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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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Strengths and limitations of this study

- Strength: Quantitative survey of meaningful sample size spanning multiple countries
- Strength: Targeted research questions were made possible by use of a social network that allowed questions to be developed based on existing conversations on the platform
- Strength: Use of social network familiar to patients may have led to increased honesty in responses to sensitive topics
- Limitation: No comparisons were made between women who had endometriosis versus women who did not have endometriosis or women who had other chronic conditions, particularly those associated with pain
- Limitation: Patient responses were self-reported and not confirmed by medical records or other data

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 decisions (eg, work, education, or personal relationships) in ways that are interrelated and can impact other areas of a patient's life. For example, chronic pain may influence the type and amount of work performed or whether a patient decides to work at all, which in turn can have financial implications on the patient's lifestyle, family, relationships, or sense of personal fulfillment.[17,18] Symptoms may determine where a patient choses to live because of financial considerations, healthcare access, or proximity to support networks. Similarly, dyspareunia related to endometriosis may lead some women to avoid intimate relationships, which may have downstream implications for marriage, family planning, and mental and emotional health.[21,22] Cumulatively, persistent symptoms of endometriosis and their impact on daily activities and family and intimate relationships can negatively impact the trajectory of women's lives and are profound and far reaching.

Examining the cumulative life-course impact of endometriosis may have an influence on a physician's ability to understand a woman's complete experience with the disease, help identify patients who are most vulnerable to its impacts, and inform options for management.[18,20,23,24] A fuller understanding of the life-course impact of endometriosis may also elucidate patterns of patient needs and identify forms of supportive multidisciplinary care necessary, including the need for early referral to specialists and other professionals who provide complementary healthcare. These needs are likely to change over time, during different phases of each patient's life. For example, teams that include gynecologists and pain specialists may help patients manage endometriosis-associated pain symptoms; reproductive endocrinologists may help manage infertility, if this occurs; sexual health counselors may collaborate with patients who have dyspareunia; and counselors/psychologists may assist with chronic stress and mental health issues.[25] Physicians who are responsive to patients' individual needs and values can positively support overall quality of life in those patients who experience infertility[26,27] and endometriosis.[21]

The objective of this multinational survey was to gain a better understanding of patient perspectives on how endometriosis impacts their daily activities and identify how the disease may influence women's major life decisions and attainment of their goals.

METHODS

Ethics approval

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

Survey development

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

Patient and public involvement

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

Participant eligibility and recruitment

Members of the social network MyEndometriosisTeam.com were recruited through 33,000 email invitations. Invitations posted on the public Facebook page for MyEndometroisisTeam.com recruited additional women to participate in the survey, which was live from October 3 to

October 25, 2018. The English-language survey was conducted among an international population of women who were at least 19 years of age and who self-identified as having endometriosis. The survey was anonymous, and answers could not be linked to individual members.

Survey analysis

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

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%), and one-fifth summed from Canada, Australia, South Africa, Ireland, New Zealand, and The Netherlands (table 1). Most women were younger than age 40 years. Almost half of the respondents were unaware of their stage of endometriosis (according to the rASRM scoring system), which was obtained at their most recent surgery (48%). Among the 52% respondents who recalled knowing their rASRM score, most reported having stage 4 (table 1).

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).

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

Additional analysis of women who believed their future and life potential were more impacted by endometriosis

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

DISCUSSION

A survey of women with endometriosis who self-reported pronounced symptoms also reported experiences that were perceived by them to negatively impact their views of the future and overall life potential. For many women, endometriosis-associated symptoms negatively affect various areas of their lives, including education and employment, relationships and social engagements, and physical well-being. Participants indicated that adverse experiences related to management of their disease and its impact on everyday life also believed that their future and life potential was negatively impacted by endometriosis.

The severity of pain reported by women who completed the online survey indicates that respondents in our study may have had a greater symptom burden than did women participating in previous studies using similar pain scales.[28-30] Women in our study also reported slightly lengthier delays in diagnosis after the onset of their first symptoms. Findings in previous studies have illustrated that delays are common in diagnosing endometriosis.[13,31-39] Although some recent literature suggests that the delay in diagnosis may be slowly improving,[37] the use of non-invasive and accurate diagnostic tools could improve diagnosis times and reduce women's pain and distress.[39,40] The delays in diagnosis reported by our study participants and others indicate many women experiencing troublesome symptoms of endometriosis may still wait extended periods before receiving a definitive diagnosis and initiating treatment.

The higher pain burden and longer diagnostic delay reported in our sample, which may include higher numbers of women who sought social network support because they were more frustrated with their disease experience, could conceivably be due in part to their longer struggles with more challenging symptoms than would be observed in the general population of women with diagnosed endometriosis. Results from a recent study using the same social network to recruit participants found that the majority of respondents rated their worst pain higher than 7 on a 10-point scale, only a little lower than the pain rating given by the women in our study.[41] Additionally, the previous study participants also experienced a diagnostic delay, supporting the theory that recruitment from this member-centered network may draw more women who have struggled longer with their disease.[41] Interestingly, overall trends in diagnostic delays observed between age groups in our study are consistent with reports in previous research, that being women whose symptom onset was at a younger age experienced longer times to diagnosis.[13,33,37]

Many respondents said they missed school and were generally unable to achieve their educational goals because of endometriosis. There is a dearth of research on the impact of endometriosis on women’s educational aspirations and their ability to achieve goals due to endometriosis-associated symptoms compared with the impact endometriosis has on professional work or other areas of life.[9] Findings from some existing studies suggest endometriosis-associated symptoms may impact grades, attendance, or completion of educational programs.[19,20,42] Although informative, these studies were more qualitative in nature and involved small sample sizes.[19,20,42] A quantitative study examining the lives of 78 women 15 years after receiving a verified diagnosis of endometriosis found only a fraction of women reported that their disease had a negative impact on their education.[11] However, the women included in that study seemed to report less frequent pain and endometriosis-related effects like depression compared with the reports made by women in our study. Furthermore, the small sample was collected at a single Norwegian hospital and the findings may not be representative of women's experiences with endometriosis on a wider scale.[11] Regardless, any impact on education is concerning, and our study results emphasize the need for additional research into this overlooked area in women with endometriosis. Research on other medical conditions, like adolescent fibromyalgia, supports that chronic pain can negatively impact education, reinforcing the likelihood that endometriosis may have a similar impact.[43,44]

Respondents in the current study also reported endometriosis-associated symptoms caused them to miss work, earn less money, prevented them from a job they would have preferred, or impeded their working full time or part time. Many health conditions that can occur with endometriosis can impact work productivity and potential, including depression, other chronic pain conditions or disorders, and digestive disorders.[45] Endometriosis was self-reported by respondents in this study, and it is possible that other chronic conditions (particularly, chronic overlapping pain conditions) may also contribute to women's perceived interference with productivity and employment opportunities. Indeed, more than half of women with symptomatic endometriosis can present with comorbid pain syndromes,[46] and these may include conditions associated with pelvic pain, like dysmenorrhea, irritable bowel syndrome, or painful bladder syndrome.[47,48] However**,** findings from previous studies have illustrated that endometriosis-associated symptoms may lead to losses in productivity both at home and in the workplace, potentially impacting professional achievement.[12,36,49,50] In our study, higher proportions of women who indicated that they were LPAF or had NRFP because of endometriosis reported painful symptoms and negative experiences compared with other respondents. Also, women who were LPAF or had NRFP more often believed it was harder for them to perform daily tasks because of their disease.

Our results further support that endometriosis symptoms are disruptive and may lead to loss of productivity, ultimately influencing women's major life decisions or consequences, including whether to work at reduced capacity or pursue preferred jobs. Results from a recent multicenter study of women with confirmed endometriosis and a matched comparison group found the disease forced some women to seek work outside desired professions, which, in turn, resulted in health-related limitations in career choices.[50] These collective findings are concerning, because satisfaction in a chosen profession—or at a minimum options available to make life decisions regarding one's profession—is an important component of an overall satisfying quality of life, and the decision to work less or pursue a less desirable job may have downstream implications for women's finances, relationships, social lives, or travel decisions.[17,50]

Respondents to our survey reported endometriosis had a negative impact on their relationships; social engagements; and ability to have children, when desired, which is consistent with findings from a host of previous studies demonstrating the negative impact of endometriosis on social well-being and health-related quality of life.[9,12,36,49] Interestingly, 46% of women in our study who reported experiencing infertility is slightly higher than the 14%–40% range reported in previous studies, again hinting at our population's higher symptom burden.[36,41,51] Other chronic pain conditions have also impacted these life-course components, including conditions related to musculoskeletal pain and chronic back pain.[52,53]

Similar to decisions involving education and professional achievement, life choices involving the pursuit of intimate relationships or starting a family may have downstream implications in other areas, like finance, psychological well-being, or employment, which may have their own downstream impacts on additional aspects of a person's life course.[17] Likewise, women frequently reported not being physically active and having poorer diets because of their disease. Although few studies have examined this aspect of endometriosis, findings from two smaller studies have suggested that pain associated with the disease may also have a negative impact on exercise and nutrition.[9,32,54]

Of particular concern was the view of many women that their disease made them increase their use of alcohol, drugs, or cigarettes. Research into whether pain and experiences related to endometriosis may be associated with higher rates of substance abuse is severely lacking. However, there are demonstrated associations between other chronic pain conditions and substance abuse that support our finding.[55,56] Results from our study draw attention to this issue and highlight substance abuse as an important avenue for additional investigations.

Findings from our study indicate that women with endometriosis may experience many healthcare-related side effects. Of particular concern, patients noted that treatments meant to help reduce the burden of endometriosis may have their own negative impact. Many women perceived that use of prescription medications and multiple surgeries to control the symptoms of endometriosis had a negative impact on their life potential, and this response was stronger in women who indicated they were LPAF or believed they had NRFP due to their disease. Results from one recent study showed that medical treatment for a condition may increase a patient's stress levels and potentially affect their psychological health.[57] Patients who were taking prescription medications and who experienced more challenging adverse effects from their therapies had higher perceived stress levels, and women undergoing multiple surgeries were especially impacted. These reports underscore the potential value of supportive psychological care for patients with endometriosis as part of effective long-term disease management.

In general, women experienced a range of consequences that they attributed to living with and managing the limitations imposed by endometriosis. While each woman experienced the impact of endometriosis differently, the majority believed that they were living life less fully than they could have because of their endometriosis-associated symptoms. This belief was informed by the symptoms and healthcare requirements they faced, and, in turn, may have influenced major life decisions that could have their own deleterious effects on personal fulfillment and life potential. The interconnectedness of effects triggered by major life decisions highlights the importance of conducting further research into the cumulative burden of debilitating diseases like endometriosis within the context of an individual’s life course.

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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AM Soliman, S Chiuve, S Cross, S Eichner, and O Antunez Flores are employees of AbbVie and may own AbbVie stocks/stock options.

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Data Sharing Statement

AbbVie is committed to responsible data sharing regarding the clinical trials and studies we sponsor. This includes access to anonymized, individual and trial-level data (analysis data sets), as well as other information (eg, protocols and clinical study reports), as long as the trials are not part of an ongoing or planned regulatory submission. This includes requests for clinical trial data for unlicensed products and indications.

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REFERENCES

1. Zondervan KT, Becker CM, Missmer SA. Endometriosis. *N Engl J Med* 2020;382:1244-56.

2. Kennedy S, Bergqvist A, Chapron C*, et al.* ESHRE guideline for the diagnosis and treatment of endometriosis. *Hum Reprod* 2005;20:2698-704.

3. Practice bulletin no. 114: management of endometriosis. *Obstet Gynecol* 2010;116:223-36.

4. Zondervan KT, Becker CM, Koga K*, et al.* Endometriosis. *Nat Rev Dis Primers* 2018;4:9.

5. De Graaff AA, D'Hooghe TM, Dunselman GA*, et al.* The significant effect of endometriosis on physical, mental and social wellbeing: results from an international cross-sectional survey. *Hum Reprod* 2013;28:2677-85.

6. Gallagher JS, DiVasta AD, Vitonis AF*, et al.* The Impact of Endometriosis on Quality of Life in Adolescents. *J Adolesc Health* 2018;63:766-72.

7. Lagana AS, La Rosa VL, Rapisarda AMC*, et al.* Anxiety and depression in patients with endometriosis: impact and management challenges. *Int J Womens Health* 2017;9:323-30.

8. Vannuccini S, Lazzeri L, Orlandini C*, et al.* Mental health, pain symptoms and systemic comorbidities in women with endometriosis: a cross-sectional study. *J Psychosom Obstet Gynaecol* 2018;39:315-20.

9. Culley L, Law C, Hudson N*, et al.* A qualitative study of the impact of endometriosis on male partners. *Hum Reprod* 2017;32:1667-73.

10. Denny E, Mann CH. Endometriosis-associated dyspareunia: the impact on women's lives. *J Fam Plann Reprod Health Care* 2007;33:189-93.

11. Fagervold B, Jenssen M, Hummelshoj L*, et al.* Life after a diagnosis with endometriosis - a 15 years follow-up study. *Acta Obstet Gynecol Scand* 2009;88:914-9.

12. Soliman AM, Coyne KS, Gries KS*, et al.* The Effect of Endometriosis Symptoms on Absenteeism and Presenteeism in the Workplace and at Home. *J Manag Care Spec Pharm* 2017;23:745-54.

13. Klein S, D'Hooghe T, Meuleman C*, et al.* What is the societal burden of endometriosis-associated symptoms? a prospective Belgian study. *Reprod Biomed Online* 2014;28:116-24.

14. Simoens S, Dunselman G, Dirksen C*, et al.* The burden of endometriosis: costs and quality of life of women with endometriosis and treated in referral centres. *Hum Reprod* 2012;27:1292-9.

15. Soliman AM, Taylor HS, Bonafede M*, et al.* Incremental direct and indirect cost burden attributed to endometriosis surgeries in the United States. *Fertil Steril* 2017;107:1181-90 e2.

16. Soliman AM, Yang H, Du EX*, et al.* The direct and indirect costs associated with endometriosis: a systematic literature review. *Hum Reprod* 2016;31:712-22.

17. Bhatti Z, Salek M, Finlay A. Chronic diseases influence major life changing decisions: a new domain in quality of life research. *J R Soc Med* 2011;104:241-50.

18. Kimball AB, Gieler U, Linder D*, et al.* Psoriasis: is the impairment to a patient's life cumulative? *J Eur Acad Dermatol Venereol* 2010;24:989-1004.

19. Huntington A, Gilmour JA. A life shaped by pain: women and endometriosis. *J Clin Nurs* 2005;14:1124-32.

20. Moradi M, Parker M, Sneddon A*, et al.* Impact of endometriosis on women's lives: a qualitative study. *BMC Womens Health* 2014;14:123.

21. Apers S, Dancet EAF, Aarts JWM*, et al.* The association between experiences with patient-centred care and health-related quality of life in women with endometriosis. *Reprod Biomed Online* 2018;36:197-205.

22. Witzeman K, Antunez Flores O, Renzelli-Cain RI*, et al.* Patient-Physician Interactions Regarding Dyspareunia with Endometriosis: Online Survey Results. *J Pain Res* 2020;13:1579-89.

23. Culley L, Law C, Hudson N*, et al.* The social and psychological impact of endometriosis on women's lives: a critical narrative review. *Hum Reprod Update* 2013;19:625-39.

24. Oehmke F, Weyand J, Hackethal A*, et al.* Impact of endometriosis on quality of life: a pilot study. *Gynecol Endocrinol* 2009;25:722-5.

25. Ugwumadu L, Chakrabarti R, Williams-Brown E*, et al.* The role of the multidisciplinary team in the management of deep infiltrating endometriosis. *Gynecol Surg* 2017;14:15.

26. Aarts JW, Huppelschoten AG, van Empel IW*, et al.* How patient-centred care relates to patients' quality of life and distress: a study in 427 women experiencing infertility. *Hum Reprod* 2012;27:488-95.

27. Gameiro S, Canavarro MC, Boivin J. Patient centred care in infertility health care: direct and indirect associations with wellbeing during treatment. *Patient Educ Couns* 2013;93:646-54.

28. Bourdel N, Alves J, Pickering G*, et al.* Systematic review of endometriosis pain assessment: how to choose a scale? *Hum Reprod Update* 2015;21:136-52.

29. Chawla S. Treatment of Endometriosis and Chronic Pelvic Pain with Letrozole and Norethindrone Acetate. *Med J Armed Forces India* 2010;66:213-5.

30. Facchin F, Barbara G, Saita E*, et al.* Impact of endometriosis on quality of life and mental health: pelvic pain makes the difference. *J Psychosom Obstet Gynaecol* 2015;36:135-41.

31. Ballard K, Lowton K, Wright J. What's the delay? A qualitative study of women's experiences of reaching a diagnosis of endometriosis. *Fertil Steril* 2006;86:1296-301.

32. Bernuit D, Ebert AD, Halis G*, et al.* Female perspectives on endometriosis: findings from the uterine bleeding and pain women's research study. *Journal of Endometriosis* 2011;3:73-85.

33. Greene R, Stratton P, Cleary SD*, et al.* Diagnostic experience among 4,334 women reporting surgically diagnosed endometriosis. *Fertil Steril* 2009;91:32-9.

34. Hadfield R, Mardon H, Barlow D*, et al.* Delay in the diagnosis of endometriosis: a survey of women from the USA and the UK. *Hum Reprod* 1996;11:878-80.

35. Hudelist G, Fritzer N, Thomas A*, et al.* Diagnostic delay for endometriosis in Austria and Germany: causes and possible consequences. *Hum Reprod* 2012;27:3412-6.

36. Nnoaham KE, Hummelshoj L, Webster P*, et al.* Impact of endometriosis on quality of life and work productivity: a multicenter study across ten countries. *Fertil Steril* 2011;96:366-73 e8.

37. Soliman AM, Fuldeore M, Snabes MC. Factors Associated with Time to Endometriosis Diagnosis in the United States. *J Womens Health (Larchmt)* 2017;26:788-97.

38. Staal AH, van der Zanden M, Nap AW. Diagnostic Delay of Endometriosis in the Netherlands. *Gynecol Obstet Invest* 2016;81:321-4.

39. Nnoaham KE, Hummelshoj L, Kennedy SH*, et al.* Developing symptom-based predictive models of endometriosis as a clinical screening tool: results from a multicenter study. *Fertil Steril* 2012;98:692-701 e5.

40. Brosens I, Puttemans P, Campo R*, et al.* Non-invasive methods of diagnosis of endometriosis. *Curr Opin Obstet Gynecol* 2003;15:519-22.

41. Lamvu G, Antunez-Flores O, Orady M*, et al.* Path to diagnosis and women's perspectives on the impact of endometriosis pain. *Journal of Endometriosis and Pelvic Pain Disorders* 2020:2284026520903214.

42. Gilmour JA, Huntington A, Wilson HV. The impact of endometriosis on work and social participation. *Int J Nurs Pract* 2008;14:443-8.

43. Murray CB, Groenewald CB, de la Vega R*, et al.* Long-term impact of adolescent chronic pain on young adult educational, vocational, and social outcomes. *Pain* 2020;161:439-45.

44. Kashikar-Zuck S, Lynch AM, Graham TB*, et al.* Social functioning and peer relationships of adolescents with juvenile fibromyalgia syndrome. *Arthritis Rheum* 2007;57:474-80.

45. de Graaf R, Tuithof M, van Dorsselaer S*, et al.* Comparing the effects on work performance of mental and physical disorders. *Soc Psychiatry Psychiatr Epidemiol* 2012;47:1873-83.

46. Smorgick N, Marsh CA, As-Sanie S*, et al.* Prevalence of pain syndromes, mood conditions, and asthma in adolescents and young women with endometriosis. *J Pediatr Adolesc Gynecol* 2013;26:171-5.

47. Yosef A, Allaire C, Williams C*, et al.* Multifactorial contributors to the severity of chronic pelvic pain in women. *Am J Obstet Gynecol* 2016;215:760 e1-60 e14.

48. Evans SF, Brooks TA, Esterman AJ*, et al.* The comorbidities of dysmenorrhea: a clinical survey comparing symptom profile in women with and without endometriosis. *J Pain Res* 2018;11:3181-94.

49. Fourquet J, Baez L, Figueroa M*, et al.* Quantification of the impact of endometriosis symptoms on health-related quality of life and work productivity. *Fertil Steril* 2011;96:107-12.

50. Sperschneider ML, Hengartner MP, Kohl-Schwartz A*, et al.* Does endometriosis affect professional life? A matched case-control study in Switzerland, Germany and Austria. *BMJ open* 2019;9:e019570.

51. Prescott J, Farland LV, Tobias DK*, et al.* A prospective cohort study of endometriosis and subsequent risk of infertility. *Hum Reprod* 2016;31:1475-82.

52. Geisser ME, Cano A, Leonard MT. Factors associated with marital satisfaction and mood among spouses of persons with chronic back pain. *J Pain* 2005;6:518-25.

53. Leonard MT, Cano A. Pain affects spouses too: personal experience with pain and catastrophizing as correlates of spouse distress. *Pain* 2006;126:139-46.

54. Fourquet J, Gao X, Zavala D*, et al.* Patients' report on how endometriosis affects health, work, and daily life. *Fertil Steril* 2010;93:2424-28.

55. Maleki N, Tahaney K, Thompson BL*, et al.* At the intersection of alcohol use disorder and chronic pain. *Neuropsychology* 2019;33:795-807.

56. Groenewald CB, Law EF, Fisher E*, et al.* Associations Between Adolescent Chronic Pain and Prescription Opioid Misuse in Adulthood. *J Pain* 2019;20:28-37.

57. Lazzeri L, Orlandini C, Vannuccini S*, et al.* Endometriosis and perceived stress: impact of surgical and medical treatment. *Gynecol Obstet Invest* 2015;79:229-33.

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

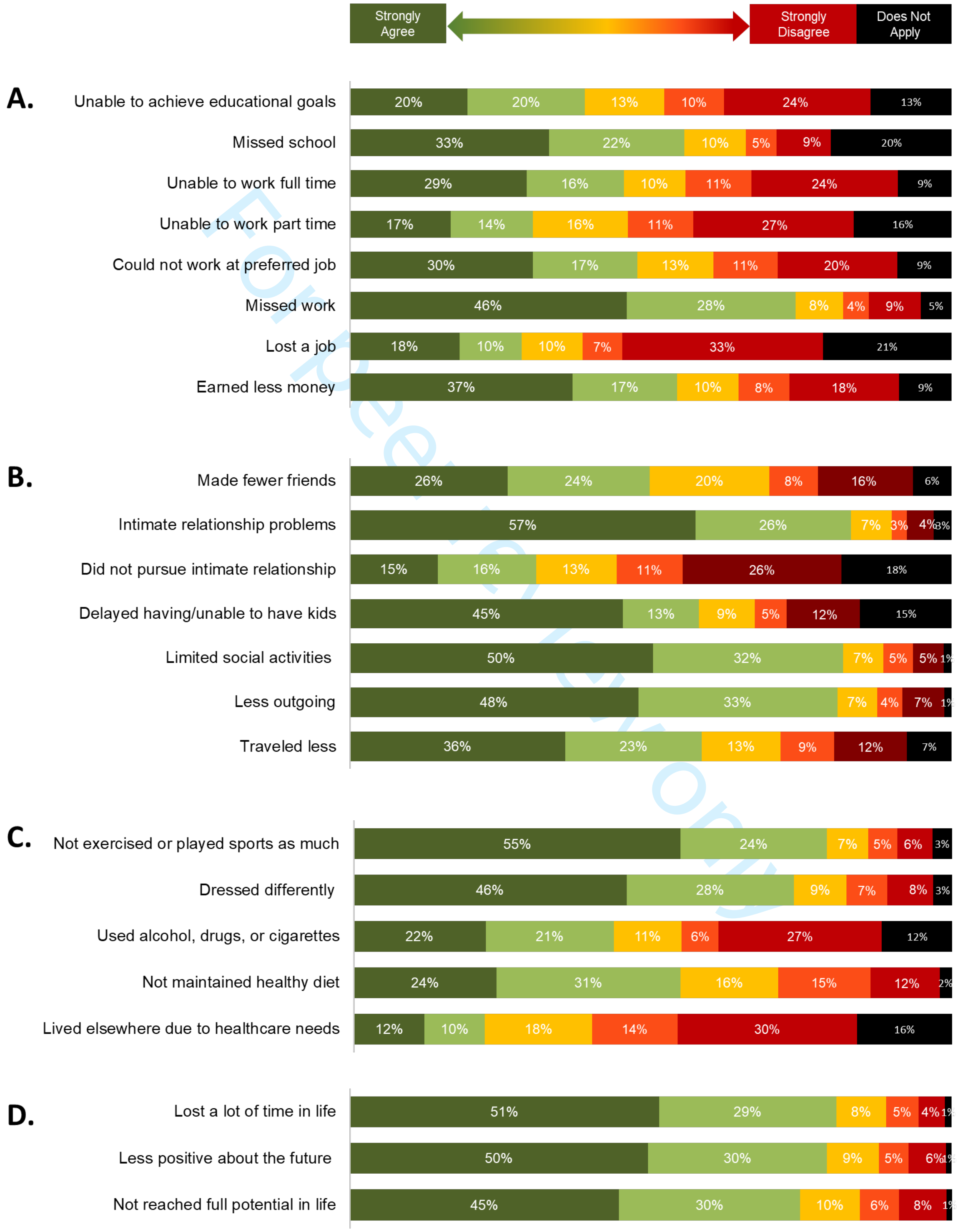
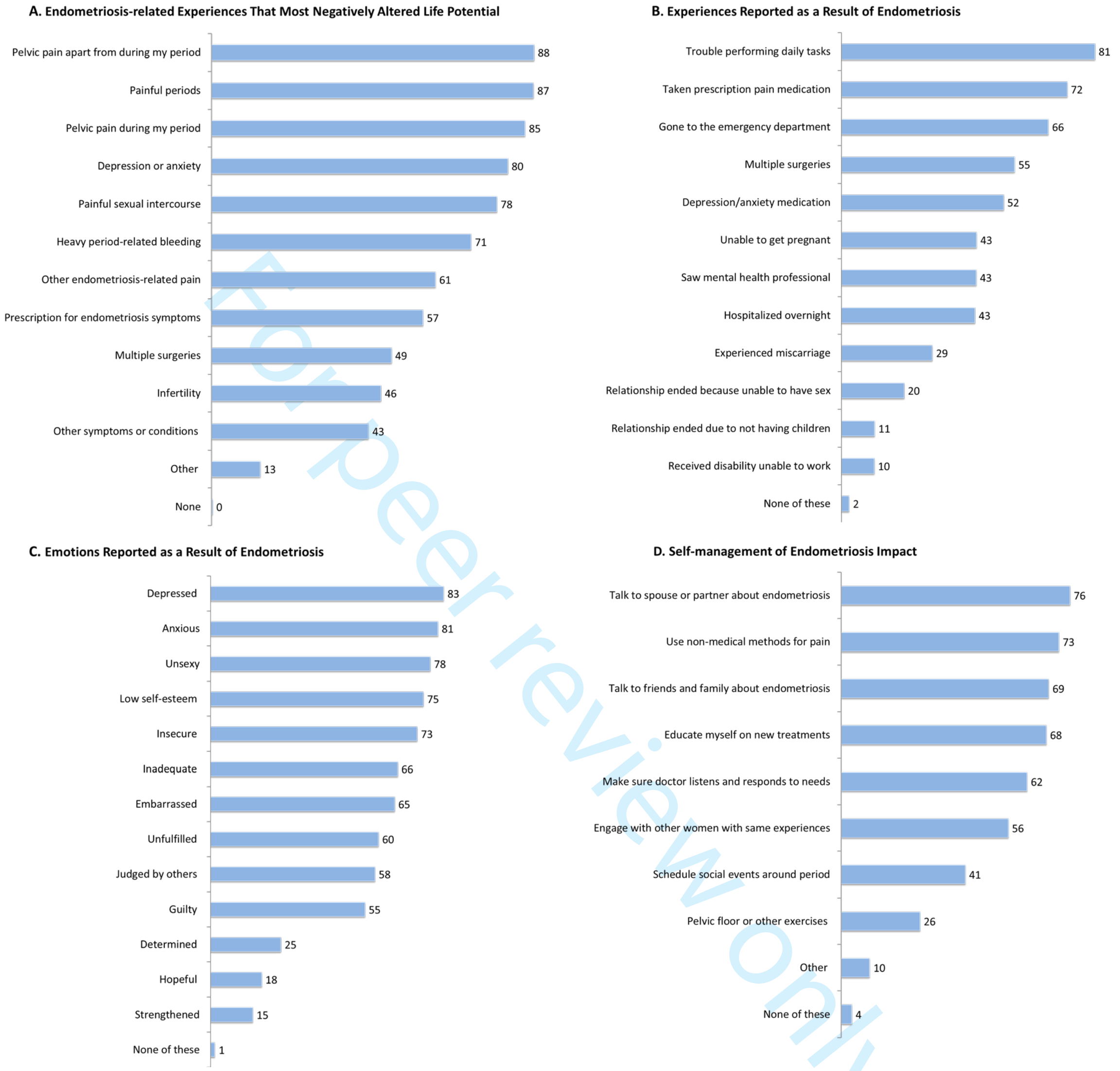

Strongly Agree
Strongly Disagree
Does Not Apply
A.
Unable to achieve educational goals 20% 20% 13% 10% 24% 13%
Missed school 33% 22% 10% 5% 9% 20%
Unable to work full time 29% 16% 10% 11% 24% 9%
Unable to work part time 17% 14% 16% 11% 27% 16%
Could not work at preferred job 30% 17% 13% 11% 20% 9%
Missed work 46% 28% 8% 4% 9% 5%
Lost a job 18% 10% 10% 7% 33% 21%
Earned less money 37% 17% 10% 8% 18% 9%
B.
Made fewer friends 26% 24% 20% 8% 16% 6%
Intimate relationship problems 57% 26% 7% 3% 4% 3%
Did not pursue intimate relationship 15% 16% 13% 11% 26% 18%
Delayed having/unable to have kids 45% 13% 9% 5% 12% 15%
Limited social activities 50% 32% 7% 5% 5% 1%
Less outgoing 48% 33% 7% 4% 7% 1%
Traveled less 36% 23% 13% 9% 12% 7%
C.
Not exercised or played sports as much 55% 24% 7% 5% 6% 3%
Dressed differently 46% 28% 9% 7% 8% 3%
Used alcohol, drugs, or cigarettes 22% 21% 11% 6% 27% 12%
Not maintained healthy diet 24% 31% 16% 15% 12% 2%
Lived elsewhere due to healthcare needs 12% 10% 18% 14% 30% 16%
D.
Lost a lot of time in life 51% 29% 8% 5% 4% 1%
Less positive about the future 50% 30% 9% 5% 6% 1%
Not reached full potential in life 45% 30% 10% 6% 8% 1%

FIGURE 2


A. Endometriosis-related Experiences That Most Negatively Altered Life Potential
Pelvic pain apart from during my period 88
Painful periods 87
Pelvic pain during my period 85
Depression or anxiety 80
Painful sexual intercourse 78
Heavy period-related bleeding 71
Other endometriosis-related pain 61
Prescription for endometriosis symptoms 57
Multiple surgeries 49
Infertility 46
Other symptoms or conditions 43
Other 13
None 0
B. Experiences Reported as a Result of Endometriosis
Trouble performing daily tasks 81
Taken prescription pain medication 72
Gone to the emergency department 66
Multiple surgeries 55
Depression/anxiety medication 52
Unable to get pregnant 43
Saw mental health professional 43
Hospitalized overnight 43
Experienced miscarriage 29
Relationship ended because unable to have sex 20
Relationship ended due to not having children 11
Received disability unable to work 10
None of these 2
C. Emotions Reported as a Result of Endometriosis
Depressed 83
Anxious 81
Unsexy 78
Low self-esteem 75
Insecure 73
Inadequate 66
Embarrassed 65
Unfulfilled 60
Judged by others 58
Guilty 55
Determined 25
Hopeful 18
Strengthened 15
None of these 1
D. Self-management of Endometriosis Impact
Talk to spouse or partner about endometriosis 76
Use non-medical methods for pain 73
Talk to friends and family about endometriosis 69
Educate myself on new treatments 68
Make sure doctor listens and responds to needs 62
Engage with other women with same experiences 56
Schedule social events around period 41
Pelvic floor or other exercises 26
Other 10
None of these 4

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

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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 (182)	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)

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

S2. What is your age?

Under 19 **(Terminate)**

19-29

30-39

40-49

50-59

60 or older

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

Stage 1 endometriosis

Stage 2 endometriosis

Stage 3 endometriosis

Stage 4 endometriosis

Not sure what stage of endometriosis I have

I do not have endometriosis (**Terminate**)

S4. In which country do you currently live?

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

Australia

Canada

Ireland

Netherlands

New Zealand

South Africa

United Kingdom

Other

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

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)

Painful sexual intercourse

Pelvic pain during my period

Pelvic pain apart from during my period

Painful periods

Heavy period-related bleeding

Other endometriosis related pain

Infertility

Depression or anxiety

Multiple surgeries

Prescription treatment to control endometriosis symptoms

Other symptoms or conditions (please specify)

Other (please specify)

None

10. Which, if any of these, have you experienced as a result of your endometriosis? Check all that apply. (Rotate order)

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

Taken prescription medication to treat depression or anxiety

Had multiple surgical procedures

Been hospitalized overnight

Gone to the emergency room

Received disability income due to being unable to work

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

Had trouble performing daily tasks

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

Was unable to get pregnant

Had a relationship end because I was unable to have children

Had a relationship end because I was unable to have sex

None of these

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

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

    Schedule social events around my period

    Engage with other women going through the same experiences

    Talk to my friends and family about endometriosis

    Talk to my spouse or partner about my endometriosis

    Pelvic floor or other exercises to lessen pain during sex

    Make sure my doctor listens and responds to my needs

    Educate myself on new treatments

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

    Other (please describe)

    None of these

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

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

Just a few last questions.

D1. Which of the following best describes the area where you live?

Urban

Suburban

Rural

Not sure / prefer not to say

D2. What is the highest level of education you have achieved?

Less than high school

Some high school

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

Some college, but no degree

Associate degree

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

Some graduate school, but no degree

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

Prefer not to answer

D3. What is your current employment status?

Working full time

Working part time

Unemployed, not looking for work

Unemployed, looking for work

Retired

Unable to work

Prefer not to answer

D4. Which of the following best describes your marital status?

Single/never married
Married
Widowed
Divorced or separated
Prefer not to answer

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

D5. Are you currently in an intimate relationship?

Yes
No
Prefer not to answer

D6. How many children, if any, do you have?

None
1
2
3
4
5 or more
Prefer not to answer

Thank you for answering these questions.

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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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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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ABSTRACT

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

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

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

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

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.

Conclusions: 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 that endometriosis has on a woman's life course and the importance of meaningful dialogue with patients may be important for improving long-term management of the disease and help identify women who are most vulnerable.

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Strengths and limitations of this study

- Strength: Quantitative survey with a meaningful sample size and sample population that spanned multiple countries
- Strength: Targeted research questions developed based on existing conversations on a social network platform
- Strength: Use of social network familiar to patients, facilitating honesty in responses to sensitive topics
- Limitation: Possible self-selection bias due to voluntary participation in an online community and no targeted sampling; quantitative data may not be generalizable to all women with endometriosis
- Limitation: Self-reported patient responses that were not confirmed by medical records or other complementary data

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] These issues have been further exacerbated by the COVID-19 pandemic, which has led to reduced access to medical care, delayed treatments, increased stress, loss of work productivity, and mandated self-isolation.[13,14]

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 and emergency departments, 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 losses of thousands of dollars per patient.[12,15-18]

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.[19,20] In contrast, few studies have examined the impact of endometriosis on a woman's life course based on how symptoms and experiences resulting from the disease influence major life events and decisions (such as whether to pursue educational opportunities, choose a career path, establish intimate relationships, and plan for a family) and the overall ability of patients to attain their life goals.[19,20] The few existing studies have small sample sizes or are qualitative, relying on informational interviews to ascertain the life-course impact of the disease, but highlight the substantial impacts that endometriosis can have on social activities, intimate relationships, education, work productivity, and psychological well-being .[11,21-23] Understanding life-course impairment, as opposed to focusing on the symptoms of the disease (such as pain or infertility, which 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 decisions (eg, work, education, or personal relationships) in ways that are interrelated and can impact other areas of a patient's life. For example, chronic pain may influence the type and amount of work performed or whether a patient decides to work at all, which, in turn, can have financial implications on the patient's lifestyle, family, relationships, or sense of personal fulfillment.[19,20] Symptoms may determine where a patient chooses to live because of financial considerations, healthcare access, or proximity to support networks. Similarly, dyspareunia related to endometriosis may lead some women to avoid intimate relationships, which may have downstream implications for marriage, family planning, and mental and emotional health.[24,25] Cumulatively, persistent symptoms of endometriosis and their impact on daily activities and family and intimate relationships can negatively impact the trajectory of women's lives and are profound and far-reaching.

The objective of this multinational survey was to gain a better understanding of patient perspectives on how endometriosis impacts their daily activities and identify how the disease may influence women's major life decisions and attainment of their goals. In addition, we sought to understand the endometriosis-related life-course impacts specifically in women who reported low optimism or low goal attainment. Insights into a patient's complete experience with endometriosis are needed to develop and provide access to effective treatments to reduce the negative impacts of endometriosis on a woman's life course. Greater awareness of the potential negative life-course impacts of endometriosis is important for helping physicians to identify and understand patients' needs and improve the long-term management of endometriosis.

METHODS

Ethics approval

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

Survey development

An online survey was created in a collaborative effort between AbbVie (North Chicago, IL, USA) and MyHealthTeams (San Francisco, CA, USA), a company that creates social networks for communities of individuals living with chronic conditions to foster discussion and provide support among people facing similar circumstances. The survey was programmed and administered through Qualtrics, an online survey tool that allows users to capture survey responses in an anonymized manner. The survey was provided in English and was available online on the social media network website MyEndometriosisTeam.com from October 3 through October 25, 2018. The 14 survey questions about women's experiences with endometriosis were based on our knowledge about the disease state, existing publications, and online conversations participants were having (**see Patient and public involvement** for further detail). In addition, the survey contained 4 screening questions and 6 demographic questions (identified as Supporting Information). The primary goal of the survey was to capture patients' perspectives on the negative impacts of endometriosis on different aspects of their life courses, including how endometriosis has affected their work, education, relationships, overall life decisions, and attainment of goals. This portion of the survey was modeled after a validated instrument created to measure life-course impact of disease in patients with psoriasis.[25] Survey questions were rotated to avoid any bias introduced by order of answer selections. Most survey questions were closed-ended and provided multiple-choice options to participants; two questions were open-ended and allowed participants to provide written responses detailing any life accomplishments they believed were impeded by endometriosis or to offer anything else they wanted to share about the impact of endometriosis on their lives. Responses were required for all closed-ended questions; therefore, no imputations for missing data were required. The survey used in this study is included in the supplementary material.

Patient and public involvement

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

Participant eligibility and recruitment

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

Survey analysis

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

[a] Patients 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*

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

Endometriosis-associated pain

Most women (56%, n=415) reported experiencing pain daily and nearly an additional one-quarter of them 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 said they “somewhat agreed” or “strongly agreed” that they had experienced difficulties achieving their educational goals (40%, n=290) or had missed school (55%, n=413) because of endometriosis-associated symptoms (figure 1A). Almost half of participants (45%, n=338) “somewhat agreed” or “strongly agreed” that they could not work full time, and a similar percentage (47%, n=355) reported not working at a job they would have preferred. Most reported that they had missed work (74%, n=550) or earned less money than they could have (54%, n=404) because of endometriosis-associated symptoms. These findings were consistent among patients in the United States compared with the rest of the world (supporting information figure 1).

Relationships and social engagements

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

Physical well-being

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

Life-course impairment overall

Overall, most women (80%, n=601) “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%, n=589), and 75% (n=556) “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 (81%, n=594); 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 (72%, n=529), visiting emergency departments (66%, n=485), having multiple surgeries (55%, n=406), being hospitalized overnight (43%, n=313), taking prescription medication for depression or anxiety (52%, n=380), or seeing a mental health professional because of their endometriosis-associated symptoms (43%, n=316). Around half of the women surveyed reported that the experiences that most negatively impacted their lives were their need to take prescription medication (57%, n=427) and the multiple surgeries for endometriosis (49%, n=363). In addition, most women surveyed reported several negative emotions that they attributed to endometriosis, including feeling depressed (83%, n=607), anxious (81%, n=592), unsexy (78%, n=572), or having low self-esteem (75%, n=554; figure 2C).

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

Additional analysis of women who believed their future and life potential were more impacted by endometriosis

Most of the sample included women who “somewhat agreed” or “strongly agreed” that they were LPAF (80%; n=589) or had NRFP in life (75%; n=556) because of endometriosis, and several questions limited to these women were further analyzed (Supporting Information table 1). Overall, the observational data in this study suggested women who believed they were LPAF or had NRFP generally reported more negative experiences than the fewer respondents who did not indicate they were LPAF (non-LPAF, 21%; n=154) or had NRFP (non-NRFP, 25%; n=187). Daily pain was reported by a higher proportion of women who believed they were LPAF or had NRPF because of endometriosis, compared with other women (62% LPAF vs 34% non-LPAF; 61% NRFP vs 40% non-NRFP; Supporting Information table 1A). More women who believed they were LPAF or had NRFP also reported negative experiences related to education and work they attributed to endometriosis, including having earned less money (61% LPAF vs 29% non-LPAF; 66% NRFP vs 21% non-NRFP), not working a preferred job (54% LPAF vs 25% non-LPAF; 58% NRFP vs 17% non-NRFP), or not achieving educational goals (44% LPAF vs 21% non-LPAF; 47% NRFP vs 16% non-NRFP) (Supporting Information table 1B). A higher proportion of women who believed their future and life potential were more impacted by their disease reported endometriosis-related experiences altered their life potential in a negative way (Supporting Information table 1C). Similarly, more of these women reported negative experiences and emotions they attributed to endometriosis (Supporting Information table 1D, E).

All women used similar strategies to cope with and mitigate the impact of endometriosis on their lives (Supporting Information table 1F).

DISCUSSION

A survey of women with endometriosis who self-reported pronounced symptoms also reported experiences that were perceived by them to negatively impact their views of the future and overall life potential. For many women, endometriosis-associated symptoms negatively affect various areas of their lives, including education and employment, relationships and social engagements, and physical well-being. Participants indicated that adverse experiences related to management of their disease and its impact on everyday life also believed that their future and life potential were negatively impacted by endometriosis.

Examining the cumulative life-course impact of endometriosis may influence a physician's ability to understand a woman's complete experience with the disease, help identify patients who are most vulnerable to its impacts, and inform options for management.[9,20,22,26] A fuller understanding of the life-course impact of endometriosis may also elucidate patterns of patient needs and identify which forms of supportive multidisciplinary care are necessary, including the need for early referral to specialists and other professionals who provide complementary healthcare. These needs are likely to change over time, during the different phases of each patient's life. For example, teams that include gynecologists and pain specialists may help patients manage endometriosis-associated pain symptoms; reproductive endocrinologists may help manage infertility, if this occurs; sexual health counselors may collaborate with patients who have dyspareunia; and counselors/psychologists may assist with chronic stress and mental health issues.[27] Physicians who are responsive to patients' individual needs and values can positively support overall quality of life in those patients who experience infertility[28,29] and other negative symptoms of endometriosis, such as chronic abdominal pain, dysmenorrhea, and dyspareunia.[24] Endometriosis may also contribute to social inequalities; further research is needed to explore this topic and develop social policies to address these inequalities.

The severity of pain reported by women who completed the online survey indicates that respondents in our study may have had a greater symptom burden than did women participating in previous studies using similar pain scales.[30-32] Women in our study also reported slightly lengthier delays in diagnosis after the onset of their first symptoms. Findings in previous studies have illustrated that delays are common in diagnosing endometriosis.[15,33-41] Although some recent literature suggests that the delay in diagnosis may be slowly improving,[39] the use of non-invasive and accurate diagnostic tools could improve diagnosis times and reduce women's pain and distress.[41,42] The delays in diagnosis reported by our study participants and others indicate many women experiencing troublesome symptoms of endometriosis may still wait extended periods before receiving a definitive diagnosis and initiating treatment.

The higher pain burden and longer diagnostic delay reported in our sample, which may include higher numbers of women who sought social network support because they were more frustrated with their disease experience, could conceivably be due in part to their longer struggles with more challenging symptoms than would be observed in the general population of women with diagnosed endometriosis. Results from a recent study using the same social network to recruit participants found that the majority of respondents rated their worst pain higher than 7 on a 10-point scale, only a little lower than the pain rating given by the women in our study.[43] Additionally, the previous study participants also experienced a diagnostic delay, supporting the theory that recruitment from this member-centered network may draw more women who have struggled longer with their disease.[43] Interestingly, overall trends in diagnostic delays observed between age groups in our study are consistent with reports in previous research, ie, women whose symptom onset occurred at a younger age experienced longer times to diagnosis.[15,35,39]

Many respondents said they missed school and were generally unable to achieve their educational goals because of endometriosis. There is a dearth of research on the impact of endometriosis on women's educational aspirations and their ability to achieve goals due to endometriosis-associated symptoms, compared with the impact endometriosis has on professional work or other areas of life.[9] Findings from some existing studies suggest endometriosis-associated symptoms may impact grades, attendance, or completion of educational programs.[21,22,44] Although informative, these studies were more qualitative in nature and involved small sample sizes.[21,22,44] A quantitative study examining the lives of 78 women 15 years after receiving a verified diagnosis of endometriosis found only a fraction of women reported that their disease had a negative impact on their education.[11] However, the women included in that study seemed to report less frequent pain and endometriosis-related effects, like depression, compared with the reports made by women in our study. Furthermore, the small sample was collected at a single Norwegian hospital and the findings may not be representative of women's experiences with endometriosis on a wider scale.[11] Regardless, any impact on education is concerning, and our study results emphasize the need for additional research into this overlooked area in women with endometriosis. Research on other medical conditions, like adolescent fibromyalgia, supports that chronic pain can negatively impact education, reinforcing the likelihood that endometriosis may have a similar impact.[45,46]

Respondents in the current study also reported endometriosis-associated symptoms caused them to miss work, earn less money, prevented them from a job they would have preferred, or impeded their working full time or part time. Many health conditions that can occur with endometriosis can impact work productivity and potential, including depression, other chronic pain conditions or disorders, and digestive disorders.[47] Endometriosis was self-reported by respondents in this study, and it is possible that other chronic conditions (particularly, chronic overlapping pain conditions) may also contribute to women's perceived interference with productivity and employment opportunities. Indeed, more than half of women with symptomatic endometriosis can present with comorbid pain syndromes,[48] and these may include conditions associated with pelvic pain, like dysmenorrhea, irritable bowel syndrome, or painful bladder syndrome.[49,50] Findings from previous studies have also illustrated that endometriosis-associated symptoms may lead to losses in productivity both at home and in the workplace, potentially impacting professional achievement.[12,38,51,52] In our study, higher proportions of women who indicated that they were LPAF or had NRFP because of endometriosis reported painful symptoms and negative experiences compared with other respondents. Also, women who were LPAF or had NRFP more often believed it was harder to perform daily tasks because of their disease.

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

Respondents to our survey reported endometriosis had a negative impact on their relationships, social engagements, and ability to have children (when desired), which is consistent with findings from a host of previous studies that demonstrated the negative impacts of endometriosis on social well-being and health-related quality of life.[9,12,38,51] Interestingly, 46% of women in our study reported experiencing infertility, which is slightly higher than the 14%–40% range reported in previous studies, again hinting at our population's higher symptom burden.[38,43,53] Other chronic pain conditions have also impacted these life-course components, including conditions related to musculoskeletal pain and chronic back pain.[54,55]

Similar to decisions involving education and professional achievement, life choices involving the pursuit of intimate relationships or starting a family may have downstream implications in other areas, like finance, psychological well-being, or employment, which may have their own downstream impacts on additional aspects of a person's life course.[19] Likewise, women frequently reported not being physically active and having poorer diets because of their disease. Although few studies have examined this aspect of endometriosis, findings from two smaller studies have suggested that pain associated with the disease may also have a negative impact on exercise and nutrition.[9,34,56]

Of particular concern was the view of many women that their disease made them increase their use of alcohol, drugs, or cigarettes. Research into whether pain and experiences related to endometriosis may be associated with higher rates of substance abuse is severely lacking. However, there are demonstrated associations between other chronic pain conditions and substance abuse that support our finding.[57,58] The results from our study draw attention to this issue and highlight substance abuse as an important avenue for additional investigation.

The findings from our study indicate that women with endometriosis may experience many healthcare-related side effects. Of particular concern, patients noted that treatments meant to help reduce the burden of endometriosis may have their own negative impact. Many women perceived that use of prescription medications and multiple surgeries to control the symptoms of endometriosis had a negative impact on their life potential, and this response was stronger in women who indicated they were LPAF or believed they had NRFP due to their disease. Results from one recent study showed that medical treatment for a condition may increase a patient's stress levels and potentially affect their psychological health.[59] Patients who were taking prescription medications and who experienced more challenging adverse effects from their therapies had higher perceived stress levels, and women undergoing multiple surgeries were especially impacted. These reports underscore the potential value of supportive psychological care for patients with endometriosis as part of effective long-term disease management.

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

In general, women experienced a range of consequences that they attributed to living with and managing the limitations imposed by endometriosis. In addition to pain, women reported that the endometriosis-related experiences that most impacted their lives in a negative way included depression or anxiety (80%), heavy menstrual bleeding (71%), the need to take prescription treatments (57%) or undergo multiple surgeries (49%), or infertility (46%). In other studies, women have reported not feeling “normal” or feminine, experiencing a range of negative emotions (eg, anger, depression, hopelessness, disappointment, and exhaustion), having limited physical or sexual activity, struggling to find appropriate treatments, feeling guilt over disrupted relationships, and suffering in silence due to endometriosis-related symptoms.[22,23]While each woman experienced the impact of endometriosis differently, the majority believed that they were living life less fully than they could have because of their endometriosis-associated symptoms. This belief was informed by the symptoms and healthcare requirements they faced, and, in turn, may have influenced major life decisions that could have their own deleterious effects on personal fulfillment and life potential. The interconnectedness of effects triggered by major life decisions highlights the importance of conducting further research into the cumulative burden of debilitating diseases like endometriosis within the context of an individual’s life course.

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.

1

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AM Soliman, S Chiuve, S Cross, S Eichner, and O Antunez Flores are employees of AbbVie and may own AbbVie stock/stock options.

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S As-Sanie earns author royalties from UpToDate and has served as a consultant for AbbVie, Myovant, and Eximis.

Data Sharing Statement

AbbVie is committed to responsible data sharing regarding the clinical trials and studies we sponsor. This includes access to anonymized, individual and trial-level data (analysis data sets), as well as other information (eg, protocols and clinical study reports), as long as the trials are not part of an ongoing or planned regulatory submission. This includes requests for clinical trial data for unlicensed products and indications.

This study data can be requested by any qualified researchers who engage in rigorous, independent scientific research, and will be provided following review and approval of a research proposal and statistical analysis plan and execution of a data sharing agreement. Data requests can be submitted at any time and the data will be accessible for 12 months, with possible extensions considered. For more information on the process, or to submit a request, visit the following link: https://www.abbvie.com/our-science/clinical-trials/clinical-trials-data-and-information-sharing/data-and-information-sharing-with-qualified-researchers.html.

REFERENCES

1. Zondervan KT, Becker CM, Missmer SA. Endometriosis. *N Engl J Med* 2020;382:1244-56.

2. Kennedy S, Bergqvist A, Chapron C*, et al.* Eshre guideline for the diagnosis and treatment of endometriosis. *Hum Reprod* 2005;20:2698-704.

3. Practice bulletin no. 114: Management of endometriosis. *Obstet Gynecol* 2010;116:223-36.

4. Zondervan KT, Becker CM, Koga K*, et al.* Endometriosis. *Nat Rev Dis Primers* 2018;4:9.

5. De Graaff AA, D'Hooghe TM, Dunselman GA*, et al.* The significant effect of endometriosis on physical, mental and social wellbeing: Results from an international cross-sectional survey. *Hum Reprod* 2013;28:2677-85.

6. Gallagher JS, DiVasta AD, Vitonis AF*, et al.* The impact of endometriosis on quality of life in adolescents. *J Adolesc Health* 2018;63:766-72.

7. Lagana AS, La Rosa VL, Rapisarda AMC*, et al.* Anxiety and depression in patients with endometriosis: Impact and management challenges. *Int J Womens Health* 2017;9:323-30.

8. Vannuccini S, Lazzeri L, Orlandini C*, et al.* Mental health, pain symptoms and systemic comorbidities in women with endometriosis: A cross-sectional study. *J Psychosom Obstet Gynaecol* 2018;39:315-20.

9. Culley L, Law C, Hudson N*, et al.* A qualitative study of the impact of endometriosis on male partners. *Hum Reprod* 2017;32:1667-73.

10. Denny E, Mann CH. Endometriosis-associated dyspareunia: The impact on women's lives. *J Fam Plann Reprod Health Care* 2007;33:189-93.

11. Fagervold B, Jenssen M, Hummelshoj L*, et al.* Life after a diagnosis with endometriosis - a 15 years follow-up study. *Acta Obstet Gynecol Scand* 2009;88:914-9.

12. Soliman AM, Coyne KS, Gries KS*, et al.* The effect of endometriosis symptoms on absenteeism and presenteeism in the workplace and at home. *J Manag Care Spec Pharm* 2017;23:745-54.

13. Leonardi M, Horne AW, Armour M*, et al.* Endometriosis and the coronavirus (covid-19) pandemic: Clinical advice and future considerations. *Frontiers in Reproductive Health* 2020;2

14. Leonardi M, Horne AW, Vincent K*, et al.* Self-management strategies to consider to combat endometriosis symptoms during the covid-19 pandemic. *Hum Reprod Open* 2020;2020:hoaa028.

15. Klein S, D'Hooghe T, Meuleman C*, et al.* What is the societal burden of endometriosis-associated symptoms? A prospective belgian study. *Reprod Biomed Online* 2014;28:116-24.

16. Simoens S, Dunselman G, Dirksen C*, et al.* The burden of endometriosis: Costs and quality of life of women with endometriosis and treated in referral centres. *Hum Reprod* 2012;27:1292-9.

17. Soliman AM, Taylor HS, Bonafede M*, et al.* Incremental direct and indirect cost burden attributed to endometriosis surgeries in the united states. *Fertil Steril* 2017;107:1181-90 e2.

18. Soliman AM, Yang H, Du EX*, et al.* The direct and indirect costs associated with endometriosis: A systematic literature review. *Hum Reprod* 2016;31:712-22.

19. Bhatti Z, Salek M, Finlay A. Chronic diseases influence major life changing decisions: A new domain in quality of life research. *J R Soc Med* 2011;104:241-50.

20. Kimball AB, Gieler U, Linder D*, et al.* Psoriasis: Is the impairment to a patient's life cumulative? *J Eur Acad Dermatol Venereol* 2010;24:989-1004.

21. Huntington A, Gilmour JA. A life shaped by pain: Women and endometriosis. *J Clin Nurs* 2005;14:1124-32.

22. Moradi M, Parker M, Sneddon A*, et al.* Impact of endometriosis on women's lives: A qualitative study. *BMC Womens Health* 2014;14:123.

23. Cole JM, Grogan S, Turley E. "The most lonely condition i can imagine": Psychosocial impacts of endometriosis on women's identity. *Feminism & Psychology* 2021;31:171-91.

24. Apers S, Dancet EAF, Aarts JWM*, et al.* The association between experiences with patient-centred care and health-related quality of life in women with endometriosis. *Reprod Biomed Online* 2018;36:197-205.

25. Witzeman K, Antunez Flores O, Renzelli-Cain RI*, et al.* Patient-physician interactions regarding dyspareunia with endometriosis: Online survey results. *J Pain Res* 2020;13:1579-89.

26. Oehmke F, Weyand J, Hackethal A*, et al.* Impact of endometriosis on quality of life: A pilot study. *Gynecol Endocrinol* 2009;25:722-5.

27. Ugwumadu L, Chakrabarti R, Williams-Brown E*, et al.* The role of the multidisciplinary team in the management of deep infiltrating endometriosis. *Gynecol Surg* 2017;14:15.

28. Aarts JW, Huppelschoten AG, van Empel IW*, et al.* How patient-centred care relates to patients' quality of life and distress: A study in 427 women experiencing infertility. *Hum Reprod* 2012;27:488-95.

29. Gameiro S, Canavarro MC, Boivin J. Patient centred care in infertility health care: Direct and indirect associations with wellbeing during treatment. *Patient Educ Couns* 2013;93:646-54.

30. Bourdel N, Alves J, Pickering G*, et al.* Systematic review of endometriosis pain assessment: How to choose a scale? *Hum Reprod Update* 2015;21:136-52.

31. Chawla S. Treatment of endometriosis and chronic pelvic pain with letrozole and norethindrone acetate. *Med J Armed Forces India* 2010;66:213-5.

32. Facchin F, Barbara G, Saita E*, et al.* Impact of endometriosis on quality of life and mental health: Pelvic pain makes the difference. *J Psychosom Obstet Gynaecol* 2015;36:135-41.

33. Ballard K, Lowton K, Wright J. What's the delay? A qualitative study of women's experiences of reaching a diagnosis of endometriosis. *Fertil Steril* 2006;86:1296-301.

34. Bernuit D, Ebert AD, Halis G*, et al.* Female perspectives on endometriosis: Findings from the uterine bleeding and pain women's research study. *Journal of Endometriosis* 2011;3:73-85.

35. Greene R, Stratton P, Cleary SD*, et al.* Diagnostic experience among 4,334 women reporting surgically diagnosed endometriosis. *Fertil Steril* 2009;91:32-9.

36. Hadfield R, Mardon H, Barlow D*, et al.* Delay in the diagnosis of endometriosis: A survey of women from the USA and the uk. *Hum Reprod* 1996;11:878-80.

37. Hudelist G, Fritzer N, Thomas A*, et al.* Diagnostic delay for endometriosis in austria and germany: Causes and possible consequences. *Hum Reprod* 2012;27:3412-6.

38. Nnoaham KE, Hummelshoj L, Webster P*, et al.* Impact of endometriosis on quality of life and work productivity: A multicenter study across ten countries. *Fertil Steril* 2011;96:366-73 e8.

39. Soliman AM, Fuldeore M, Snabes MC. Factors associated with time to endometriosis diagnosis in the united states. *J Womens Health (Larchmt)* 2017;26:788-97.

40. Staal AH, van der Zanden M, Nap AW. Diagnostic delay of endometriosis in the netherlands. *Gynecol Obstet Invest* 2016;81:321-4.

41. Nnoaham KE, Hummelshoj L, Kennedy SH*, et al.* Developing symptom-based predictive models of endometriosis as a clinical screening tool: Results from a multicenter study. *Fertil Steril* 2012;98:692-701 e5.

42. Brosens I, Puttemans P, Campo R*, et al.* Non-invasive methods of diagnosis of endometriosis. *Curr Opin Obstet Gynecol* 2003;15:519-22.

43. Lamvu G, Antunez-Flores O, Orady M*, et al.* Path to diagnosis and women's perspectives on the impact of endometriosis pain. *Journal of Endometriosis and Pelvic Pain Disorders* 2020:2284026520903214.

44. Gilmour JA, Huntington A, Wilson HV. The impact of endometriosis on work and social participation. *Int J Nurs Pract* 2008;14:443-8.

45. Murray CB, Groenewald CB, de la Vega R*, et al.* Long-term impact of adolescent chronic pain on young adult educational, vocational, and social outcomes. *Pain* 2020;161:439-45.

46. Kashikar-Zuck S, Lynch AM, Graham TB*, et al.* Social functioning and peer relationships of adolescents with juvenile fibromyalgia syndrome. *Arthritis Rheum* 2007;57:474-80.

47. de Graaf R, Tuithof M, van Dorsselaer S*, et al.* Comparing the effects on work performance of mental and physical disorders. *Soc Psychiatry Psychiatr Epidemiol* 2012;47:1873-83.

48. Smorgick N, Marsh CA, As-Sanie S*, et al.* Prevalence of pain syndromes, mood conditions, and asthma in adolescents and young women with endometriosis. *J Pediatr Adolesc Gynecol* 2013;26:171-5.

49. Yosef A, Allaire C, Williams C*, et al.* Multifactorial contributors to the severity of chronic pelvic pain in women. *Am J Obstet Gynecol* 2016;215:760 e1-60 e14.

50. Evans SF, Brooks TA, Esterman AJ*, et al.* The comorbidities of dysmenorrhea: A clinical survey comparing symptom profile in women with and without endometriosis. *J Pain Res* 2018;11:3181-94.

51. Fourquet J, Baez L, Figueroa M*, et al.* Quantification of the impact of endometriosis symptoms on health-related quality of life and work productivity. *Fertil Steril* 2011;96:107-12.

52. Sperschneider ML, Hengartner MP, Kohl-Schwartz A*, et al.* Does endometriosis affect professional life? A matched case-control study in switzerland, germany and austria. *BMJ open* 2019;9:e019570.

53. Prescott J, Farland LV, Tobias DK*, et al.* A prospective cohort study of endometriosis and subsequent risk of infertility. *Hum Reprod* 2016;31:1475-82.

54. Geisser ME, Cano A, Leonard MT. Factors associated with marital satisfaction and mood among spouses of persons with chronic back pain. *J Pain* 2005;6:518-25.

55. Leonard MT, Cano A. Pain affects spouses too: Personal experience with pain and catastrophizing as correlates of spouse distress. *Pain* 2006;126:139-46.

56. Fourquet J, Gao X, Zavala D*, et al.* Patients' report on how endometriosis affects health, work, and daily life. *Fertil Steril* 2010;93:2424-28.

57. Maleki N, Tahaney K, Thompson BL*, et al.* At the intersection of alcohol use disorder and chronic pain. *Neuropsychology* 2019;33:795-807.

58. Groenewald CB, Law EF, Fisher E*, et al.* Associations between adolescent chronic pain and prescription opioid misuse in adulthood. *J Pain* 2019;20:28-37.

59. Lazzeri L, Orlandini C, Vannuccini S*, et al.* Endometriosis and perceived stress: Impact of surgical and medical treatment. *Gynecol Obstet Invest* 2015;79:229-33.

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, and (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 impacts 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

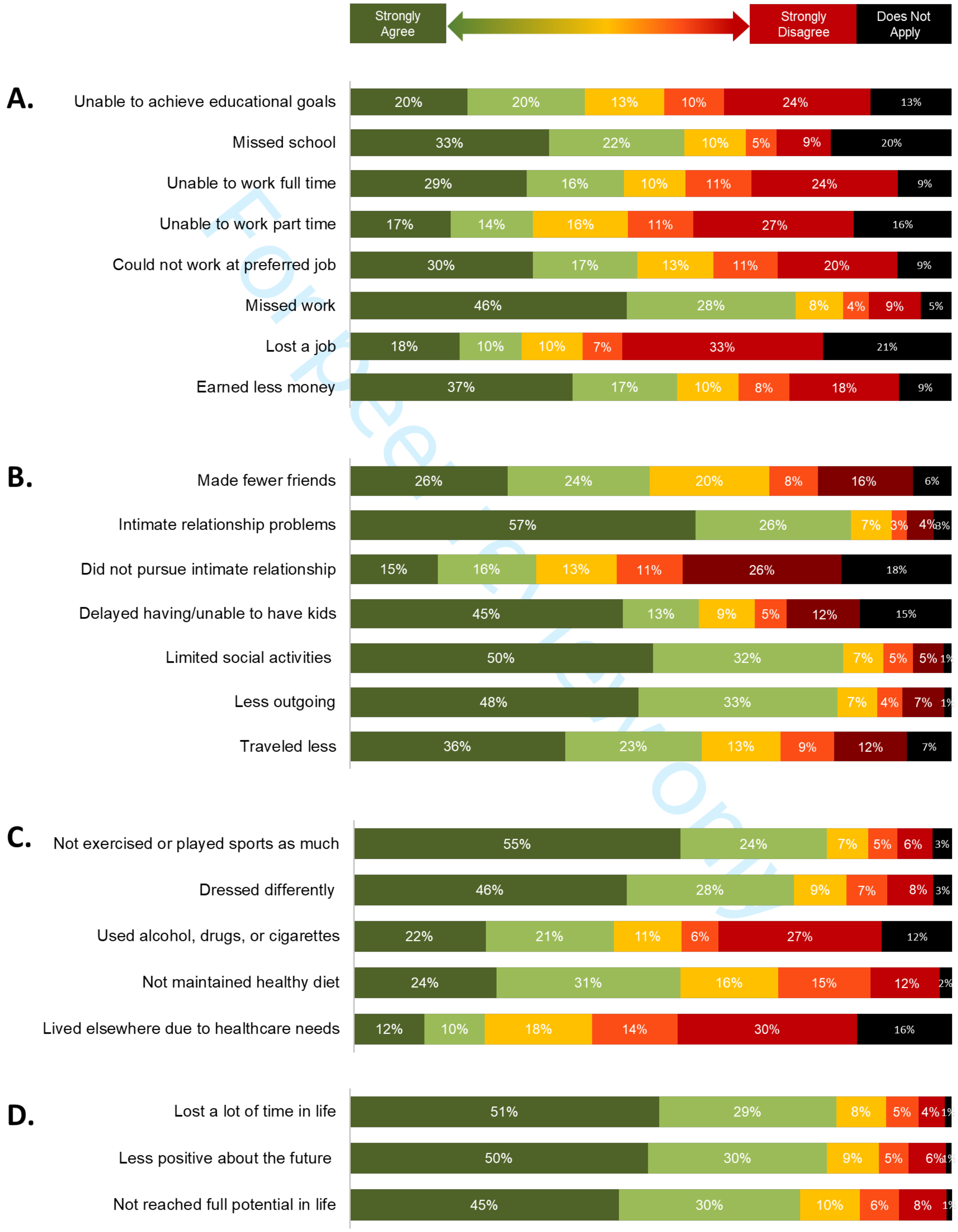
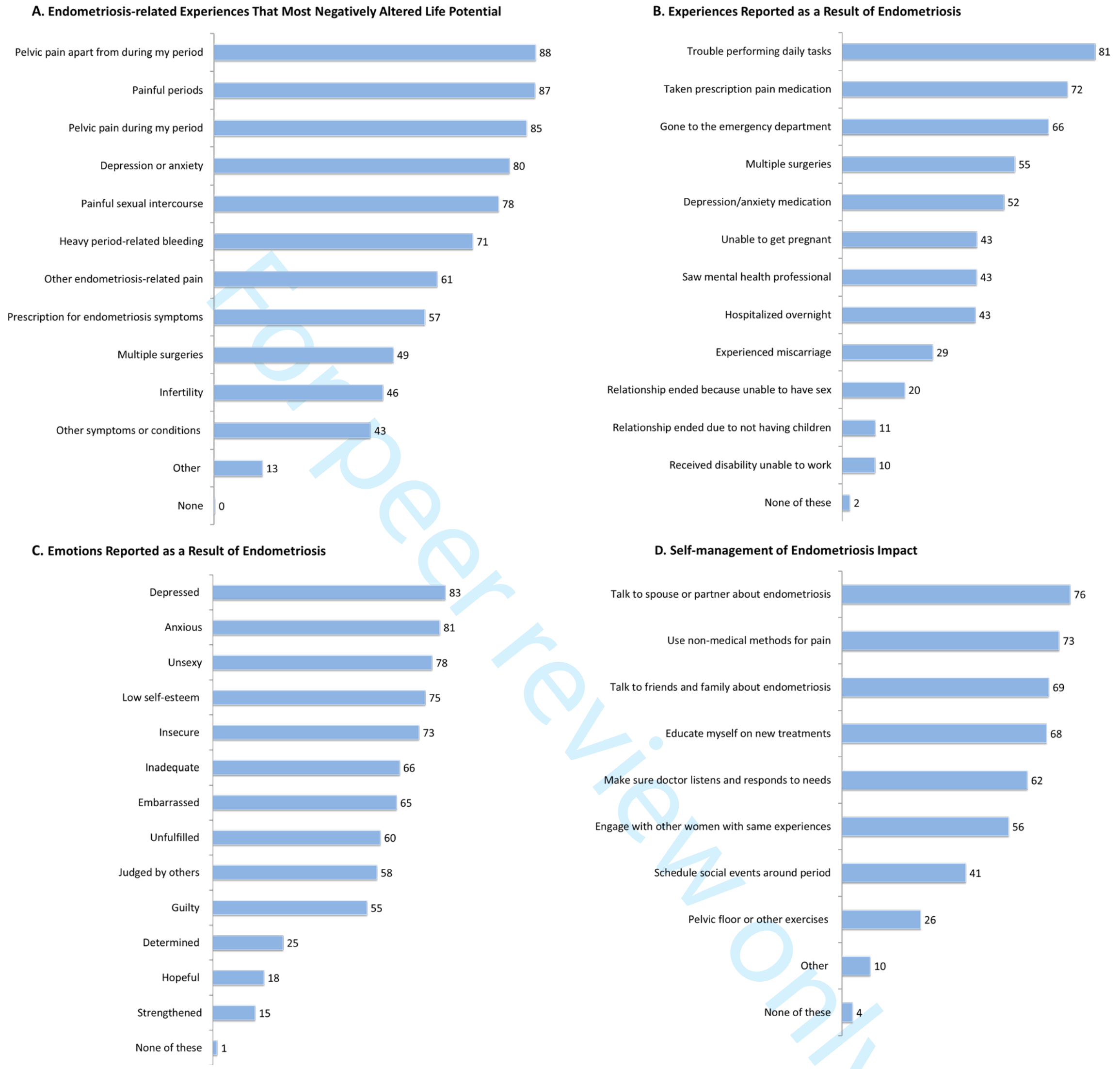

Strongly Agree
Strongly Disagree
Does Not Apply
A.
Unable to achieve educational goals 20% 20% 13% 10% 24% 13%
Missed school 33% 22% 10% 5% 9% 20%
Unable to work full time 29% 16% 10% 11% 24% 9%
Unable to work part time 17% 14% 16% 11% 27% 16%
Could not work at preferred job 30% 17% 13% 11% 20% 9%
Missed work 46% 28% 8% 4% 9% 5%
Lost a job 18% 10% 10% 7% 33% 21%
Earned less money 37% 17% 10% 8% 18% 9%
B.
Made fewer friends 26% 24% 20% 8% 16% 6%
Intimate relationship problems 57% 26% 7% 3% 4% 3%
Did not pursue intimate relationship 15% 16% 13% 11% 26% 18%
Delayed having/unable to have kids 45% 13% 9% 5% 12% 15%
Limited social activities 50% 32% 7% 5% 5% 1%
Less outgoing 48% 33% 7% 4% 7% 1%
Traveled less 36% 23% 13% 9% 12% 7%
C.
Not exercised or played sports as much 55% 24% 7% 5% 6% 3%
Dressed differently 46% 28% 9% 7% 8% 3%
Used alcohol, drugs, or cigarettes 22% 21% 11% 6% 27% 12%
Not maintained healthy diet 24% 31% 16% 15% 12% 2%
Lived elsewhere due to healthcare needs 12% 10% 18% 14% 30% 16%
D.
Lost a lot of time in life 51% 29% 8% 5% 4% 1%
Less positive about the future 50% 30% 9% 5% 6% 1%
Not reached full potential in life 45% 30% 10% 6% 8% 1%

FIGURE 2


A. Endometriosis-related Experiences That Most Negatively Altered Life Potential
Pelvic pain apart from during my period 88
Painful periods 87
Pelvic pain during my period 85
Depression or anxiety 80
Painful sexual intercourse 78
Heavy period-related bleeding 71
Other endometriosis-related pain 61
Prescription for endometriosis symptoms 57
Multiple surgeries 49
Infertility 46
Other symptoms or conditions 43
Other 13
None 0
B. Experiences Reported as a Result of Endometriosis
Trouble performing daily tasks 81
Taken prescription pain medication 72
Gone to the emergency department 66
Multiple surgeries 55
Depression/anxiety medication 52
Unable to get pregnant 43
Saw mental health professional 43
Hospitalized overnight 43
Experienced miscarriage 29
Relationship ended because unable to have sex 20
Relationship ended due to not having children 11
Received disability unable to work 10
None of these 2
C. Emotions Reported as a Result of Endometriosis
Depressed 83
Anxious 81
Unsexy 78
Low self-esteem 75
Insecure 73
Inadequate 66
Embarrassed 65
Unfulfilled 60
Judged by others 58
Guilty 55
Determined 25
Hopeful 18
Strengthened 15
None of these 1
D. Self-management of Endometriosis Impact
Talk to spouse or partner about endometriosis 76
Use non-medical methods for pain 73
Talk to friends and family about endometriosis 69
Educate myself on new treatments 68
Make sure doctor listens and responds to needs 62
Engage with other women with same experiences 56
Schedule social events around period 41
Pelvic floor or other exercises 26
Other 10
None of these 4

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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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 (182)	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)

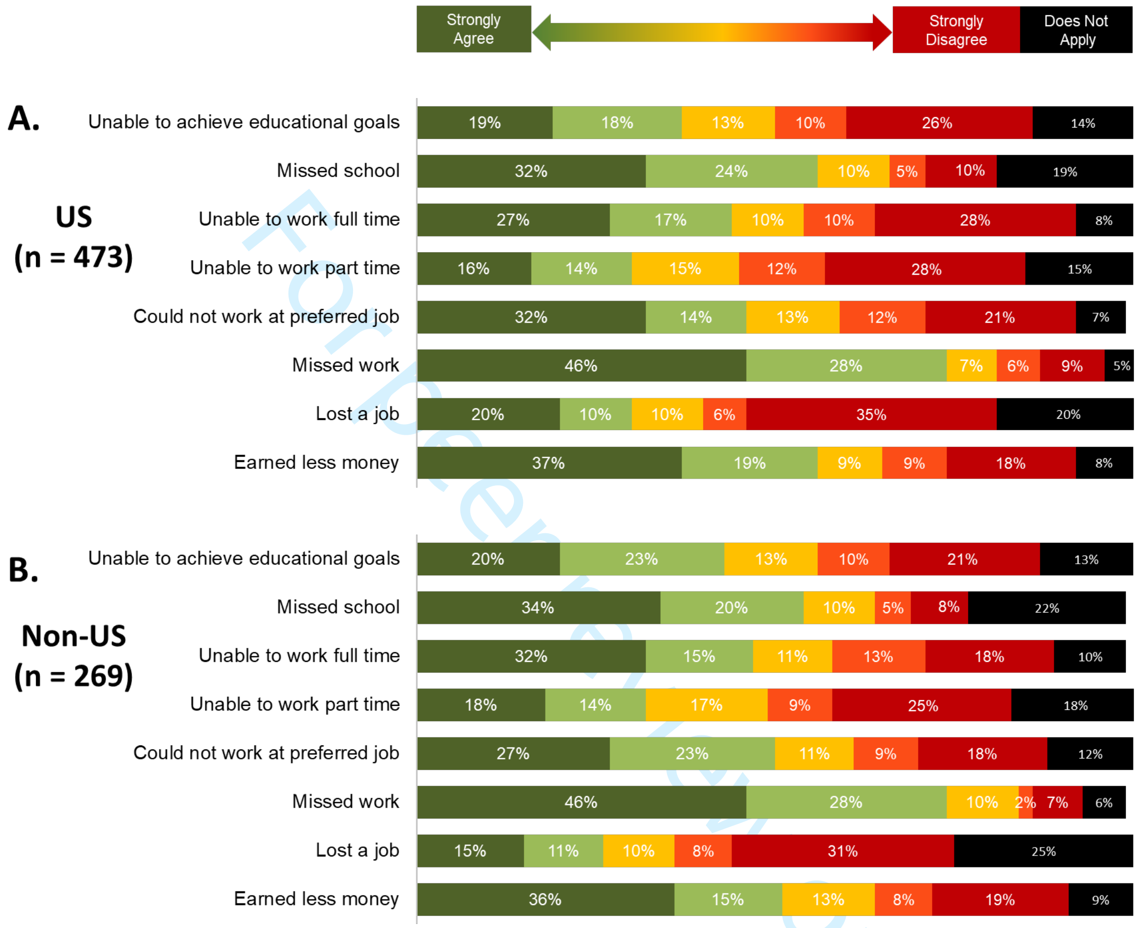
S1C	Pelvic pain apart from period	Painful periods	Pelvic pain during period	Depression or anxiety	Painful sexual intercourse	Heavy period-related bleeding	Other endometriosis-related pain	Taken prescription for symptoms	Multiple surgeries	Infertility	Other symptoms or conditions
Total, n (%) (N = 743)	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

S2. What is your age?

Under 19 **(Terminate)**

19-29

30-39

40-49

50-59

60 or older

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

Stage 1 endometriosis

Stage 2 endometriosis

Stage 3 endometriosis

Stage 4 endometriosis

Not sure what stage of endometriosis I have

I do not have endometriosis (**Terminate**)

S4. In which country do you currently live?

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

Australia

Canada

Ireland

Netherlands

New Zealand

South Africa

United Kingdom

Other

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	Somewhat Disagr	Neutral	Somewhat Agree	Strongly agree	Not Applicable
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)

Painful sexual intercourse

Pelvic pain during my period

Pelvic pain apart from during my period

Painful periods

Heavy period-related bleeding

Other endometriosis related pain

Infertility

Depression or anxiety

Multiple surgeries

Prescription treatment to control endometriosis symptoms

Other symptoms or conditions (please specify)

Other (please specify)

None

10. Which, if any, of these, have you experienced as a result of your endometriosis? Check all that apply. (Rotate order)

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

Taken prescription medication to treat depression or anxiety

Had multiple surgical procedures

Been hospitalized overnight

Gone to the emergency room

Received disability income due to being unable to work

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

Had trouble performing daily tasks

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

Was unable to get pregnant

Had a relationship end because I was unable to have children

Had a relationship end because I was unable to have sex

None of these

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

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

    Schedule social events around my period

    Engage with other women going through the same experiences

    Talk to my friends and family about endometriosis

    Talk to my spouse or partner about my endometriosis

    Pelvic floor or other exercises to lessen pain during sex

    Make sure my doctor listens and responds to my needs

    Educate myself on new treatments

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

    Other (please describe)

    None of these

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

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

Just a few last questions.

D1. Which of the following best describes the area where you live?

Urban

Suburban

Rural

Not sure / prefer not to say

D2. What is the highest level of education you have achieved?

Less than high school

Some high school

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

Some college, but no degree

Associate degree

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

Some graduate school, but no degree

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

Prefer not to answer

D3. What is your current employment status?

Working full time

Working part time

Unemployed, not looking for work

Unemployed, looking for work

Retired

Unable to work

Prefer not to answer

D4. Which of the following best describes your marital status?

Single/never married

Married

Widowed

Divorced or separated

Prefer not to answer

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

D5. Are you currently in an intimate relationship?

Yes

No

Prefer not to answer

D6. How many children, if any, do you have?

None

1

2

3

4

5 or more

Prefer not to answer

Thank you for answering these questions.

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 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, lines1-7; page 22, lines 14-17; page 23, lines 1-2
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.

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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Keywords:	GYNAECOLOGY, Community gynaecology < GYNAECOLOGY, QUALITATIVE RESEARCH

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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Word Count: 4506 words

Key Words: Qualitative Research; Gynaecology; Community Gynaecology

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ABSTRACT

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

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

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

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

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.

Conclusions: 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 that endometriosis has on a woman's life course and the importance of meaningful dialogue with patients may be important for improving long-term management of the disease and help identify women who are most vulnerable.

Abstract Word Count: 291 (300 word maximum)

Strengths and limitations of this study

- Strength: Quantitative survey with a meaningful sample size and sample population that spanned multiple countries
- Strength: Targeted research questions developed based on existing conversations on a social network platform
- Strength: Use of social network familiar to patients, facilitating honesty in responses to sensitive topics
- Limitation: Possible self-selection bias due to voluntary participation in an online community and no targeted sampling; quantitative data may not be generalizable to all women with endometriosis
- Limitation: Self-reported patient responses that were not confirmed by medical records or other complementary data

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] These issues have been further exacerbated by the COVID-19 pandemic, which has led to reduced access to medical care, delayed treatments, increased stress, loss of work productivity, and mandated self-isolation.[13,14]

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 and emergency departments, 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 losses of thousands of dollars per patient.[12,15-18]

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.[19,20] In contrast, few studies have examined the impact of endometriosis on a woman's life course (ie, "life-course impairment") based on how symptoms and experiences resulting from the disease influence major life events and decisions (such as whether to pursue educational opportunities, choose a career path, establish intimate relationships, and plan for a family) and the overall ability of patients to attain their life goals.[19,20] The few existing studies have small sample sizes or are qualitative, relying on informational interviews to ascertain the life-course impact of the disease, but highlight the substantial impacts that endometriosis can have on social activities, intimate relationships, education, work productivity, and psychological well-being .[11,21-23] Understanding life-course impairment, as opposed to focusing on the symptoms of the disease (such as pain or infertility, which 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 decisions (eg, work, education, or personal relationships) in ways that are interrelated and can impact other areas of a patient's life. For example, chronic pain may influence the type and amount of work performed or whether a patient decides to work at all, which, in turn, can have financial implications on the patient's lifestyle, family, relationships, or sense of personal fulfillment.[19,20] Symptoms may determine where a patient chooses to live because of financial considerations, healthcare access, or proximity to support networks. Similarly, dyspareunia related to endometriosis may lead some women to avoid intimate relationships, which may have downstream implications for marriage, family planning, and mental and emotional health.[24,25] Cumulatively, persistent symptoms of endometriosis and their impact on daily activities and family and intimate relationships can negatively impact the trajectory of women's lives and are profound and far-reaching.

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

METHODS

Ethics approval

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

Survey development

An online survey was created in a collaborative effort between AbbVie (North Chicago, IL, USA) and MyHealthTeams (San Francisco, CA, USA), a company that creates social networks for communities of individuals living with chronic conditions to foster discussion and provide support among people facing similar circumstances. The survey was programmed and administered through Qualtrics, an online survey tool that allows users to capture survey responses in an anonymized manner. The survey was provided in English and was available online on the social media network website MyEndometriosisTeam.com from October 3 through October 25, 2018. The 14 survey questions about women's experiences with endometriosis were based on our knowledge about the disease state, existing publications, and online conversations participants were having (**see Patient and public involvement** for further detail). In addition, the survey contained 4 screening questions and 6 demographic questions (identified as Supporting Information). The primary goal of the survey was to capture patients' perspectives on the negative impacts of endometriosis on different aspects of their life courses, including how endometriosis has affected their work, education, relationships, overall life decisions, and attainment of goals. This portion of the survey was modeled after a validated instrument created to measure life-course impact of disease in patients with psoriasis.[25] This tool was used as a starting point for model development as it has been validated for another chronic disease with excess psychological and psychosocial burden, has been used clinically, and was published in the scientific literature. Survey questions were rotated to avoid any bias introduced by order of answer selections. Most survey questions were closed-ended and provided multiple-choice options to participants; two questions were open-ended and allowed participants to provide written responses detailing any life accomplishments they believed were impeded by endometriosis or to offer anything else they wanted to share about the impact of endometriosis on their lives. Responses were required for all closed-ended questions; therefore, no imputations for missing data were required. The survey used in this study is included in the supplementary material.

Patient and public involvement

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

Participant eligibility and recruitment

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

Survey analysis

Descriptive statistics were used to tabulate survey responses in this cross-sectional study. After descriptive statistics were quantified for all respondents, a subanalysis was performed that restricted the survey responder population to women who “somewhat agreed” or “strongly agreed” that they were “less positive about the future” (LPAF) or that they “had not reached their full potential” (NRFP) because of endometriosis. These two questions were selected for this 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 (%)**

who reported low optimism or low goal attainment. For this analysis, life-course impairment was defined as respondents who “somewhat agreed” or “strongly agreed” that endometriosis had negatively impacted their education, employment, relationships, social activities, and physical and emotional well-being.

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).

	(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)

[a] Patients 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.

Diagnosis and symptoms

Diagnosis

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

Endometriosis-associated pain

Most women (56%, n=415) reported experiencing pain daily and nearly an additional one-quarter of them 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 said they “somewhat agreed” or “strongly agreed” that they had experienced difficulties achieving their educational goals (40%, n=290) or had missed school (55%, n=413) because of endometriosis-associated symptoms (figure 1A). Almost half of participants (45%, n=338) “somewhat agreed” or “strongly agreed” that they could not work full time, and a similar percentage (47%, n=355) reported not working at a job they would have preferred. Most reported that they had missed work (74%, n=550) or earned less money than they could have (54%, n=404) because of endometriosis-associated symptoms. These findings were consistent among patients in the United States compared with the rest of the world (supporting information figure 1).

Relationships and social engagements

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

Physical well-being

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

Life-course impairment overall

Overall, most women (80%, n=601) “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%, n=589), and 75% (n=556) “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 (81%, n=594); 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 (72%, n=529), visiting emergency departments (66%, n=485), having multiple surgeries (55%, n=406), being hospitalized overnight (43%, n=313), taking prescription medication for depression or anxiety (52%, n=380), or seeing a mental health professional because of their endometriosis-associated symptoms (43%, n=316). Around half of the women surveyed reported that the experiences that most negatively impacted their lives were their need to take prescription medication (57%, n=427) and the multiple surgeries for endometriosis (49%, n=363). In addition, most women surveyed reported several negative emotions that they attributed to endometriosis, including feeling depressed (83%, n=607), anxious (81%, n=592), unsexy (78%, n=572), or having low self-esteem (75%, n=554; figure 2C).

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

Additional analysis of women who believed their future and life potential were more impacted by endometriosis

Most of the sample included women who “somewhat agreed” or “strongly agreed” that they were LPAF (80%; n=589) or had NRFP in life (75%; n=556) because of endometriosis, and several questions limited to these women were further analyzed (Supporting Information table 1). Overall, the observational data in this study suggested women who believed they were LPAF or had NRFP generally reported more negative experiences than the fewer respondents who did not indicate they were LPAF (non-LPAF, 21%; n=154) or had NRFP (non-NRFP, 25%; n=187). Daily pain was reported by 62% of women who believed they were LPAF and 61% of women who had NRFP because of endometriosis (34% non-LPAF and 40% non-NRFP; Supporting Information table 1A). Women who believed they were LPAF or had NRFP also reported negative experiences related to education and work they attributed to endometriosis, including having earned less money (61% LPAF, 29% non-LPAF, 66% NRFP, and 21% non-NRFP), not working a preferred job (54% LPAF, 25% non-LPAF, 58% NRFP, 17% non-NRFP), or not achieving educational goals (44% LPAF, 21% non-LPAF, 47% NRFP, 16% non-NRFP)

(Supporting Information table 1B). Most women who believed their future and life potential were more impacted by their disease reported endometriosis-related experiences altered their life potential in a negative way (Supporting Information table 1C). Similarly, many of these women reported negative experiences and emotions they attributed to endometriosis (Supporting Information table 1D, E). All women used similar strategies to cope with and mitigate the impact of endometriosis on their lives (Supporting Information table 1F).

DISCUSSION

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

Study implications

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

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

Many respondents said they missed school and were generally unable to achieve their educational goals because of endometriosis. There is a dearth of research on the impact of endometriosis on women's educational aspirations and their ability to achieve goals due to endometriosis-associated symptoms, compared with the impact endometriosis has on professional work or other areas of life.[9] Findings from some existing studies suggest endometriosis-associated symptoms may impact grades, attendance, or completion of educational programs.[21,22,40] Although informative, these studies were more qualitative in nature and involved small sample sizes.[21,22,40] A quantitative study examining the lives of 78 women 15 years after receiving a verified diagnosis of endometriosis found only a fraction of women reported that their disease had a negative impact on their education.[11] However, the women included in that study seemed to report less frequent pain and endometriosis-related effects, like depression, compared with the reports made by women in our study. Furthermore, the small sample was collected at a single Norwegian hospital and the findings may not be representative of women's experiences with endometriosis on a wider scale.[11] Regardless, any impact on education is concerning, and our study results emphasize the need for additional research into this overlooked area in women with endometriosis. Research on other medical conditions, like adolescent fibromyalgia, supports that chronic pain can negatively impact education, reinforcing the likelihood that endometriosis may have a similar impact.[41,42]

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

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

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

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

Although few studies have examined this aspect of endometriosis, findings from two smaller studies have suggested that pain associated with the disease may also have a negative impact on exercise and nutrition.[9,30,52]

Of particular concern was the view of many women that their disease made them increase their use of alcohol, drugs, or cigarettes. Research into whether pain and experiences related to endometriosis may be associated with higher rates of substance abuse is severely lacking. However, there are demonstrated associations between other chronic pain conditions and substance abuse that support our finding.[53,54] The results from our study draw attention to this issue and highlight substance abuse as an important avenue for additional investigation.

The findings from our study indicate that women with endometriosis may experience many healthcare-related side effects. Of particular concern, patients noted that treatments meant to help reduce the burden of endometriosis may have their own negative impact. Many women perceived that use of prescription medications and multiple surgeries to control the symptoms of endometriosis had a negative impact on their life potential, and this response was also observed in women who indicated they were LPAF or believed they had NRFP due to their disease. Results from one recent study showed that medical treatment for a condition may increase a patient's stress levels and potentially affect their psychological health.[55] Patients who were taking prescription medications and who experienced more challenging adverse effects from their therapies had higher perceived stress levels, and women undergoing multiple surgeries were especially impacted. These reports underscore the potential value of supportive psychological care for patients with endometriosis as part of effective long-term disease management.

In general, women experienced a range of consequences that they attributed to living with and managing the limitations imposed by endometriosis. In addition to pain, women reported that the endometriosis-related experiences that most impacted their lives in a negative way included depression or anxiety (80%), heavy menstrual bleeding (71%), the need to take prescription treatments (57%) or undergo multiple surgeries (49%), or infertility (46%). In other studies, women have reported not feeling “normal” or feminine, experiencing a range of negative emotions (eg, anger, depression, hopelessness, disappointment, and exhaustion), having limited physical or sexual activity, struggling to find appropriate treatments, feeling guilt over disrupted relationships, and suffering in silence due to endometriosis-related symptoms.[22,23]While each woman experienced the impact of endometriosis differently, the majority believed that they were living life less fully than they could have because of their endometriosis-associated symptoms. This belief was informed by the symptoms and healthcare requirements they faced, and, in turn, may have influenced major life decisions that could have their own deleterious effects on personal fulfillment and life potential. The interconnectedness of effects triggered by major life decisions highlights the importance of conducting further research into the cumulative burden of debilitating diseases like endometriosis within the context of an individual’s life course.

Strengths and limitations

Limitations of this study include the selection of participants from an online community with voluntary participation, no targeted sampling, and no way to calculate a response rate. The participants were generally well educated, had access to health care, and participated in an online social network. Data on race, ethnicity, or socioeconomic status were not collected. Patients who experienced the most significant psychosocial impacts of endometriosis or lacked the resources to access the online community may not have been represented in the sample population, whereas the patients who were most affected by severe pelvic pain may have been more likely to participate in the study. These factors may have led to self-selection bias; therefore, the results of this study may not be generalizable to the overall population of patients with endometriosis. Any between-group comparisons are observational in nature and no definitive conclusions can be made in the absence of formal statistical analysis.

Future implications

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

Conclusion

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

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Data Sharing Statement

AbbVie is committed to responsible data sharing regarding the clinical trials and studies we sponsor. This includes access to anonymized, individual and trial-level data (analysis data sets), as well as other information (eg, protocols and clinical study reports), as long as the trials are not part of an ongoing or planned regulatory submission. This includes requests for clinical trial data for unlicensed products and indications.

This study data can be requested by any qualified researchers who engage in rigorous, independent scientific research, and will be provided following review and approval of a research proposal and statistical analysis plan and execution of a data sharing agreement. Data requests can be submitted at any time and the data will be accessible for 12 months, with possible extensions considered. For more information on the process, or to submit a request, visit the following link: https://www.abbvie.com/our-science/clinical-trials/clinical-trials-data-and-information-sharing/data-and-information-sharing-with-qualified-researchers.html.

REFERENCES

1. Zondervan KT, Becker CM, Missmer SA. Endometriosis. *N Engl J Med* 2020;382:1244-56.

2. Kennedy S, Bergqvist A, Chapron C*, et al.* Eshre guideline for the diagnosis and treatment of endometriosis. *Hum Reprod* 2005;20:2698-704.

3. Practice bulletin no. 114: Management of endometriosis. *Obstet Gynecol* 2010;116:223-36.

4. Zondervan KT, Becker CM, Koga K*, et al.* Endometriosis. *Nat Rev Dis Primers* 2018;4:9.

5. De Graaff AA, D'Hooghe TM, Dunselman GA*, et al.* The significant effect of endometriosis on physical, mental and social wellbeing: Results from an international cross-sectional survey. *Hum Reprod* 2013;28:2677-85.

6. Gallagher JS, DiVasta AD, Vitonis AF*, et al.* The impact of endometriosis on quality of life in adolescents. *J Adolesc Health* 2018;63:766-72.

7. Lagana AS, La Rosa VL, Rapisarda AMC*, et al.* Anxiety and depression in patients with endometriosis: Impact and management challenges. *Int J Womens Health* 2017;9:323-30.

8. Vannuccini S, Lazzeri L, Orlandini C*, et al.* Mental health, pain symptoms and systemic comorbidities in women with endometriosis: A cross-sectional study. *J Psychosom Obstet Gynaecol* 2018;39:315-20.

9. Culley L, Law C, Hudson N*, et al.* A qualitative study of the impact of endometriosis on male partners. *Hum Reprod* 2017;32:1667-73.

10. Denny E, Mann CH. Endometriosis-associated dyspareunia: The impact on women's lives. *J Fam Plann Reprod Health Care* 2007;33:189-93.

11. Fagervold B, Jenssen M, Hummelshoj L, *et al.* Life after a diagnosis with endometriosis - a 15 years follow-up study. *Acta Obstet Gynecol Scand* 2009;88:914-9.

12. Soliman AM, Coyne KS, Gries KS, *et al.* The effect of endometriosis symptoms on absenteeism and presenteeism in the workplace and at home. *J Manag Care Spec Pharm* 2017;23:745-54.

13. Leonardi M, Horne AW, Armour M, *et al.* Endometriosis and the coronavirus (covid-19) pandemic: Clinical advice and future considerations. *Frontiers in Reproductive Health* 2020;2

14. Leonardi M, Horne AW, Vincent K, *et al.* Self-management strategies to consider to combat endometriosis symptoms during the covid-19 pandemic. *Hum Reprod Open* 2020;2020:hoaa028.

15. Klein S, D'Hooghe T, Meuleman C, *et al.* What is the societal burden of endometriosis-associated symptoms? A prospective belgian study. *Reprod Biomed Online* 2014;28:116-24.

16. Simoens S, Dunselman G, Dirksen C, *et al.* The burden of endometriosis: Costs and quality of life of women with endometriosis and treated in referral centres. *Hum Reprod* 2012;27:1292-9.

17. Soliman AM, Taylor HS, Bonafede M, *et al.* Incremental direct and indirect cost burden attributed to endometriosis surgeries in the united states. *Fertil Steril* 2017;107:1181-90 e2.

18. Soliman AM, Yang H, Du EX, *et al.* The direct and indirect costs associated with endometriosis: A systematic literature review. *Hum Reprod* 2016;31:712-22.

19. Bhatti Z, Salek M, Finlay A. Chronic diseases influence major life changing decisions: A new domain in quality of life research. *J R Soc Med* 2011;104:241-50.

20. Kimball AB, Gieler U, Linder D*, et al.* Psoriasis: Is the impairment to a patient's life cumulative? *J Eur Acad Dermatol Venereol* 2010;24:989-1004.

21. Huntington A, Gilmour JA. A life shaped by pain: Women and endometriosis. *J Clin Nurs* 2005;14:1124-32.

22. Moradi M, Parker M, Sneddon A*, et al.* Impact of endometriosis on women's lives: A qualitative study. *BMC Womens Health* 2014;14:123.

23. Cole JM, Grogan S, Turley E. "The most lonely condition i can imagine": Psychosocial impacts of endometriosis on women's identity. *Feminism & Psychology* 2021;31:171-91.

24. Apers S, Dancet EAF, Aarts JWM*, et al.* The association between experiences with patient-centred care and health-related quality of life in women with endometriosis. *Reprod Biomed Online* 2018;36:197-205.

25. Witzeman K, Antunez Flores O, Renzelli-Cain RI*, et al.* Patient-physician interactions regarding dyspareunia with endometriosis: Online survey results. *J Pain Res* 2020;13:1579-89.

26. Bourdel N, Alves J, Pickering G*, et al.* Systematic review of endometriosis pain assessment: How to choose a scale? *Hum Reprod Update* 2015;21:136-52.

27. Chawla S. Treatment of endometriosis and chronic pelvic pain with letrozole and norethindrone acetate. *Med J Armed Forces India* 2010;66:213-5.

28. Facchin F, Barbara G, Saita E*, et al.* Impact of endometriosis on quality of life and mental health: Pelvic pain makes the difference. *J Psychosom Obstet Gynaecol* 2015;36:135-41.

29. Ballard K, Lowton K, Wright J. What's the delay? A qualitative study of women's experiences of reaching a diagnosis of endometriosis. *Fertil Steril* 2006;86:1296-301.

30. Bernuit D, Ebert AD, Halis G*, et al.* Female perspectives on endometriosis: Findings from the uterine bleeding and pain women's research study. *Journal of Endometriosis* 2011;3:73-85.

31. Greene R, Stratton P, Cleary SD*, et al.* Diagnostic experience among 4,334 women reporting surgically diagnosed endometriosis. *Fertil Steril* 2009;91:32-9.

32. Hadfield R, Mardon H, Barlow D*, et al.* Delay in the diagnosis of endometriosis: A survey of women from the USA and the uk. *Hum Reprod* 1996;11:878-80.

33. Hudelist G, Fritzer N, Thomas A*, et al.* Diagnostic delay for endometriosis in austria and germany: Causes and possible consequences. *Hum Reprod* 2012;27:3412-6.

34. Nnoaham KE, Hummelshoj L, Webster P*, et al.* Impact of endometriosis on quality of life and work productivity: A multicenter study across ten countries. *Fertil Steril* 2011;96:366-73 e8.

35. Soliman AM, Fuldeore M, Snabes MC. Factors associated with time to endometriosis diagnosis in the united states. *J Womens Health (Larchmt)* 2017;26:788-97.

36. Staal AH, van der Zanden M, Nap AW. Diagnostic delay of endometriosis in the netherlands. *Gynecol Obstet Invest* 2016;81:321-4.

37. Nnoaham KE, Hummelshoj L, Kennedy SH*, et al.* Developing symptom-based predictive models of endometriosis as a clinical screening tool: Results from a multicenter study. *Fertil Steril* 2012;98:692-701 e5.

38. Brosens I, Puttemans P, Campo R*, et al.* Non-invasive methods of diagnosis of endometriosis. *Curr Opin Obstet Gynecol* 2003;15:519-22.

39. Lamvu G, Antunez-Flores O, Orady M*, et al.* Path to diagnosis and women's perspectives on the impact of endometriosis pain. *Journal of Endometriosis and Pelvic Pain Disorders* 2020:2284026520903214.

40. Gilmour JA, Huntington A, Wilson HV. The impact of endometriosis on work and social participation. *Int J Nurs Pract* 2008;14:443-8.

41. Murray CB, Groenewald CB, de la Vega R*, et al.* Long-term impact of adolescent chronic pain on young adult educational, vocational, and social outcomes. *Pain* 2020;161:439-45.

42. Kashikar-Zuck S, Lynch AM, Graham TB*, et al.* Social functioning and peer relationships of adolescents with juvenile fibromyalgia syndrome. *Arthritis Rheum* 2007;57:474-80.

43. de Graaf R, Tuithof M, van Dorsselaer S*, et al.* Comparing the effects on work performance of mental and physical disorders. *Soc Psychiatry Psychiatr Epidemiol* 2012;47:1873-83.

44. Smorgick N, Marsh CA, As-Sanie S*, et al.* Prevalence of pain syndromes, mood conditions, and asthma in adolescents and young women with endometriosis. *J Pediatr Adolesc Gynecol* 2013;26:171-5.

45. Yosef A, Allaire C, Williams C*, et al.* Multifactorial contributors to the severity of chronic pelvic pain in women. *Am J Obstet Gynecol* 2016;215:760 e1-60 e14.

46. Evans SF, Brooks TA, Esterman AJ*, et al.* The comorbidities of dysmenorrhea: A clinical survey comparing symptom profile in women with and without endometriosis. *J Pain Res* 2018;11:3181-94.

47. Fourquet J, Baez L, Figueroa M*, et al.* Quantification of the impact of endometriosis symptoms on health-related quality of life and work productivity. *Fertil Steril* 2011;96:107-12.

48. Sperschneider ML, Hengartner MP, Kohl-Schwartz A*, et al.* Does endometriosis affect professional life? A matched case-control study in switzerland, germany and austria. *BMJ open* 2019;9:e019570.

49. Prescott J, Farland LV, Tobias DK*, et al.* A prospective cohort study of endometriosis and subsequent risk of infertility. *Hum Reprod* 2016;31:1475-82.

50. Geisser ME, Cano A, Leonard MT. Factors associated with marital satisfaction and mood among spouses of persons with chronic back pain. *J Pain* 2005;6:518-25.

51. Leonard MT, Cano A. Pain affects spouses too: Personal experience with pain and catastrophizing as correlates of spouse distress. *Pain* 2006;126:139-46.

52. Fourquet J, Gao X, Zavala D*, et al.* Patients' report on how endometriosis affects health, work, and daily life. *Fertil Steril* 2010;93:2424-28.

53. Maleki N, Tahaney K, Thompson BL*, et al.* At the intersection of alcohol use disorder and chronic pain. *Neuropsychology* 2019;33:795-807.

54. Groenewald CB, Law EF, Fisher E*, et al.* Associations between adolescent chronic pain and prescription opioid misuse in adulthood. *J Pain* 2019;20:28-37.

55. Lazzeri L, Orlandini C, Vannuccini S*, et al.* Endometriosis and perceived stress: Impact of surgical and medical treatment. *Gynecol Obstet Invest* 2015;79:229-33.

56. Oehmke F, Weyand J, Hackethal A*, et al.* Impact of endometriosis on quality of life: A pilot study. *Gynecol Endocrinol* 2009;25:722-5.

57. Ugwumadu L, Chakrabarti R, Williams-Brown E*, et al.* The role of the multidisciplinary team in the management of deep infiltrating endometriosis. *Gynecol Surg* 2017;14:15.

58. Aarts JW, Huppelschoten AG, van Empel IW*, et al.* How patient-centred care relates to patients' quality of life and distress: A study in 427 women experiencing infertility. *Hum Reprod* 2012;27:488-95.

59. Gameiro S, Canavarro MC, Boivin J. Patient centred care in infertility health care: Direct and indirect associations with wellbeing during treatment. *Patient Educ Couns* 2013;93:646-54.

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, and (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 impacts 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

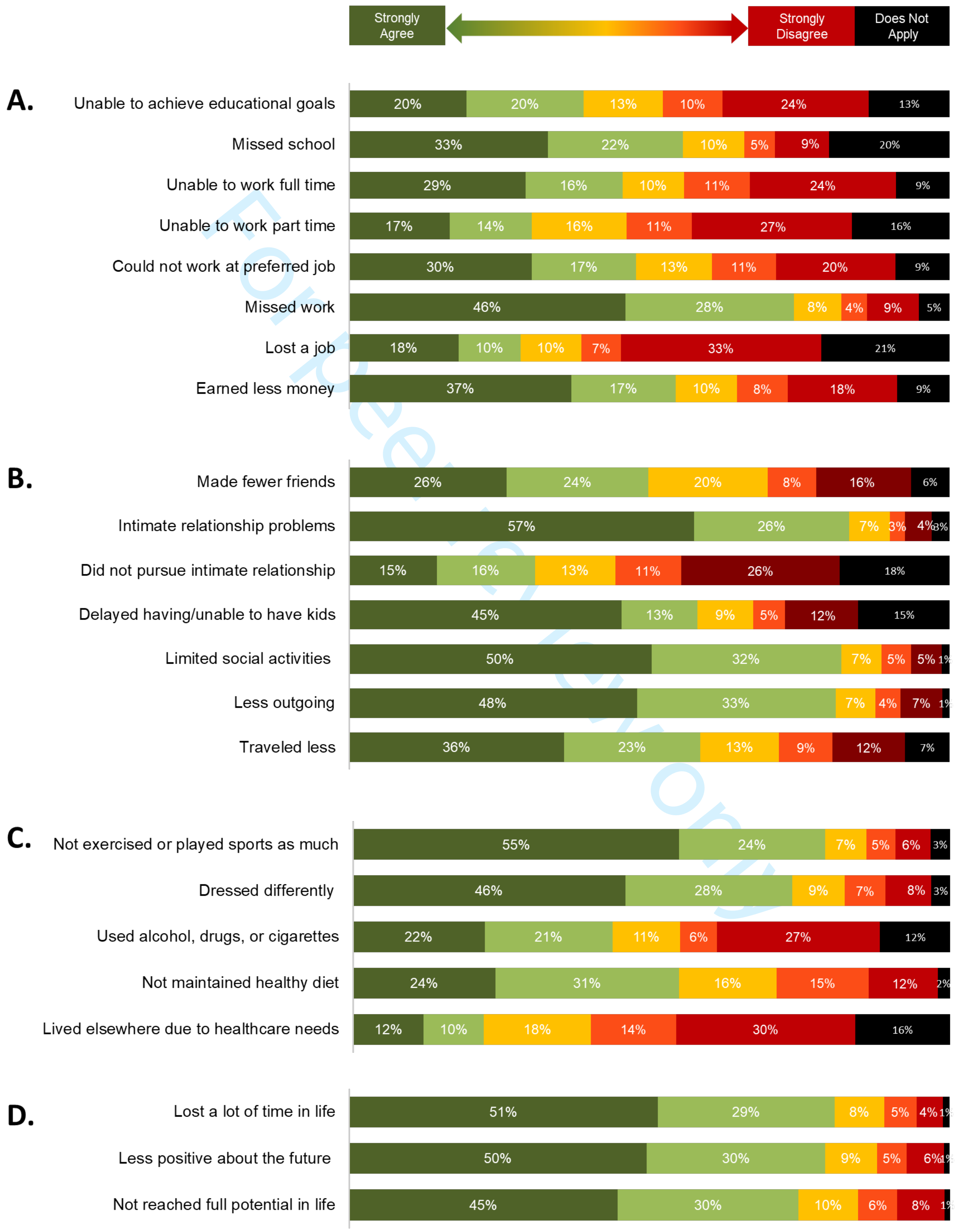
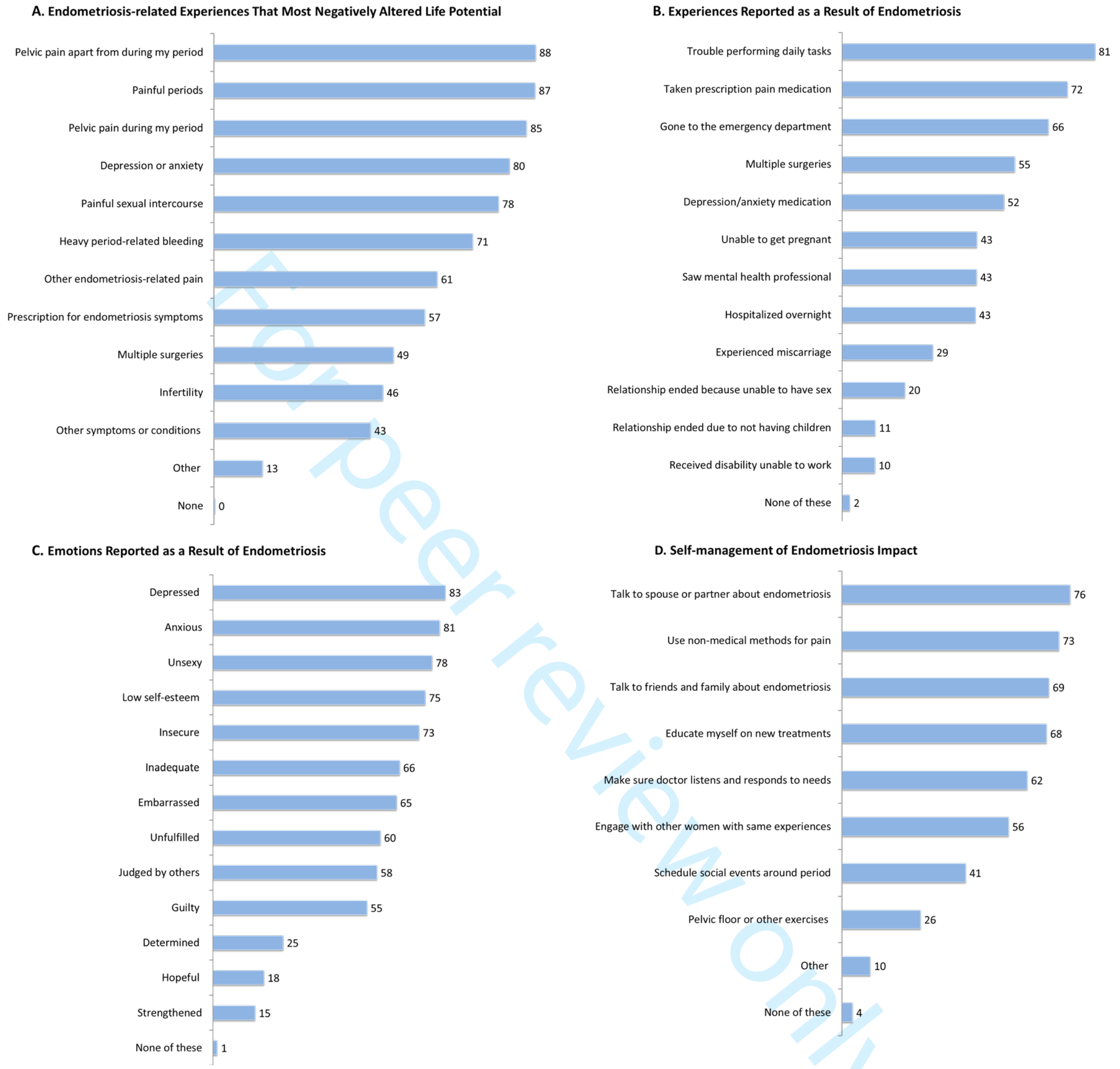

Strongly Agree
Strongly Disagree
Does Not Apply
A.
Unable to achieve educational goals 20% 20% 13% 10% 24% 13%
Missed school 33% 22% 10% 5% 9% 20%
Unable to work full time 29% 16% 10% 11% 24% 9%
Unable to work part time 17% 14% 16% 11% 27% 16%
Could not work at preferred job 30% 17% 13% 11% 20% 9%
Missed work 46% 28% 8% 4% 9% 5%
Lost a job 18% 10% 10% 7% 33% 21%
Earned less money 37% 17% 10% 8% 18% 9%
B.
Made fewer friends 26% 24% 20% 8% 16% 6%
Intimate relationship problems 57% 26% 7% 3% 4% 3%
Did not pursue intimate relationship 15% 16% 13% 11% 26% 18%
Delayed having/unable to have kids 45% 13% 9% 5% 12% 15%
Limited social activities 50% 32% 7% 5% 5% 1%
Less outgoing 48% 33% 7% 4% 7% 1%
Traveled less 36% 23% 13% 9% 12% 7%
C.
Not exercised or played sports as much 55% 24% 7% 5% 6% 3%
Dressed differently 46% 28% 9% 7% 8% 3%
Used alcohol, drugs, or cigarettes 22% 21% 11% 6% 27% 12%
Not maintained healthy diet 24% 31% 16% 15% 12% 2%
Lived elsewhere due to healthcare needs 12% 10% 18% 14% 30% 16%
D.
Lost a lot of time in life 51% 29% 8% 5% 4% 1%
Less positive about the future 50% 30% 9% 5% 6% 1%
Not reached full potential in life 45% 30% 10% 6% 8% 1%

FIGURE 2


A. Endometriosis-related Experiences That Most Negatively Altered Life Potential
Pelvic pain apart from during my period 88
Painful periods 87
Pelvic pain during my period 85
Depression or anxiety 80
Painful sexual intercourse 78
Heavy period-related bleeding 71
Other endometriosis-related pain 61
Prescription for endometriosis symptoms 57
Multiple surgeries 49
Infertility 46
Other symptoms or conditions 43
Other 13
None 0
B. Experiences Reported as a Result of Endometriosis
Trouble performing daily tasks 81
Taken prescription pain medication 72
Gone to the emergency department 66
Multiple surgeries 55
Depression/anxiety medication 52
Unable to get pregnant 43
Saw mental health professional 43
Hospitalized overnight 43
Experienced miscarriage 29
Relationship ended because unable to have sex 20
Relationship ended due to not having children 11
Received disability unable to work 10
None of these 2
C. Emotions Reported as a Result of Endometriosis
Depressed 83
Anxious 81
Unsexy 78
Low self-esteem 75
Insecure 73
Inadequate 66
Embarrassed 65
Unfulfilled 60
Judged by others 58
Guilty 55
Determined 25
Hopeful 18
Strengthened 15
None of these 1
D. Self-management of Endometriosis Impact
Talk to spouse or partner about endometriosis 76
Use non-medical methods for pain 73
Talk to friends and family about endometriosis 69
Educate myself on new treatments 68
Make sure doctor listens and responds to needs 62
Engage with other women with same experiences 56
Schedule social events around period 41
Pelvic floor or other exercises 26
Other 10
None of these 4

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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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 (182)	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)

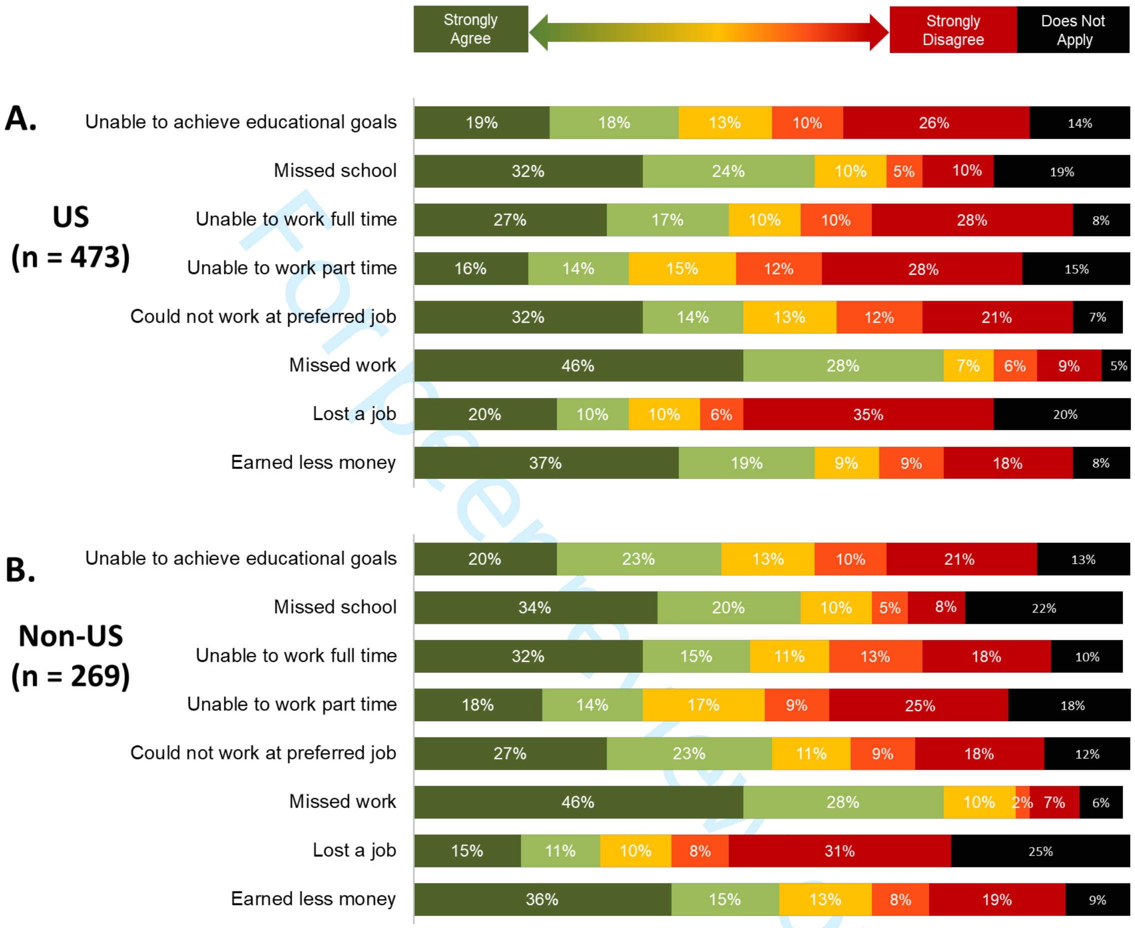
S1C	Pelvic pain apart from period	Painful periods	Pelvic pain during period	Depression or anxiety	Painful sexual intercourse	Heavy period-related bleeding	Other endometriosis-related pain	Taken prescription for symptoms	Multiple surgeries	Infertility	Other symptoms or conditions
Total, n (%) (N = 743)	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

S2. What is your age?

Under 19 **(Terminate)**

19-29

30-39

40-49

50-59

60 or older

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

Stage 1 endometriosis

Stage 2 endometriosis

Stage 3 endometriosis

Stage 4 endometriosis

Not sure what stage of endometriosis I have

I do not have endometriosis (**Terminate**)

S4. In which country do you currently live?

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

Australia

Canada

Ireland

Netherlands

New Zealand

South Africa

United Kingdom

Other

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	Somewhat Disagr	Neutral	Somewhat Agree	Strongly agree	Not Applicable
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)

Painful sexual intercourse

Pelvic pain during my period

Pelvic pain apart from during my period

Painful periods

Heavy period-related bleeding

Other endometriosis related pain

Infertility

Depression or anxiety

Multiple surgeries

Prescription treatment to control endometriosis symptoms

Other symptoms or conditions (please specify)

Other (please specify)

None

10. Which, if any, of these, have you experienced as a result of your endometriosis? Check all that apply. (Rotate order)

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

Taken prescription medication to treat depression or anxiety

Had multiple surgical procedures

Been hospitalized overnight

Gone to the emergency room

Received disability income due to being unable to work

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

Had trouble performing daily tasks

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

Was unable to get pregnant

Had a relationship end because I was unable to have children

Had a relationship end because I was unable to have sex

None of these

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

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

    Schedule social events around my period

    Engage with other women going through the same experiences

    Talk to my friends and family about endometriosis

    Talk to my spouse or partner about my endometriosis

    Pelvic floor or other exercises to lessen pain during sex

    Make sure my doctor listens and responds to my needs

    Educate myself on new treatments

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

    Other (please describe)

    None of these

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

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

Just a few last questions.

D1. Which of the following best describes the area where you live?

Urban

Suburban

Rural

Not sure / prefer not to say

D2. What is the highest level of education you have achieved?

Less than high school

Some high school

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

Some college, but no degree

Associate degree

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

Some graduate school, but no degree

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

Prefer not to answer

D3. What is your current employment status?

Working full time

Working part time

Unemployed, not looking for work

Unemployed, looking for work

Retired

Unable to work

Prefer not to answer

D4. Which of the following best describes your marital status?

Single/never married

Married

Widowed

Divorced or separated

Prefer not to answer

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

D5. Are you currently in an intimate relationship?

Yes

No

Prefer not to answer

D6. How many children, if any, do you have?

None

1

2

3

4

5 or more

Prefer not to answer

Thank you for answering these questions.

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

Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	Page 9, lines 19-20
		(*b*) Describe any methods used to examine subgroups and interactions	Page 9, lines 19-20; page 10, lines 1-8
		(*c*) Explain how missing data were addressed	Page 8, lines 22-23
		(*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 11-12
		(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 10, lines 13-21; 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 22-23)
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 1-5; supporting information pages 2-6

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

*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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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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ABSTRACT

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

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

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

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

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.

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

Abstract Word Count: 298 (300 word maximum)

Strengths and limitations of this study

- A strength of our study is use of a quantitative survey with a meaningful sample size and sample population that spanned multiple countries.
- This study is strengthened by targeted research questions developed based on existing conversations on a social network platform.
- Another strength of this study is the use of a social network familiar to patients, facilitating honesty in responses to sensitive topics.
- An important limitation of our study is possible self-selection bias due to voluntary participation in an online community and no targeted sampling; quantitative data may therefore not be generalizable to all women with endometriosis.
- The study is limited by self-reported patient responses that were not confirmed by medical records or other complementary data.

INTRODUCTION

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] These issues have been further exacerbated by the COVID-19 pandemic, which has led to reduced access to medical care, delayed treatments, increased stress, loss of work productivity, and mandated self-isolation.[13,14]

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 and emergency departments, 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 losses of thousands of dollars per patient.[12,15-18]

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.[19,20] In contrast, few studies have examined the impact of endometriosis on a woman's life course (ie, "life-course impairment") based on how symptoms and experiences resulting from the disease influence major life events and decisions (such as whether to pursue educational opportunities, choose a career path, establish intimate relationships, and plan for a family) and the overall ability of patients to attain their life goals.[19,20] The few existing studies have small sample sizes or are qualitative, relying on informational interviews to ascertain the life-course impact of the disease, but highlight the substantial impacts that endometriosis can have on social activities, intimate relationships, education, work productivity, and psychological well-being .[11,21-23] Understanding life-course impairment, as opposed to focusing on the symptoms of the disease (such as pain or infertility, which 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 decisions (eg, work, education, or personal relationships) in ways that are interrelated and can impact other areas of a patient's life. For example, chronic pain may influence the type and amount of work performed or whether a patient decides to work at all, which, in turn, can have financial implications on the patient's lifestyle, family, relationships, or sense of personal fulfillment.[19,20] Symptoms may determine where a patient chooses to live because of financial considerations, healthcare access, or proximity to support networks. Similarly, dyspareunia related to endometriosis may lead some women to avoid intimate relationships, which may have downstream implications for marriage, family planning, and mental and emotional health.[24,25] Cumulatively, persistent symptoms of endometriosis and their impact on daily activities and family and intimate relationships can negatively impact the trajectory of women's lives and are profound and far-reaching.

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

METHODS

Ethics approval

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

Survey development

An online survey was created in a collaborative effort between AbbVie (North Chicago, IL, USA) and MyHealthTeams (San Francisco, CA, USA), a company that creates social networks for communities of individuals living with chronic conditions to foster discussion and provide support among people facing similar circumstances. The survey was programmed and administered through Qualtrics, an online survey tool that allows users to capture survey responses in an anonymized manner. The survey was provided in English and was available online on the social media network website MyEndometriosisTeam.com from October 3 through October 25, 2018. The 14 survey questions about women's experiences with endometriosis were based on our knowledge about the disease state, existing publications, and online conversations participants were having (see 'Patient and public involvement' for further detail). In addition, the survey contained 4 screening questions and 6 demographic questions (identified as Supporting Information). The primary goal of the survey was to capture patients' perspectives on the negative impacts of endometriosis on different aspects of their life courses, including how endometriosis has affected their work, education, relationships, overall life decisions, and attainment of goals. This portion of the survey was modeled after a validated instrument created to measure life-course impact of disease in patients with psoriasis.[25] This tool was used as a starting point for model development as it has been validated for another chronic disease with excess psychological and psychosocial burden, has been used clinically, and was published in the scientific literature. Survey questions were rotated to avoid any bias introduced by order of answer selections. Most survey questions were closed-ended and provided multiple-choice options to participants; two questions were open-ended and allowed participants to provide written responses detailing any life accomplishments they believed were impeded by endometriosis or to offer anything else they wanted to share about the impact of endometriosis on their lives. Responses were required for all closed-ended questions; therefore, no imputations for missing data were required. The survey used in this study is included in the supplementary material.

Patient and public involvement

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

Participant eligibility and recruitment

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

Survey analysis

Descriptive statistics were used to tabulate survey responses in this cross-sectional study. After descriptive statistics were quantified for all respondents, a subanalysis was performed that restricted the survey responder population to women who “somewhat agreed” or “strongly agreed” that they were “less positive about the future” (LPAF) or that they “had not reached their full potential” (NRFP) because of endometriosis. These two questions were selected for this 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)**

who reported low optimism or low goal attainment. For this analysis, life-course impairment was defined as respondents who “somewhat agreed” or “strongly agreed” that endometriosis had negatively impacted their education, employment, relationships, social activities, and physical and emotional well-being.

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).

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)

[a] Patients 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.

Diagnosis and symptoms

Diagnosis

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

Endometriosis-associated pain

Most women (56%, n=415) reported experiencing pain daily and nearly an additional one-quarter of them 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 said they “somewhat agreed” or “strongly agreed” that they had experienced difficulties achieving their educational goals (40%, n=290) or had missed school (55%, n=413) because of endometriosis-associated symptoms (figure 1A). Almost half of participants (45%, n=338) “somewhat agreed” or “strongly agreed” that they could not work full time, and a similar percentage (47%, n=355) reported not working at a job they would have preferred. Most reported that they had missed work (74%, n=550) or earned less money than they could have (54%, n=404) because of endometriosis-associated symptoms. These findings were consistent among patients in the United States compared with the rest of the world (supporting information figure 1).

Relationships and social engagements

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

Physical well-being

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

Life-course impairment overall

Overall, most women (80%, n=601) “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%, n=589), and 75% (n=556) “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 (81%, n=594); 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 (72%, n=529), visiting emergency departments (66%, n=485), having multiple surgeries (55%, n=406), being hospitalized overnight (43%, n=313), taking prescription medication for depression or anxiety (52%, n=380), or seeing a mental health professional because of their endometriosis-associated symptoms (43%, n=316). Around half of the women surveyed reported that the experiences that most negatively impacted their lives were their need to take prescription medication (57%, n=427) and the multiple surgeries for endometriosis (49%, n=363). In addition, most women surveyed reported several negative emotions that they attributed to endometriosis, including feeling depressed (83%, n=607), anxious (81%, n=592), unsexy (78%, n=572), or having low self-esteem (75%, n=554; figure 2C).

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

Additional analysis of women who believed their future and life potential were more impacted by endometriosis

Most of the sample included women who “somewhat agreed” or “strongly agreed” that they were LPAF (80%; n=589) or had NRFP in life (75%; n=556) because of endometriosis, and several questions limited to these women were further analyzed (Supporting Information table 1). Overall, the observational data in this study suggested women who believed they were LPAF or had NRFP generally reported more negative experiences than the fewer respondents who did not indicate they were LPAF (non-LPAF, 21%; n=154) or had NRFP (non-NRFP, 25%; n=187). Daily pain was reported by 62% of women who believed they were LPAF and 61% of women who had NRFP because of endometriosis (34% non-LPAF and 40% non-NRFP; Supporting Information table 1A). Women who believed they were LPAF or had NRFP also reported negative experiences related to education and work they attributed to endometriosis, including having earned less money (61% LPAF, 29% non-LPAF, 66% NRFP, and 21% non-NRFP), not working a preferred job (54% LPAF, 25% non-LPAF, 58% NRFP, 17% non-NRFP), or not achieving educational goals (44% LPAF, 21% non-LPAF, 47% NRFP, 16% non-NRFP)

(Supporting Information table 1B). Most women who believed their future and life potential were more impacted by their disease reported endometriosis-related experiences altered their life potential in a negative way (Supporting Information table 1C). Similarly, many of these women reported negative experiences and emotions they attributed to endometriosis (Supporting Information table 1D, E). All women used similar strategies to cope with and mitigate the impact of endometriosis on their lives (Supporting Information table 1F).

DISCUSSION

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

Study implications

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

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

Many respondents said they missed school and were generally unable to achieve their educational goals because of endometriosis. There is a dearth of research on the impact of endometriosis on women's educational aspirations and their ability to achieve goals due to endometriosis-associated symptoms, compared with the impact endometriosis has on professional work or other areas of life.[9] Findings from some existing studies suggest endometriosis-associated symptoms may impact grades, attendance, or completion of educational programs.[21,22,40] Although informative, these studies were more qualitative in nature and involved small sample sizes.[21,22,40] A quantitative study examining the lives of 78 women 15 years after receiving a verified diagnosis of endometriosis found only a fraction of women reported that their disease had a negative impact on their education.[11] However, the women included in that study seemed to report less frequent pain and endometriosis-related effects, like depression, compared with the reports made by women in our study. Furthermore, the small sample was collected at a single Norwegian hospital and the findings may not be representative of women's experiences with endometriosis on a wider scale.[11] Regardless, any impact on education is concerning, and our study results emphasize the need for additional research into this overlooked area in women with endometriosis. Research on other medical conditions, like adolescent fibromyalgia, supports that chronic pain can negatively impact education, reinforcing the likelihood that endometriosis may have a similar impact.[41,42]

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

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

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

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

Although few studies have examined this aspect of endometriosis, findings from two smaller studies have suggested that pain associated with the disease may also have a negative impact on exercise and nutrition.[9,30,52]

Of particular concern was the view of many women that their disease made them increase their use of alcohol, drugs, or cigarettes. Research into whether pain and experiences related to endometriosis may be associated with higher rates of substance abuse is severely lacking. However, there are demonstrated associations between other chronic pain conditions and substance abuse that support our finding.[53,54] The results from our study draw attention to this issue and highlight substance abuse as an important avenue for additional investigation.

The findings from our study indicate that women with endometriosis may experience many healthcare-related side effects. Of particular concern, patients noted that treatments meant to help reduce the burden of endometriosis may have their own negative impact. Many women perceived that use of prescription medications and multiple surgeries to control the symptoms of endometriosis had a negative impact on their life potential, and this response was also observed in women who indicated they were LPAF or believed they had NRFP due to their disease. Results from one recent study showed that medical treatment for a condition may increase a patient's stress levels and potentially affect their psychological health.[55] Patients who were taking prescription medications and who experienced more challenging adverse effects from their therapies had higher perceived stress levels, and women undergoing multiple surgeries were especially impacted. These reports underscore the potential value of supportive psychological care for patients with endometriosis as part of effective long-term disease management.

In general, women experienced a range of consequences that they attributed to living with and managing the limitations imposed by endometriosis. In addition to pain, women reported that the endometriosis-related experiences that most impacted their lives in a negative way included depression or anxiety (80%), heavy menstrual bleeding (71%), the need to take prescription treatments (57%) or undergo multiple surgeries (49%), or infertility (46%). In other studies, women have reported not feeling “normal” or feminine, experiencing a range of negative emotions (eg, anger, depression, hopelessness, disappointment, and exhaustion), having limited physical or sexual activity, struggling to find appropriate treatments, feeling guilt over disrupted relationships, and suffering in silence due to endometriosis-related symptoms.[22,23]While each woman experienced the impact of endometriosis differently, the majority believed that they were living life less fully than they could have because of their endometriosis-associated symptoms. This belief was informed by the symptoms and healthcare requirements they faced, and, in turn, may have influenced major life decisions that could have their own deleterious effects on personal fulfillment and life potential. The interconnectedness of effects triggered by major life decisions highlights the importance of conducting further research into the cumulative burden of debilitating diseases like endometriosis within the context of an individual’s life course.

Strengths and limitations

Limitations of this study include the selection of participants from an online community with voluntary participation, no targeted sampling, and no way to calculate a response rate. The participants were generally well educated, had access to health care, and participated in an online patient social network. Data on race, ethnicity, or socioeconomic status were not collected. Patients who experienced the most significant psychosocial impacts of endometriosis or lacked the resources to access the online community may not have been represented in the sample population, whereas the patients who were most affected by severe pelvic pain may have been more likely to participate in the study. These factors may have led to self-selection bias; therefore, the results of this study may not be generalizable to the overall population of patients with endometriosis. Any between-group comparisons are observational in nature and no definitive conclusions can be made in the absence of formal statistical analysis.

Future implications

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

Conclusion

In our international survey of the impact of endometriosis on a woman's life course, most respondents self-reported a high burden associated with the disease that affected overall life potential in many different ways. The findings of this survey add to our understanding of women's experiences with endometriosis.

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Contributors

SAM, FT, OAF, AH, BS, and SA-S contributed to the study concept and design. BS contributed to data acquisition and statistical analysis. SAM, FT, AMS, SEC, SC, SE, OAF, AH, BS, and SA-S contributed to data interpretation.

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Competing interests

SA Missmer is a consultant for AbbVie, Oratel Diagnostics, and Celmatix and receives research support from the National Institutes of Health, Department of Defense, and Marriott Family Foundations.

FF Tu has received research support from NICHD-NIH and NIDDK-NIH, earns royalties from UpToDate, has served as a consultant for AbbVie, Myovant, and Uroshape, and conducts sponsored research for Eximis and Dot Laboratories.

AM Soliman, S Chiuve, S Cross, S Eichner, and O Antunez Flores are employees of AbbVie and may own AbbVie stock/stock options.

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B Schneider is an employee of MyHealthTeams, which received compensation for the study and conducted the research on behalf of AbbVie.

S As-Sanie earns author royalties from UpToDate and has served as a consultant for AbbVie, Myovant, and Eximis.

Data availability statement

AbbVie is committed to responsible data sharing regarding the clinical trials and studies we sponsor. This includes access to anonymized, individual and trial-level data (analysis data sets), as well as other information (eg, protocols and clinical study reports), as long as the trials are not part of an ongoing or planned regulatory submission. This includes requests for clinical trial data for unlicensed products and indications.

This study data can be requested by any qualified researchers who engage in rigorous, independent scientific research, and will be provided following review and approval of a research proposal and statistical analysis plan and execution of a data sharing agreement. Data requests can be submitted at any time and the data will be accessible for 12 months, with possible extensions considered. For more information on the process, or to submit a request, visit the following link: https://www.abbvie.com/our-science/clinical-trials/clinical-trials-data-and-information-sharing/data-and-information-sharing-with-qualified-researchers.html.

REFERENCES

1. Zondervan KT, Becker CM, Missmer SA. Endometriosis. *N Engl J Med* 2020;382:1244-56.

2. Kennedy S, Bergqvist A, Chapron C*, et al.* Eshre guideline for the diagnosis and treatment of endometriosis. *Hum Reprod* 2005;20:2698-704.

3. Practice bulletin no. 114: Management of endometriosis. *Obstet Gynecol* 2010;116:223-36.

4. Zondervan KT, Becker CM, Koga K*, et al.* Endometriosis. *Nat Rev Dis Primers* 2018;4:9.

5. De Graaff AA, D'Hooghe TM, Dunselman GA*, et al.* The significant effect of endometriosis on physical, mental and social wellbeing: Results from an international cross-sectional survey. *Hum Reprod* 2013;28:2677-85.

6. Gallagher JS, DiVasta AD, Vitonis AF*, et al.* The impact of endometriosis on quality of life in adolescents. *J Adolesc Health* 2018;63:766-72.

7. Lagana AS, La Rosa VL, Rapisarda AMC*, et al.* Anxiety and depression in patients with endometriosis: Impact and management challenges. *Int J Womens Health* 2017;9:323-30.

8. Vannuccini S, Lazzeri L, Orlandini C*, et al.* Mental health, pain symptoms and systemic comorbidities in women with endometriosis: A cross-sectional study. *J Psychosom Obstet Gynaecol* 2018;39:315-20.

9. Culley L, Law C, Hudson N*, et al.* A qualitative study of the impact of endometriosis on male partners. *Hum Reprod* 2017;32:1667-73.

10. Denny E, Mann CH. Endometriosis-associated dyspareunia: The impact on women's lives. *J Fam Plann Reprod Health Care* 2007;33:189-93.

11. Fagervold B, Jenssen M, Hummelshoj L*, et al.* Life after a diagnosis with endometriosis - a 15 years follow-up study. *Acta Obstet Gynecol Scand* 2009;88:914-9.

12. Soliman AM, Coyne KS, Gries KS*, et al.* The effect of endometriosis symptoms on absenteeism and presenteeism in the workplace and at home. *J Manag Care Spec Pharm* 2017;23:745-54.

13. Leonardi M, Horne AW, Armour M*, et al.* Endometriosis and the coronavirus (covid-19) pandemic: Clinical advice and future considerations. *Frontiers in Reproductive Health* 2020;2

14. Leonardi M, Horne AW, Vincent K*, et al.* Self-management strategies to consider to combat endometriosis symptoms during the covid-19 pandemic. *Hum Reprod Open* 2020;2020:hoaa028.

15. Klein S, D'Hooghe T, Meuleman C*, et al.* What is the societal burden of endometriosis-associated symptoms? A prospective belgian study. *Reprod Biomed Online* 2014;28:116-24.

16. Simoens S, Dunselman G, Dirksen C*, et al.* The burden of endometriosis: Costs and quality of life of women with endometriosis and treated in referral centres. *Hum Reprod* 2012;27:1292-9.

17. Soliman AM, Taylor HS, Bonafede M*, et al.* Incremental direct and indirect cost burden attributed to endometriosis surgeries in the united states. *Fertil Steril* 2017;107:1181-90 e2.

18. Soliman AM, Yang H, Du EX*, et al.* The direct and indirect costs associated with endometriosis: A systematic literature review. *Hum Reprod* 2016;31:712-22.

19. Bhatti Z, Salek M, Finlay A. Chronic diseases influence major life changing decisions: A new domain in quality of life research. *J R Soc Med* 2011;104:241-50.

20. Kimball AB, Gieler U, Linder D*, et al.* Psoriasis: Is the impairment to a patient's life cumulative? *J Eur Acad Dermatol Venereol* 2010;24:989-1004.

21. Huntington A, Gilmour JA. A life shaped by pain: Women and endometriosis. *J Clin Nurs* 2005;14:1124-32.

22. Moradi M, Parker M, Sneddon A*, et al.* Impact of endometriosis on women's lives: A qualitative study. *BMC Womens Health* 2014;14:123.

23. Cole JM, Grogan S, Turley E. "The most lonely condition i can imagine": Psychosocial impacts of endometriosis on women's identity. *Feminism & Psychology* 2021;31:171-91.

24. Apers S, Dancet EAF, Aarts JWM*, et al.* The association between experiences with patient-centred care and health-related quality of life in women with endometriosis. *Reprod Biomed Online* 2018;36:197-205.

25. Witzeman K, Antunez Flores O, Renzelli-Cain RI*, et al.* Patient-physician interactions regarding dyspareunia with endometriosis: Online survey results. *J Pain Res* 2020;13:1579-89.

26. Bourdel N, Alves J, Pickering G*, et al.* Systematic review of endometriosis pain assessment: How to choose a scale? *Hum Reprod Update* 2015;21:136-52.

27. Chawla S. Treatment of endometriosis and chronic pelvic pain with letrozole and norethindrone acetate. *Med J Armed Forces India* 2010;66:213-5.

28. Facchin F, Barbara G, Saita E*, et al.* Impact of endometriosis on quality of life and mental health: Pelvic pain makes the difference. *J Psychosom Obstet Gynaecol* 2015;36:135-41.

29. Ballard K, Lowton K, Wright J. What's the delay? A qualitative study of women's experiences of reaching a diagnosis of endometriosis. *Fertil Steril* 2006;86:1296-301.

30. Bernuit D, Ebert AD, Halis G*, et al.* Female perspectives on endometriosis: Findings from the uterine bleeding and pain women's research study. *Journal of Endometriosis* 2011;3:73-85.

31. Greene R, Stratton P, Cleary SD*, et al.* Diagnostic experience among 4,334 women reporting surgically diagnosed endometriosis. *Fertil Steril* 2009;91:32-9.

32. Hadfield R, Mardon H, Barlow D*, et al.* Delay in the diagnosis of endometriosis: A survey of women from the USA and the uk. *Hum Reprod* 1996;11:878-80.

33. Hudelist G, Fritzer N, Thomas A*, et al.* Diagnostic delay for endometriosis in austria and germany: Causes and possible consequences. *Hum Reprod* 2012;27:3412-6.

34. Nnoaham KE, Hummelshoj L, Webster P*, et al.* Impact of endometriosis on quality of life and work productivity: A multicenter study across ten countries. *Fertil Steril* 2011;96:366-73 e8.

35. Soliman AM, Fuldeore M, Snabes MC. Factors associated with time to endometriosis diagnosis in the united states. *J Womens Health (Larchmt)* 2017;26:788-97.

36. Staal AH, van der Zanden M, Nap AW. Diagnostic delay of endometriosis in the Netherlands. *Gynecol Obstet Invest* 2016;81:321-4.

37. Nnoaham KE, Hummelshoj L, Kennedy SH*, et al.* Developing symptom-based predictive models of endometriosis as a clinical screening tool: Results from a multicenter study. *Fertil Steril* 2012;98:692-701 e5.

38. Brosens I, Puttemans P, Campo R*, et al.* Non-invasive methods of diagnosis of endometriosis. *Curr Opin Obstet Gynecol* 2003;15:519-22.

39. Lamvu G, Antunez-Flores O, Orady M, *et al.* Path to diagnosis and women's perspectives on the impact of endometriosis pain. *Journal of Endometriosis and Pelvic Pain Disorders* 2020:2284026520903214.

40. Gilmour JA, Huntington A, Wilson HV. The impact of endometriosis on work and social participation. *Int J Nurs Pract* 2008;14:443-8.

41. Murray CB, Groenewald CB, de la Vega R, *et al.* Long-term impact of adolescent chronic pain on young adult educational, vocational, and social outcomes. *Pain* 2020;161:439-45.

42. Kashikar-Zuck S, Lynch AM, Graham TB, *et al.* Social functioning and peer relationships of adolescents with juvenile fibromyalgia syndrome. *Arthritis Rheum* 2007;57:474-80.

43. de Graaf R, Tuithof M, van Dorsselaer S, *et al.* Comparing the effects on work performance of mental and physical disorders. *Soc Psychiatry Psychiatr Epidemiol* 2012;47:1873-83.

44. Smorgick N, Marsh CA, As-Sanie S, *et al.* Prevalence of pain syndromes, mood conditions, and asthma in adolescents and young women with endometriosis. *J Pediatr Adolesc Gynecol* 2013;26:171-5.

45. Yosef A, Allaire C, Williams C, *et al.* Multifactorial contributors to the severity of chronic pelvic pain in women. *Am J Obstet Gynecol* 2016;215:760 e1-60 e14.

46. Evans SF, Brooks TA, Esterman AJ, *et al.* The comorbidities of dysmenorrhea: A clinical survey comparing symptom profile in women with and without endometriosis. *J Pain Res* 2018;11:3181-94.

47. Fourquet J, Baez L, Figueroa M, *et al.* Quantification of the impact of endometriosis symptoms on health-related quality of life and work productivity. *Fertil Steril* 2011;96:107-12.

48. Sperschneider ML, Hengartner MP, Kohl-Schwartz A*, et al.* Does endometriosis affect professional life? A matched case-control study in switzerland, germany and austria. *BMJ open* 2019;9:e019570.

49. Prescott J, Farland LV, Tobias DK*, et al.* A prospective cohort study of endometriosis and subsequent risk of infertility. *Hum Reprod* 2016;31:1475-82.

50. Geisser ME, Cano A, Leonard MT. Factors associated with marital satisfaction and mood among spouses of persons with chronic back pain. *J Pain* 2005;6:518-25.

51. Leonard MT, Cano A. Pain affects spouses too: Personal experience with pain and catastrophizing as correlates of spouse distress. *Pain* 2006;126:139-46.

52. Fourquet J, Gao X, Zavala D*, et al.* Patients' report on how endometriosis affects health, work, and daily life. *Fertil Steril* 2010;93:2424-28.

53. Maleki N, Tahaney K, Thompson BL*, et al.* At the intersection of alcohol use disorder and chronic pain. *Neuropsychology* 2019;33:795-807.

54. Groenewald CB, Law EF, Fisher E*, et al.* Associations between adolescent chronic pain and prescription opioid misuse in adulthood. *J Pain* 2019;20:28-37.

55. Lazzeri L, Orlandini C, Vannuccini S*, et al.* Endometriosis and perceived stress: Impact of surgical and medical treatment. *Gynecol Obstet Invest* 2015;79:229-33.

56. Oehmke F, Weyand J, Hackethal A*, et al.* Impact of endometriosis on quality of life: A pilot study. *Gynecol Endocrinol* 2009;25:722-5.

57. Ugwumadu L, Chakrabarti R, Williams-Brown E*, et al.* The role of the multidisciplinary team in the management of deep infiltrating endometriosis. *Gynecol Surg* 2017;14:15.

58. Aarts JW, Huppelschoten AG, van Empel IW*, et al.* How patient-centred care relates to patients' quality of life and distress: A study in 427 women experiencing infertility. *Hum Reprod* 2012;27:488-95.

59. Gameiro S, Canavarro MC, Boivin J. Patient centred care in infertility health care: Direct and indirect associations with wellbeing during treatment. *Patient Educ Couns* 2013;93:646-54.

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, and (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 impacts 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

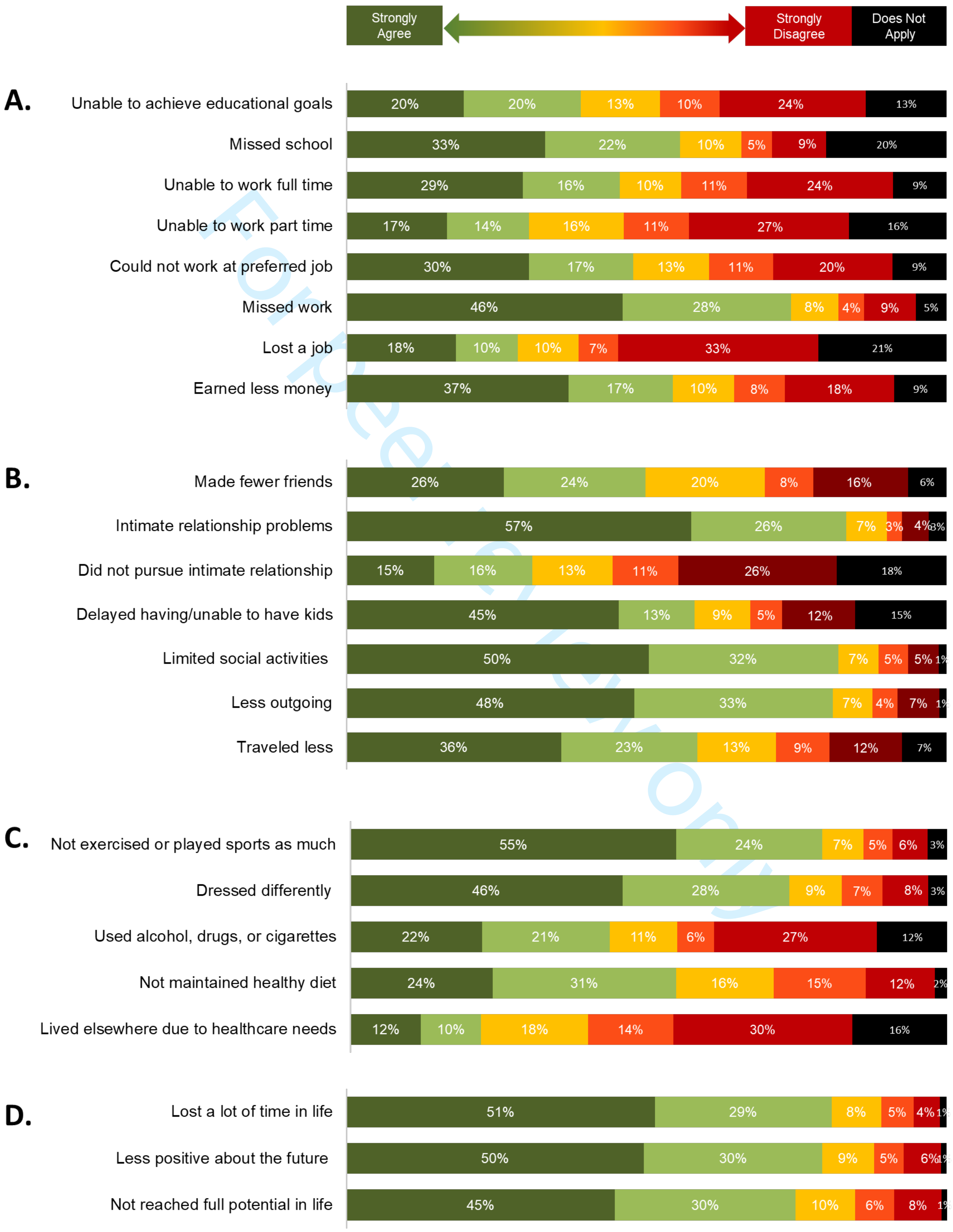
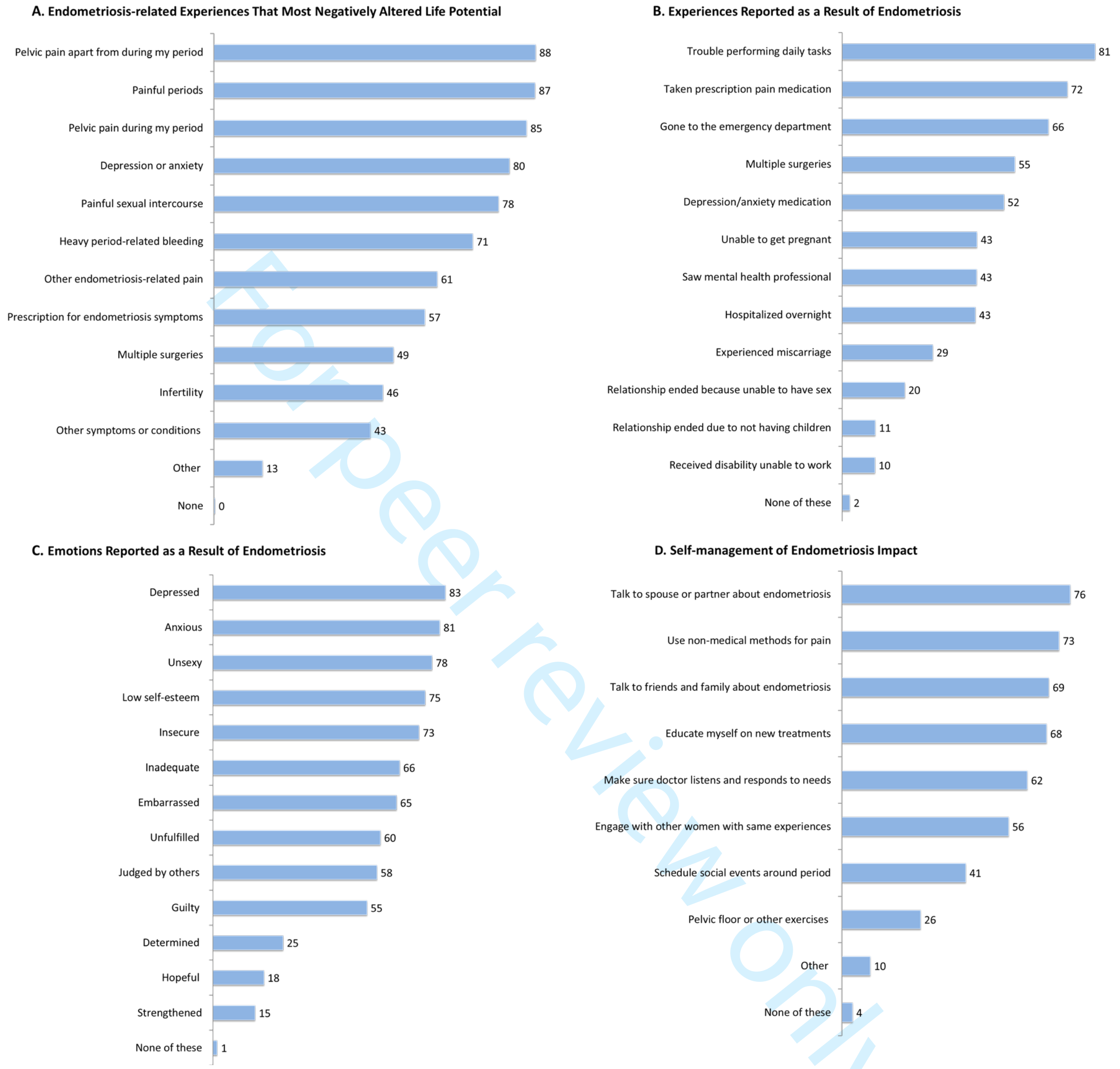

Strongly Agree
Strongly Disagree
Does Not Apply
A.
Unable to achieve educational goals 20% 20% 13% 10% 24% 13%
Missed school 33% 22% 10% 5% 9% 20%
Unable to work full time 29% 16% 10% 11% 24% 9%
Unable to work part time 17% 14% 16% 11% 27% 16%
Could not work at preferred job 30% 17% 13% 11% 20% 9%
Missed work 46% 28% 8% 4% 9% 5%
Lost a job 18% 10% 10% 7% 33% 21%
Earned less money 37% 17% 10% 8% 18% 9%
B.
Made fewer friends 26% 24% 20% 8% 16% 6%
Intimate relationship problems 57% 26% 7% 3% 4% 3%
Did not pursue intimate relationship 15% 16% 13% 11% 26% 18%
Delayed having/unable to have kids 45% 13% 9% 5% 12% 15%
Limited social activities 50% 32% 7% 5% 5% 1%
Less outgoing 48% 33% 7% 4% 7% 1%
Traveled less 36% 23% 13% 9% 12% 7%
C.
Not exercised or played sports as much 55% 24% 7% 5% 6% 3%
Dressed differently 46% 28% 9% 7% 8% 3%
Used alcohol, drugs, or cigarettes 22% 21% 11% 6% 27% 12%
Not maintained healthy diet 24% 31% 16% 15% 12% 2%
Lived elsewhere due to healthcare needs 12% 10% 18% 14% 30% 16%
D.
Lost a lot of time in life 51% 29% 8% 5% 4% 1%
Less positive about the future 50% 30% 9% 5% 6% 1%
Not reached full potential in life 45% 30% 10% 6% 8% 1%

FIGURE 2


A. Endometriosis-related Experiences That Most Negatively Altered Life Potential
Pelvic pain apart from during my period 88
Painful periods 87
Pelvic pain during my period 85
Depression or anxiety 80
Painful sexual intercourse 78
Heavy period-related bleeding 71
Other endometriosis-related pain 61
Prescription for endometriosis symptoms 57
Multiple surgeries 49
Infertility 46
Other symptoms or conditions 43
Other 13
None 0
B. Experiences Reported as a Result of Endometriosis
Trouble performing daily tasks 81
Taken prescription pain medication 72
Gone to the emergency department 66
Multiple surgeries 55
Depression/anxiety medication 52
Unable to get pregnant 43
Saw mental health professional 43
Hospitalized overnight 43
Experienced miscarriage 29
Relationship ended because unable to have sex 20
Relationship ended due to not having children 11
Received disability unable to work 10
None of these 2
C. Emotions Reported as a Result of Endometriosis
Depressed 83
Anxious 81
Unsexy 78
Low self-esteem 75
Insecure 73
Inadequate 66
Embarrassed 65
Unfulfilled 60
Judged by others 58
Guilty 55
Determined 25
Hopeful 18
Strengthened 15
None of these 1
D. Self-management of Endometriosis Impact
Talk to spouse or partner about endometriosis 76
Use non-medical methods for pain 73
Talk to friends and family about endometriosis 69
Educate myself on new treatments 68
Make sure doctor listens and responds to needs 62
Engage with other women with same experiences 56
Schedule social events around period 41
Pelvic floor or other exercises 26
Other 10
None of these 4

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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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 (182)	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)

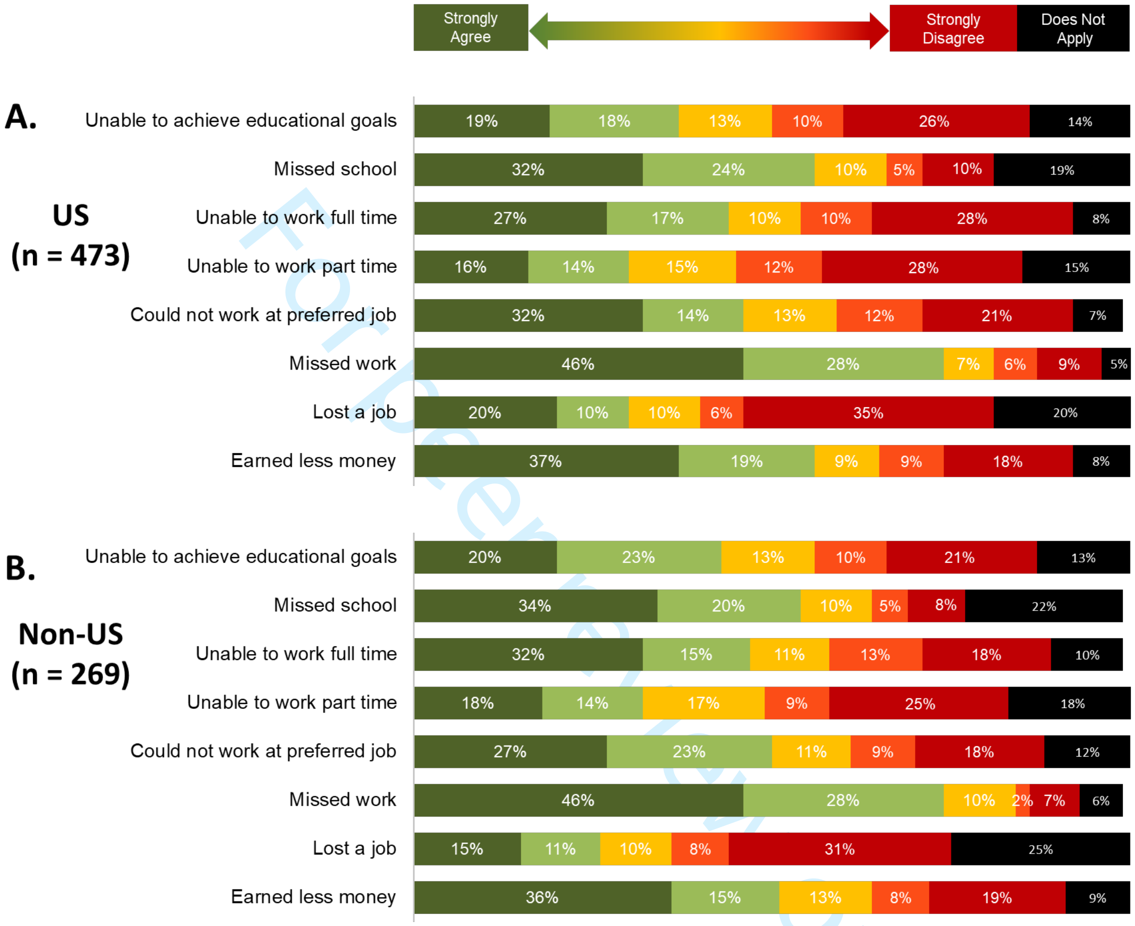
S1E

	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

S2. What is your age?

Under 19 **(Terminate)**

19-29

30-39

40-49

50-59

60 or older

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

Stage 1 endometriosis

Stage 2 endometriosis

Stage 3 endometriosis

Stage 4 endometriosis

Not sure what stage of endometriosis I have

I do not have endometriosis (**Terminate**)

S4. In which country do you currently live?

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

Australia

Canada

Ireland

Netherlands

New Zealand

South Africa

United Kingdom

Other

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

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)

Painful sexual intercourse

Pelvic pain during my period

Pelvic pain apart from during my period

Painful periods

Heavy period-related bleeding

Other endometriosis related pain

Infertility

Depression or anxiety

Multiple surgeries

Prescription treatment to control endometriosis symptoms

Other symptoms or conditions (please specify)

Other (please specify)

None

10. Which, if any, of these, have you experienced as a result of your endometriosis? Check all that apply. (Rotate order)

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

Taken prescription medication to treat depression or anxiety

Had multiple surgical procedures

Been hospitalized overnight

Gone to the emergency room

Received disability income due to being unable to work

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

Had trouble performing daily tasks

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

Was unable to get pregnant

Had a relationship end because I was unable to have children

Had a relationship end because I was unable to have sex

None of these

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

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

Schedule social events around my period

Engage with other women going through the same experiences

Talk to my friends and family about endometriosis

Talk to my spouse or partner about my endometriosis

Pelvic floor or other exercises to lessen pain during sex

Make sure my doctor listens and responds to my needs

Educate myself on new treatments

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

Other (please describe)

None of these

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

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

Just a few last questions.

D1. Which of the following best describes the area where you live?

Urban

Suburban

Rural

Not sure / prefer not to say

D2. What is the highest level of education you have achieved?

Less than high school

Some high school

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

Some college, but no degree

Associate degree

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

Some graduate school, but no degree

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

Prefer not to answer

D3. What is your current employment status?

Working full time

Working part time

Unemployed, not looking for work

Unemployed, looking for work

Retired

Unable to work

Prefer not to answer

D4. Which of the following best describes your marital status?

Single/never married

Married

Widowed

Divorced or separated

Prefer not to answer

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

D5. Are you currently in an intimate relationship?

Yes

No

Prefer not to answer

D6. How many children, if any, do you have?

None

1

2

3

4

5 or more

Prefer not to answer

Thank you for answering these questions.

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

Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	Page 9, lines 19-20
		(*b*) Describe any methods used to examine subgroups and interactions	Page 9, lines 19-20; page 10, lines 1-8
		(*c*) Explain how missing data were addressed	Page 8, lines 22-23
		(*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 11-12
		(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 10, lines 13-21; page 11-12, Table 1
		(b) Indicate number of participants with missing data for each variable of interest	N/A (no missing data; see page 8, lines 22-23)
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 1-5; supporting information pages 2-6

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.