the impact of their endometriosis in different ways (figure 2D). Most
10 4 commonly, this included talking to a spouse or partner about their condition, using non-medical
11 5 strategies (such as diet or exercise) to control their pain, and seeking support from friends and
12 6 family.

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19 7 **Additional analysis of women who believed their future and life potential were more**
20 8 **impacted by endometriosis**

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25 9 Most of the sample included women who “somewhat agreed” or “strongly agreed” that they were
26 10 LPAF (80%; n=589) or had NRFP in life (75%; n=556) because of endometriosis, and several
27 11 questions limited to these women were further analyzed (Supporting Information table 1).
28
29 12 Overall, the observational data in this study suggested women who believed they were LPAF or
30 13 had NRFP generally reported more negative experiences than the fewer respondents who did
31 14 not indicate they were LPAF (non-LPAF, 21%; n=154) or had NRFP (non-NRFP, 25%; n=187).
32
33 15 Daily pain was reported by 62% of women who believed they were LPAF and 61% of women
34 16 who had NRFP because of endometriosis (34% non-LPAF and 40% non-NRFP; Supporting
35 17 Information table 1A). Women who believed they were LPAF or had NRFP also reported
36 18 negative experiences related to education and work they attributed to endometriosis, including
37 19 having earned less money (61% LPAF, 29% non-LPAF, 66% NRFP, and 21% non-NRFP), not
38 20 working a preferred job (54% LPAF, 25% non-LPAF, 58% NRFP, 17% non-NRFP), or not
39 21 achieving educational goals (44% LPAF, 21% non-LPAF, 47% NRFP, 16% non-NRFP)
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41 22 (Supporting Information table 1B). Most women who believed their future and life potential were
42 23 more impacted by their disease reported endometriosis-related experiences altered their life
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1 potential in a negative way (Supporting Information table 1C). Similarly, many of these women
2 reported negative experiences and emotions they attributed to endometriosis (Supporting
3 Information table 1D, E). All women used similar strategies to cope with and mitigate the impact
4 of endometriosis on their lives (Supporting Information table 1F).

6 **DISCUSSION**

7 This survey found that women with endometriosis who self-reported pronounced symptoms
8 reported experiences that negatively impacted their perspective of the future and overall life
9 potential. For many women, endometriosis-associated symptoms negatively affect various
10 areas of their lives, including education and employment, relationships and social engagements,
11 and physical well-being. Participants indicated that adverse experiences related to management
12 of their disease and its impact on everyday life also believed that their future and life potential
13 were negatively impacted by endometriosis.

14 **Study implications**

15 The severity of pain reported by women who completed the online survey indicates that
16 respondents in our study may have had a greater symptom burden than did women participating
17 in previous studies using similar pain scales.²⁶⁻²⁸ Women in our study also reported slightly
18 lengthier delays in diagnosis after the onset of their first symptoms. Findings in previous studies
19 have illustrated that delays are common in diagnosing endometriosis.^{15,29-37} Although some
20 recent literature suggests that the delay in diagnosis may be slowly improving,³⁵ the use of non-
21 invasive and accurate diagnostic tools could improve diagnosis times and reduce women's pain
22 and distress.^{37,38} The delays in diagnosis reported by our study participants and others indicate

1 many women experiencing troublesome symptoms of endometriosis may still wait extended
2 periods before receiving a definitive diagnosis and initiating treatment.

3 The higher pain burden and longer diagnostic delay reported in our sample, which may include
4 higher numbers of women who sought social network support because they were more
5 frustrated with their disease experience, could conceivably be due in part to their longer
6 struggles with more challenging symptoms than would be observed in the general population of
7 women with diagnosed endometriosis. Results from a recent study using the same social
8 network to recruit participants found that the majority of respondents rated their worst pain
9 higher than 7 on a 10-point scale, only a little lower than the pain rating given by the women in
10 our study.³⁹ Additionally, the previous study participants also experienced a diagnostic delay,
11 supporting the theory that recruitment from this member-centered network may draw more
12 women who have struggled longer with their disease.³⁹ Interestingly, overall trends in diagnostic
13 delays observed between age groups in our study are consistent with reports in previous
14 research, ie, women whose symptom onset occurred at a younger age experienced longer
15 times to diagnosis.^{15,31,35}

16 Many respondents said they missed school and were generally unable to achieve their
17 educational goals because of endometriosis. There is a dearth of research on the impact of
18 endometriosis on women's educational aspirations and their ability to achieve goals due to
19 endometriosis-associated symptoms, compared with the impact endometriosis has on
20 professional work or other areas of life.⁹ Findings from some existing studies suggest
21 endometriosis-associated symptoms may impact grades, attendance, or completion of
22 educational programs.^{21,22,40} Although informative, these studies were more qualitative in nature
23 and involved small sample sizes.^{21,22,40} A quantitative study examining the lives of 78 women
24 15 years after receiving a verified diagnosis of endometriosis found only a fraction of women

1 reported that their disease had a negative impact on their education.¹¹ However, the women
2 included in that study seemed to report less frequent pain and endometriosis-related effects, like
3 depression, compared with the reports made by women in our study. Furthermore, the small
4 sample was collected at a single Norwegian hospital and the findings may not be representative
5 of women's experiences with endometriosis on a wider scale.¹¹ Regardless, any impact on
6 education is concerning, and our study results emphasize the need for additional research into
7 this overlooked area in women with endometriosis. Research on other medical conditions, like
8 adolescent fibromyalgia, supports that chronic pain can negatively impact education, reinforcing
9 the likelihood that endometriosis may have a similar impact.^{41,42}

10 Respondents in the current study also reported endometriosis-associated symptoms caused
11 them to miss work, earn less money, prevented them from a job they would have preferred, or
12 impeded their working full time or part time. Many health conditions that can occur with
13 endometriosis can impact work productivity and potential, including depression, other chronic
14 pain conditions or disorders, and digestive disorders.⁴³ Endometriosis was self-reported by
15 respondents in this study, and it is possible that other chronic conditions (particularly, chronic
16 overlapping pain conditions) may also contribute to women's perceived interference with
17 productivity and employment opportunities. Indeed, more than half of women with symptomatic
18 endometriosis can present with comorbid pain syndromes,⁴⁴ and these may include conditions
19 associated with pelvic pain, like dysmenorrhea, irritable bowel syndrome, or painful bladder
20 syndrome.^{45,46} Findings from previous studies have also illustrated that endometriosis-
21 associated symptoms may lead to losses in productivity both at home and in the workplace,
22 potentially impacting professional achievement.^{12,34,47,48} In our study, most women who indicated
23 that they were LPAF or had NRFP because of endometriosis reported painful symptoms and
24 negative experiences. Also, women who were LPAF or had NRFP often believed it was harder
25 to perform daily tasks because of their disease.

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3 1 Our results further support that endometriosis symptoms are disruptive and may lead to loss of
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5 2 productivity, ultimately influencing women's major life decisions or consequences, including
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7 3 whether to work at reduced capacity or pursue preferred jobs. Results from a recent multicenter
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9 4 study of women with confirmed endometriosis and a matched comparison group found the
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11 5 disease forced some women to seek work outside desired professions, which, in turn, resulted
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13 6 in health-related limitations in career choices.⁴⁸ These collective findings are concerning
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15 7 because satisfaction in a chosen profession—or, at a minimum, the options available to make
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17 8 life decisions regarding one's profession—is an important component of an overall satisfying
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19 9 quality of life, and the decision to work less or pursue a less desirable job may have
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21 10 downstream implications for women's finances, relationships, social lives, or travel
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24 11 decisions.^{19,48}

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28 12 Respondents to our survey reported endometriosis had a negative impact on their relationships,
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30 13 social engagements, and ability to have children (when desired), which is consistent with
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32 14 findings from a host of previous studies that demonstrated the negative impacts of
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34 15 endometriosis on social well-being and health-related quality of life.^{9,12,34,47} Interestingly, 46% of
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36 16 women in our study reported experiencing infertility, which is slightly higher than the 14%–40%
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38 17 range reported in previous studies, again hinting at our population's higher symptom
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40 18 burden.^{34,39,49} Other chronic pain conditions have also impacted these life-course components,
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42 19 including conditions related to musculoskeletal pain and chronic back pain.^{50,51}

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46 20 Similar to decisions involving education and professional achievement, life choices involving the
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48 21 pursuit of intimate relationships or starting a family may have downstream implications in other
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50 22 areas, like finance, psychological well-being, or employment, which may have their own
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52 23 downstream impacts on additional aspects of a person's life course.¹⁹ Likewise, women
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54 24 frequently reported not being physically active and having poorer diets because of their disease.

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3 1 Although few studies have examined this aspect of endometriosis, findings from two smaller
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5 2 studies have suggested that pain associated with the disease may also have a negative impact
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7 3 on exercise and nutrition.^{9,30,52}
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11 4 Of particular concern was the view of many women that their disease made them increase their
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13 5 use of alcohol, drugs, or cigarettes. Research into whether pain and experiences related to
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15 6 endometriosis may be associated with higher rates of substance abuse is severely lacking.
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17 7 However, there are demonstrated associations between other chronic pain conditions and
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19 8 substance abuse that support our finding.^{53,54} The results from our study draw attention to this
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21 9 issue and highlight substance abuse as an important avenue for additional investigation.
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26 10 The findings from our study indicate that women with endometriosis may experience many
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28 11 healthcare-related side effects. Of particular concern, patients noted that treatments meant to
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30 12 help reduce the burden of endometriosis may have their own negative impact. Many women
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32 13 perceived that use of prescription medications and multiple surgeries to control the symptoms of
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34 14 endometriosis had a negative impact on their life potential, and this response was also observed
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36 15 in women who indicated they were LPAF or believed they had NRFP due to their disease.
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38 16 Results from one recent study showed that medical treatment for a condition may increase a
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40 17 patient's stress levels and potentially affect their psychological health.⁵⁵ Patients who were
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42 18 taking prescription medications and who experienced more challenging adverse effects from
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44 19 their therapies had higher perceived stress levels, and women undergoing multiple surgeries
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46 20 were especially impacted. These reports underscore the potential value of supportive
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48 21 psychological care for patients with endometriosis as part of effective long-term disease
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50 22 management.
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3 1 In general, women experienced a range of consequences that they attributed to living with and
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5 2 managing the limitations imposed by endometriosis. In addition to pain, women reported that the
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7 3 endometriosis-related experiences that most impacted their lives in a negative way included
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9 4 depression or anxiety (80%), heavy menstrual bleeding (71%), the need to take prescription
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11 5 treatments (57%) or undergo multiple surgeries (49%), or infertility (46%). In other studies,
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13 6 women have reported not feeling “normal” or feminine, experiencing a range of negative
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15 7 emotions (eg, anger, depression, hopelessness, disappointment, and exhaustion), having
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17 8 limited physical or sexual activity, struggling to find appropriate treatments, feeling guilt over
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19 9 disrupted relationships, and suffering in silence due to endometriosis-related
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21 10 symptoms.^{22,23} While each woman experienced the impact of endometriosis differently, the
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23 11 majority believed that they were living life less fully than they could have because of their
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25 12 endometriosis-associated symptoms. This belief was informed by the symptoms and healthcare
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27 13 requirements they faced, and, in turn, may have influenced major life decisions that could have
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29 14 their own deleterious effects on personal fulfillment and life potential. The interconnectedness of
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31 15 effects triggered by major life decisions highlights the importance of conducting further research
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33 16 into the cumulative burden of debilitating diseases like endometriosis within the context of an
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35 17 individual’s life course.

18 **Strengths and limitations**

19 Limitations of this study include the selection of participants from an online community with
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21 20 voluntary participation, no targeted sampling, and no way to calculate a response rate. The
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23 21 participants were generally well educated, had access to health care, and participated in an
24
25 22 online patient social network. Data on race, ethnicity, or socioeconomic status were not
26
27 23 collected. Patients who experienced the most significant psychosocial impacts of endometriosis
28
29 24 or lacked the resources to access the online community may not have been represented in the

1 sample population, whereas the patients who were most affected by severe pelvic pain may
2 have been more likely to participate in the study. These factors may have led to self-selection
3 bias; therefore, the results of this study may not be generalizable to the overall population of
4 patients with endometriosis. Any between-group comparisons are observational in nature and
5 no definitive conclusions can be made in the absence of formal statistical analysis.

6 **Future implications**

7 Examining the cumulative life-course impact of endometriosis may influence a physician's ability
8 to understand a woman's complete experience with the disease, help identify patients who are
9 most vulnerable to its impacts, and inform options for management.^{9,20,22,56} A fuller
10 understanding of the life-course impact of endometriosis may also elucidate patterns of patient
11 needs and identify which forms of supportive multidisciplinary care are necessary, including the
12 need for early referral to specialists and other professionals who provide complementary
13 healthcare. These needs are likely to change over time, during the different phases of each
14 patient's life. For example, teams that include gynecologists and pain specialists may help
15 patients manage endometriosis-associated pain symptoms; reproductive endocrinologists may
16 help manage infertility, if this occurs; sexual health counselors may collaborate with patients
17 who have dyspareunia; and counselors/psychologists may assist with chronic stress and mental
18 health issues.⁵⁷ Physicians who are responsive to patients' individual needs and values can
19 positively support overall quality of life in those patients who experience infertility^{58,59} and other
20 negative symptoms of endometriosis, such as chronic abdominal pain, dysmenorrhea, and
21 dyspareunia.²⁴ Endometriosis may also contribute to social inequalities; further research is
22 needed to explore this topic and develop social policies to address these inequalities.

1 **Conclusion**

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6 2 In our international survey of the impact of endometriosis on a woman's life course, most
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8 3 respondents self-reported a high burden associated with the disease that affected overall life
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10 4 potential in many different ways. The findings of this survey add to our understanding of
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12 5 women's experiences with endometriosis.
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10 SAM, FT, OAF, AH, BS, and SA-S contributed to the study concept and design. BS contributed
11
12 to data acquisition and statistical analysis. SAM, FT, AMS, SEC, SC, SE, OAF, AH, BS, and
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14 SA-S contributed to data interpretation.
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16 **Competing interests**

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28
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30
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47 48 17 **Data availability statement** 49

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51 18 AbbVie is committed to responsible data sharing regarding the clinical trials and
52
53 19 studies we sponsor. This includes access to anonymized, individual and trial-level data
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55 20 (analysis data sets), as well as other information (eg, protocols and clinical study
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3 1 reports), as long as the trials are not part of an ongoing or planned regulatory
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5 2 submission. This includes requests for clinical trial data for unlicensed products and
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7 3 indications.
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10 4 This study data can be requested by any qualified researchers who engage in rigorous,
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12 5 independent scientific research, and will be provided following review and approval of a
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14 6 research proposal and statistical analysis plan and execution of a data sharing
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16 7 agreement. Data requests can be submitted at any time and the data will be accessible
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18 8 for 12 months, with possible extensions considered. For more information on the
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20 9 process, or to submit a request, visit the following link: [https://www.abbvie.com/our-](https://www.abbvie.com/our-science/clinical-trials/clinical-trials-data-and-information-sharing/data-and-information-sharing-with-qualified-researchers.html)
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22 10 [science/clinical-trials/clinical-trials-data-and-information-sharing/data-and-information-](https://www.abbvie.com/our-science/clinical-trials/clinical-trials-data-and-information-sharing/data-and-information-sharing-with-qualified-researchers.html)
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24 11 [sharing-with-qualified-researchers.html](https://www.abbvie.com/our-science/clinical-trials/clinical-trials-data-and-information-sharing/data-and-information-sharing-with-qualified-researchers.html).
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3 **1 FIGURE LEGENDS**
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7 **2 Figure 1. Life-course impact of endometriosis**
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10 3 Women were asked to indicate how much they agreed with statements involving the impact of
11
12 4 endometriosis on (A) educational and professional achievements, (B) social life and
13
14 5 relationships, (C) physical well-being, and (D) overall life course.
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18 **6 Figure 2. Experiences and emotions attributed to endometriosis**
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20 7 Respondents were asked to select which experiences related to endometriosis had the most
21
22 8 negative impacts on their life potential (A). Women were also asked to indicate which general
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24 9 negative experiences (B) and emotions (C) they had undergone because of endometriosis and
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26 10 what kinds of approaches they had taken to manage the impact of endometriosis (D).
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FIGURE 1

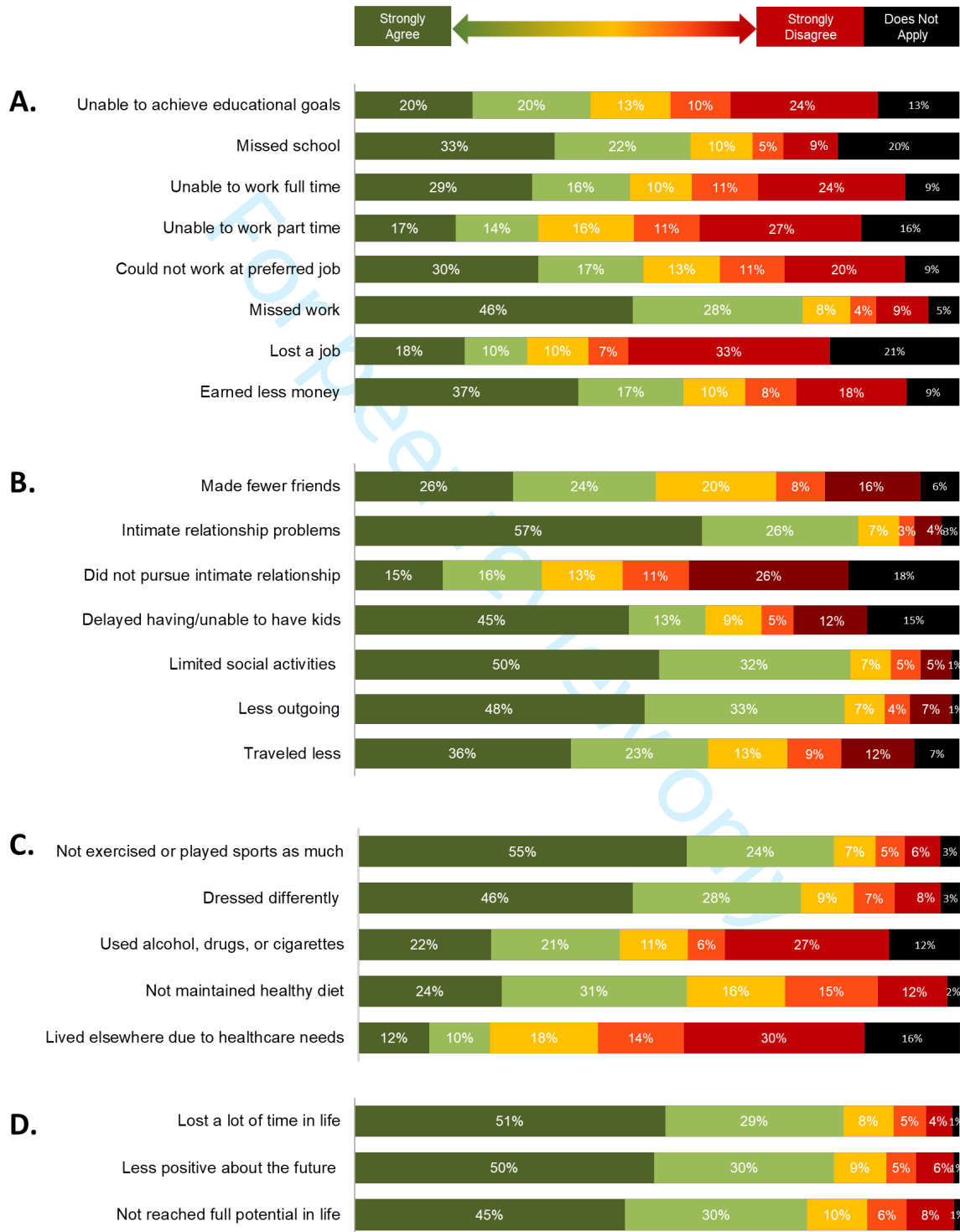
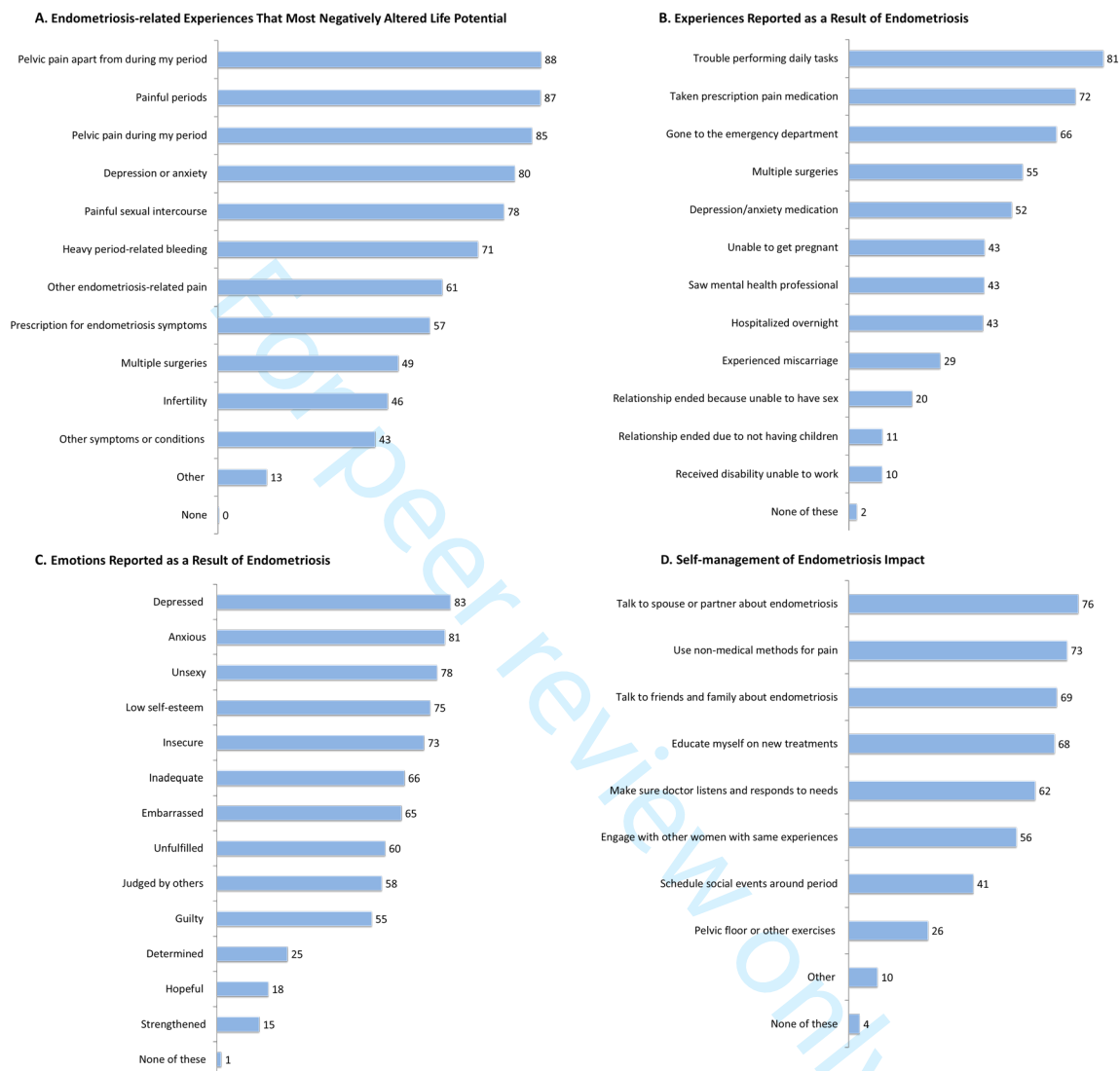


FIGURE 2



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3 **The impact of endometriosis on women's life decisions and goal attainment measured in**
4 **a cross-sectional survey of members of an online patient community**
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9 Stacey A Missmer,¹ Frank F Tu,² Ahmed M Soliman,³ Stephanie E Chiuve,³ Sarah Cross,³
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11 Samantha Eichner,³ Oscar Antunez Flores,³ Andrew W Horne,⁴ Beth Schneider,⁵ Sawsan As-
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SUPPORTING INFORMATION

Supporting Information Table 1. Women indicated how much they agreed or disagreed with the impact of endometriosis on the following: (A) pain, (B) work and education, (C) life experiences altered in a negative way, (D) impact on life, (E) feelings, and (F) management of impact.

Supporting Information Figure 1. Impact of endometriosis on educational and professional achievements in the United States (A) and in the rest of the world (B).

Survey. MyEndometriosisTeam Survey – Life Course Impact Survey

Supporting Information Table 1.

S1A	Daily	A few times a week	A few times a month	Weekly	Monthly	Every few months	Never	Once or twice a year
Total, n (%) (N = 743)	415 (55.9)	160 (21.5)	78 (10.5)	43 (5.8)	31 (4.2)	9 (1.2)	4 (0.5)	3 (0.4)
Less positive about future, n (%) (n = 589)	362 (61.5)	120 (20.4)	50 (8.5)	31 (5.3)	16 (2.7)	6 (1.0)	2 (0.3)	2 (0.3)
Remaining respondents (n = 154)	53 (34.4)	40 (26.0)	28 (18.2)	12 (7.8)	15 (9.7)	3 (1.9)	2 (1.3)	1 (0.6)
Did not reach full potential, n (%) (n = 556)	341 (61.3)	121 (21.8)	44 (7.9)	28 (5.0)	13 (2.3)	6 (1.1)	2 (0.4)	1 (0.2)
Remaining respondents (n = 187)	74 (39.6)	39 (20.9)	15 (8.0)	34 (18.2)	18 (9.6)	3 (1.6)	2 (1.1)	2 (1.1)

S1B	Missed days of work	Missed school	Earned less money	Could not work at preferred job	Unable to work full time	Unable to achieve educational goals	Unable to work part time	Lost a job
Total, n (%) (N = 743)	550 (74.9)	413 (56.3)	404 (55.0)	355 (48.4)	338 (46.0)	290 (39.5)	226 (30.8)	212 (28.9)
Less positive about future, n (%) (n = 589)	463 (78.6)	343 (58.2)	359 (61.0)	316 (53.7)	300 (50.9)	257 (43.6)	202 (34.3)	190 (32.3)
Remaining respondents (n = 154)	87 (56.5)	70 (45.5)	45 (29.2)	39 (25.3)	38 (24.7)	33 (21.4)	24 (15.6)	22 (14.3)
Did not reach full potential, n (%) (n = 556)	448 (80.6)	329 (59.2)	365 (65.6)	323 (58.1)	295 (53.1)	261 (46.9)	205 (36.9)	193 (34.7)
Remaining respondents (n = 187)	102 (54.5)	84 (44.9)	39 (20.9)	32 (17.1)	43 (23.0)	29 (15.5)	21 (11.2)	19 (10.2)

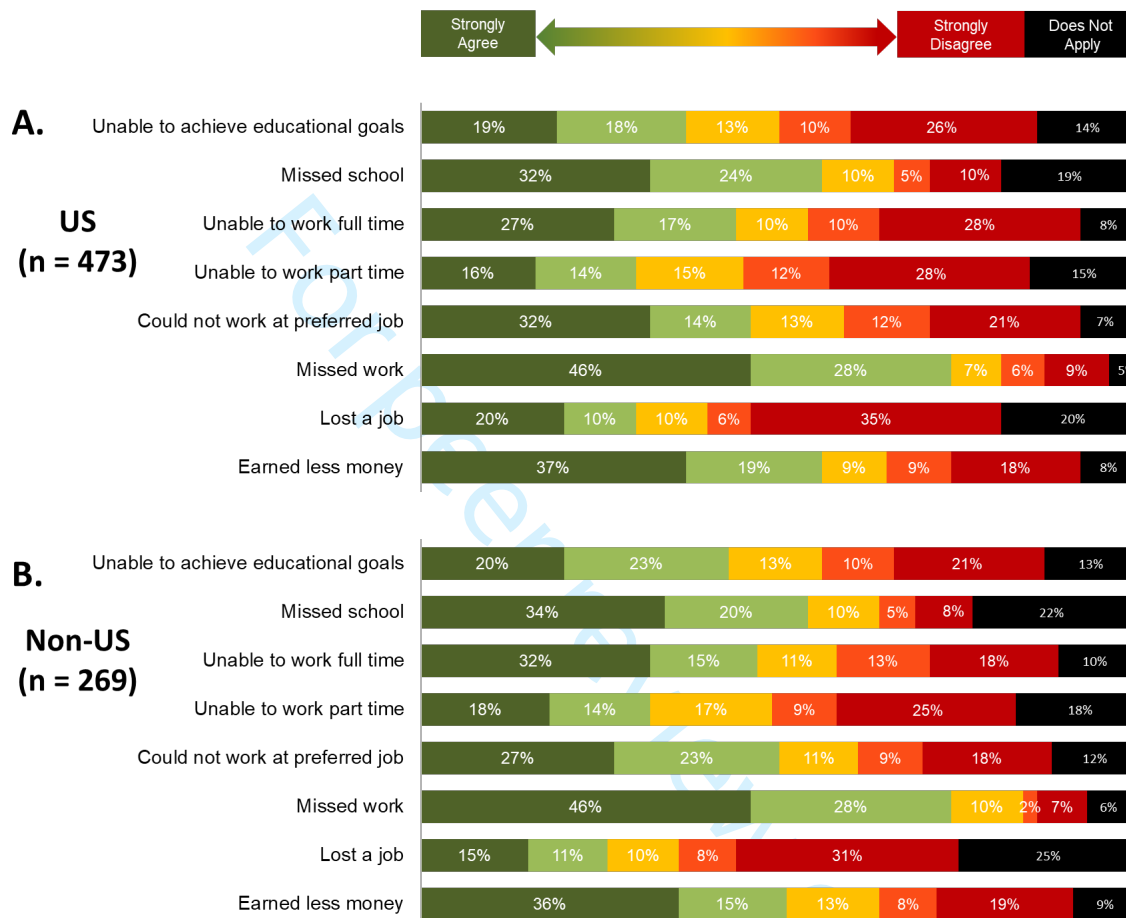
S1C	Pelvic pain apart from period	Painful periods	Pelvic pain during period	Depression or anxiety	Painful sexual intercourse	Heavy period- related bleeding	Other endometriosis- related pain	Taken prescription for symptoms	Multiple surgeries	Infertility	Other symptoms or conditions
Total, n (%) (N = 743)	651 (87.6)	650 (87.5)	633 (85.2)	598 (80.5)	576 (77.5)	524 (70.5)	452 (60.8)	427 (57.5)	363 (48.9)	342 (46.0)	317 (42.7)
Less positive about future, n (%) (n = 589)	528 (89.6)	517 (87.8)	506 (85.9)	505 (85.7)	461 (78.3)	413 (70.1)	382 (64.9)	353 (59.9)	297 (50.4)	272 (46.2)	268 (45.5)
Remaining respondents (n = 154)	123 (79.9)	133 (86.4)	127 (82.5)	93 (60.4)	115 (74.7)	111 (72.1)	70 (45.5)	74 (48.1)	66 (42.9)	70 (45.5)	49 (31.8)
Did not reach full potential, n (%) (n = 556)	500 (89.9)	491 (88.3)	482 (86.7)	476 (85.6)	430 (77.3)	400 (71.9)	366 (65.8)	332 (59.7)	284 (51.1)	261 (46.9)	259 (46.6)
Remaining respondents (n = 187)	151 (80.7)	159 (85.0)	151 (80.7)	122 (65.2)	146 (78.1)	124 (66.3)	86 (46.0)	95 (50.8)	79 (42.2)	81 (43.3)	58 (31.0)

S1D	Trouble performing daily tasks	Taken Rx pain medication	Gone to ER	Multiple surgeries	Depression/ anxiety medication	Unable to get pregnant	Saw mental health professional	Hospitalized overnight	Experienced miscarriage	Relationship ended because unable to have sex
Total, n (%) (N = 743)	594 (80.9)	529 (72.1)	485 (66.1)	406 (55.3)	380 (51.8)	317 (43.2)	316 (43.1)	313 (42.6)	213 (29.0)	147 (20.0)
Less positive about future, n (%) (n = 589)	500 (84.9)	442 (75.0)	406 (68.9)	333 (56.5)	327 (55.5)	251 (42.6)	276 (46.9)	266 (45.2)	167 (28.4)	132 (22.4)
Remaining respondents (n = 154)	94 (61.0)	87 (56.5)	79 (51.3)	73 (47.4)	53 (34.4)	66 (42.9)	40 (26.0)	47 (30.5)	46 (29.9)	15 (9.7)
Did not reach full potential, n (%) (n = 556)	478 (86.0)	421 (75.7)	390 (70.1)	311 (55.9)	308 (55.4)	239 (43.0)	265 (47.7)	249 (44.8)	166 (29.9)	132 (23.7)
Remaining respondents (n = 187)	116 (62.0)	108 (57.8)	95 (50.8)	95 (50.8)	72 (38.5)	78 (41.7)	51 (27.3)	64 (34.2)	47 (25.1)	15 (8.0)

S1E	Depressed	Anxious	Unsexy	Low self-esteem	Insecure	Inadequate	Embarrassed	Unfulfilled	Judged by others	Guilty
Total, n (%) (N = 743)	607 (82.7)	592 (80.7)	572 (77.9)	554 (75.5)	538 (73.3)	487 (66.3)	479 (65.3)	437 (59.5)	428 (58.3)	402 (54.8)
Less positive about future, n (%) (n = 589)	517 (87.8)	491 (83.4)	468 (79.5)	478 (81.2)	469 (79.6)	421 (71.5)	415 (70.5)	387 (65.7)	380 (64.5)	350 (59.4)
Remaining respondents (n = 154)	90 (58.4)	101 (65.6)	104 (67.5)	76 (49.4)	69 (44.8)	66 (42.9)	64 (41.6)	50 (32.5)	48 (31.2)	52 (33.8)
Did not reach full potential, n (%) (n = 556)	487 (87.6)	462 (83.1)	441 (79.3)	443 (79.7)	434 (78.1)	401 (72.1)	393 (70.7)	375 (67.4)	352 (63.3)	330 (59.4)
Remaining respondents (n = 187)	120 (64.2)	130 (69.5)	131 (70.1)	111 (59.4)	104 (55.6)	86 (46.0)	86 (46.0)	62 (33.2)	76 (40.6)	72 (38.5)

S1F	Talk to spouse or partner	Use non-medical methods for pain	Talk to friends and family	Educate self on treatments	Make doctor listen and respond to needs	Engage with other women with same experiences	Schedule social events around period	Pelvic floor or other exercises	Other	None of these
Total, n (%) (N = 743)	560 (76.3)	533 (72.6)	508 (69.2)	502 (68.4)	455 (62.0)	409 (55.7)	304 (41.4)	193 (26.3)	70 (9.5)	26 (3.5)
Less positive about future, n (%) (n = 589)	445 (75.6)	425 (72.2)	409 (69.4)	409 (69.4)	369 (62.6)	337 (57.2)	257 (43.6)	162 (27.5)	61 (10.4)	19 (3.2)
Remaining respondents (n = 154)	115 (74.7)	108 (70.1)	99 (64.3)	93 (60.4)	86 (55.8)	72 (46.8)	47 (30.5)	31 (20.1)	9 (5.8)	7 (4.5)
Did not reach full potential, n (%) (n = 556)	418 (75.2)	405 (72.8)	383 (68.9)	394 (70.9)	345 (62.1)	325 (58.5)	246 (44.2)	153 (27.5)	59 (10.6)	20 (3.6)
Remaining respondents (n = 187)	142 (75.9)	128 (68.4)	125 (66.8)	108 (57.8)	110 (58.8)	84 (44.9)	58 (31.0)	40 (21.4)	11 (5.9)	6 (3.2)

Supporting Information Figure 1.



Survey.

MyEndometriosisTeam Survey – Life Course Impact Survey

Introduction

Part of our mission at MyEndometriosisTeam is to help build awareness and understanding of the impact that endometriosis can have on daily life. Creating a better understanding of what other women with endometriosis go through is important to many members. The aim of this study is to understand real-life experiences of women living with chronic endometriosis. This includes how it may influence life choices and any long-lasting effect it has.

This survey should take approximately 8 minutes to complete. Your participation is completely voluntary, and your responses are anonymous. MyEndometriosisTeam never shares any personally identifying information. Highlights of the findings of this research survey will be shared back with the MyEndometriosisTeam community. We are conducting this survey in collaboration with one of our pharmaceutical partners. This is one of the ways we keep MyEndometriosisTeam free while making sure your voice is heard. If you have any questions regarding the survey, please contact support@myendometriosisteam.com.

If you are 19 years of age or older, live in the United States (excluding Puerto Rico), understand the statements above and freely consent to participate in this research, click on the “Yes, I agree” button to begin the survey.

Yes, I agree

No thanks, I'd rather not participate

Section 1: Screening Questions

S1. Which of the following describes you?

Male (**Terminate**)

Female

1
2
3 S2. What is your age?
4

5 Under 19 (**Terminate**)
6

7 19-29
8

9 30-39
10

11 40-49
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13 50-59
14

15 60 or older
16
17

18
19 S3. Which one of the following best describes your condition?
20

21 Stage 1 endometriosis
22

23 Stage 2 endometriosis
24

25 Stage 3 endometriosis
26

27 Stage 4 endometriosis
28

29 Not sure what stage of endometriosis I have
30

31 I do not have endometriosis (**Terminate**)
32
33

34 S4. In which country do you currently live?
35

36 United States (excluding Puerto Rico) (**Continue**)
37

38 Australia
39

40 Canada
41

42 Ireland
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44 Netherlands
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46 New Zealand
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48 South Africa
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50 United Kingdom
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52 Other
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Section 1: Endometriosis Severity

1. At what age did your endometriosis symptoms begin? (drop-down menu)
2. At approximately what age did you start your first period? (drop-down menu)
3. Thinking about when you first started to experience endometriosis symptoms, approximately how many years did it take before you were diagnosed with endometriosis? (drop-down menu)
4. Did you ever have a surgical procedure, such as a laparoscopy or laparotomy, to confirm you have endometriosis?
 - Yes
 - No
 - Not sure
5. Which one of the following best describes how often you typically feel some type of endometriosis-related pain?
 - Daily
 - A few times a week
 - Weekly
 - A few times a month
 - Monthly
 - Every few months
 - Once or twice a year
 - Never

6. Please rate how severe your endometriosis related pain has been at its worst in the last 12 months using a scale from 0 to 10, where 0=no pain and 10=worst imaginable pain. (Drop down menu).

7. Over the years, has your endometriosis related pain gotten better, gotten worse, or stayed the same?

Gotten much better

Gotten somewhat better

Stayed the same

Gotten somewhat worse

Gotten much worse

Section 2: Impact on Quality of Life and Life Choices

8. Please indicate how much you agree or disagree with the following statements about the impact endometriosis has had **on your entire life up to now**.

(Rotate order)

Because of my endometriosis:

(Please select one box for each row)	Strongly disagree	Some-what Disagr	Neutral	Some-what Agree	Strongly agree	Not Applic-able
I was unable to achieve my educational goals	1	2	3	4	5	6
I missed many days of school	1	2	3	4	5	6
I was unable to work full time	1	2	3	4	5	6
I was unable to work part time	1	2	3	4	5	6
I could not work at the job I would have preferred	1	2	3	4	5	6

I missed many days of work	1	2	3	4	5	6
I lost a job	1	2	3	4	5	6
I earned less money than I could have	1	2	3	4	5	6
I made fewer friends	1	2	3	4	5	6
I have had problems with sexual or intimate relationships	1	2	3	4	5	6
I have not dated or pursued an intimate relationship	1	2	3	4	5	6
I have delayed having or have been unable to have children	1	2	3	4	5	6
I have limited my social activities	1	2	3	4	5	6
I have not exercised or played sports as much as I would have liked	1	2	3	4	5	6
I do not live where I would like due to my healthcare needs	1	2	3	4	5	6
I lost a lot of time in my life	1	2	3	4	5	6
I have travelled less than I would have liked	1	2	3	4	5	6
I have dressed differently than I would have liked	1	2	3	4	5	6
I have used alcohol, drugs or smoked cigarettes	1	2	3	4	5	6
I have not maintained a healthy diet	1	2	3	4	5	6
I have been less outgoing	1	2	3	4	5	6
I have been less positive about the future	1	2	3	4	5	6
I have not reached my full potential in life	1	2	3	4	5	6

- 1
2
3 9. What endometriosis-related experiences, if any, do you think have most contributed to
4 altering your life potential in a negative way? Select all that apply. (Rotate order)
5
6

7 Painful sexual intercourse

8 Pelvic pain during my period

9 Pelvic pain apart from during my period

10 Painful periods

11 Heavy period-related bleeding

12 Other endometriosis related pain

13 Infertility

14 Depression or anxiety

15 Multiple surgeries

16 Prescription treatment to control endometriosis symptoms

17 Other symptoms or conditions (please specify)

18 Other (please specify)

19 None
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3 10. Which, if any, of these, have you experienced as a result of your endometriosis? Check
4 all that apply. (Rotate order)
5
6

7 Taken prescription medication for the pain (for example, opioids)

8 Taken prescription medication to treat depression or anxiety

9 Had multiple surgical procedures

10 Been hospitalized overnight

11 Gone to the emergency room

12 Received disability income due to being unable to work

13 Had a miscarriage (whether or not it was due to having endometriosis)

14 Had trouble performing daily tasks

15 Saw a mental health professional (eg., psychiatrist, counselor)

16 Was unable to get pregnant

17 Had a relationship end because I was unable to have children

18 Had a relationship end because I was unable to have sex

19 None of these
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11. And which, if any, of these emotions, have you experienced as a result of your endometriosis? Check all that apply. (Rotate order)

I have felt...

Low self esteem

Judged by others

Inadequate

Unsexy

Insecure

Guilty

Determined

Strengthened

Hopeful

Embarrassed

Unfulfilled

Depressed

Anxious

None of these

For peer review only

- 1
2
3 12. Which of the following, if any, have you done to help manage the impact of endometriosis?
4 Select all that apply. (rotate order)
5

6
7 Schedule social events around my period

8
9 Engage with other women going through the same experiences

10
11 Talk to my friends and family about endometriosis

12
13 Talk to my spouse or partner about my endometriosis

14
15 Pelvic floor or other exercises to lessen pain during sex

16
17 Make sure my doctor listens and responds to my needs

18
19 Educate myself on new treatments

20
21 Use non-medical methods for controlling pain (e.g., ice or heat, lubricants during sex)

22
23 Other (please describe)

24
25 None of these

- 26
27 13. Because of endometriosis, is there anything you feel you were unable to accomplish in
28 your life? (open end)

- 29
30 14. Is there anything else you would like us to know about the impact endometriosis has had
31 on your life? (open end)
32

33 Just a few last questions.
34
35
36

- 37 D1. Which of the following best describes the area where you live?
38
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40

41 Urban

42 Suburban

43 Rural

44 Not sure / prefer not to say
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3 D2. What is the highest level of education you have achieved?
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7 Less than high school

8 Some high school

9 High school or equivalent (e. g., GED)

10 Some college, but no degree

11 Associate degree

12 College degree (e.g., B.A., B.S.)

13 Some graduate school, but no degree

14 Graduate school (e.g., M.S., M.D., Ph.D.)

15 Prefer not to answer
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25 D3. What is your current employment status?
26
27

28 Working full time

29 Working part time

30 Unemployed, not looking for work

31 Unemployed, looking for work

32 Retired

33 Unable to work

34 Prefer not to answer
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3 D4. Which of the following best describes your marital status?
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7 Single/never married

8 Married

9 Widowed

10 Divorced or separated

11 Prefer not to answer

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18 (Skip D5 if “married” or “prefer not to answer” selected in D4)
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22 D5. Are you currently in an intimate relationship?
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26 Yes

27 No

28 Prefer not to answer
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33 D6. How many children, if any, do you have?
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38 None

39 1

40 2

41 3

42 4

43 5 or more

44 Prefer not to answer
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52 Thank you for answering these questions.
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STROBE Statement—Checklist of items that should be included in reports of ***cross-sectional studies***

	Item No	Recommendation	Location in Manuscript
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	Page 1, lines 1-2
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	Page 3, lines 1-22; page 4, lines 1-6
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	Page 5, lines 1-23; page 6, lines 1-18
Objectives	3	State specific objectives, including any prespecified hypotheses	Page 7, lines 1-11
Methods			
Study design	4	Present key elements of study design early in the paper	Page 7, lines 19-21; page 8, lines 1-23; page 9, lines 1-17
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	Page 8, lines 4-5; page 9, lines 11-17
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants	Page 9, lines 11-17
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	N/A
Data sources/measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	Page 7, lines 20-21; page 8, lines 1-23; supporting information pages 7-17
Bias	9	Describe any efforts to address potential sources of bias	Page 8, lines 17-18; page 9, lines 16-17
Study size	10	Explain how the study size was arrived at	Page 9, lines 5-6 and 11-16
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	Page 9, lines 19-20; page 10, lines 1-8

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2	Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	Page 9, lines 19-20
3			(b) Describe any methods used to examine subgroups and interactions	Page 9, lines 19-20; page 10, lines 1-8
4			(c) Explain how missing data were addressed	Page 8, lines 22-23
5			(d) If applicable, describe analytical methods taking account of sampling strategy	N/A
6			(e) Describe any sensitivity analyses	N/A
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12	Results			
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14	Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	Page 10, lines 11-12
15			(b) Give reasons for non-participation at each stage	N/A
16			(c) Consider use of a flow diagram	N/A
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21	Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	Page 10, lines 13-21; page 11-12, Table 1
22			(b) Indicate number of participants with missing data for each variable of interest	N/A (no missing data; see page 8, lines 22-23)
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27	Outcome data	15*	Report numbers of outcome events or summary measures	Pages 12-14; page 15, lines 1-7; Figures 1-2
28				
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30	Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	N/A
31			(b) Report category boundaries when continuous variables were categorized	N/A
32			(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	N/A
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38	Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	Page 15, lines 8-23; page 16, lines 1-5; supporting information pages 2-6
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Discussion			
Key results	18	Summarise key results with reference to study objectives	Page 16, lines 8-14; page 23, lines 1-5
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	Page 4, lines 15-19; page 21, lines 19-24; page 22, lines 1-5
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	Page 16, lines 16-23; pages 17-22
Generalisability	21	Discuss the generalisability (external validity) of the study results	Page 21, lines 1-17; page 22, lines 7-22; page 23, lines 1-5
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	Page 24, lines 11-12

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.