

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

Stacey A Missmer,^{1,2,3} Frank Tu,^{4,5} Ahmed M Soliman,⁶ Stephanie E Chiuve,⁶ Sarah Cross,⁶ Samantha Eichner,⁶ Oscar Antunez Flores,⁶ Andrew Horne,⁷ Beth Schneider,⁸ Sawsan As-Sanie⁹

¹Department of Epidemiology, Harvard T. H. Chan School of Public Health, Boston, Massachusetts, USA

²Boston Center for Endometriosis, Boston, Massachusetts, USA

³Department of Obstetrics, Gynecology, and Reproductive Biology, Michigan State University, Grand Rapids, Michigan, USA

⁴Department of Obstetrics and Gynecology, NorthShore University Health System, Evanston, Illinois, USA

⁵Department of Obstetrics and Gynecology, Pritzker School of Medicine, University of Chicago, Evanston, Illinois, USA

⁶AbbVie Inc., North Chicago, Illinois, USA

⁷Medical Research Council Centre for Reproductive Health, University of Edinburgh, Edinburgh, UK

⁸MyHealthTeams, San Francisco, California, USA

⁹Department of Obstetrics and Gynecology, University of Michigan, Ann Arbor, Michigan, USA

SUPPLEMENTAL FILE

Supplemental 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.

Supplemental 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

Supplemental Table 1.

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

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

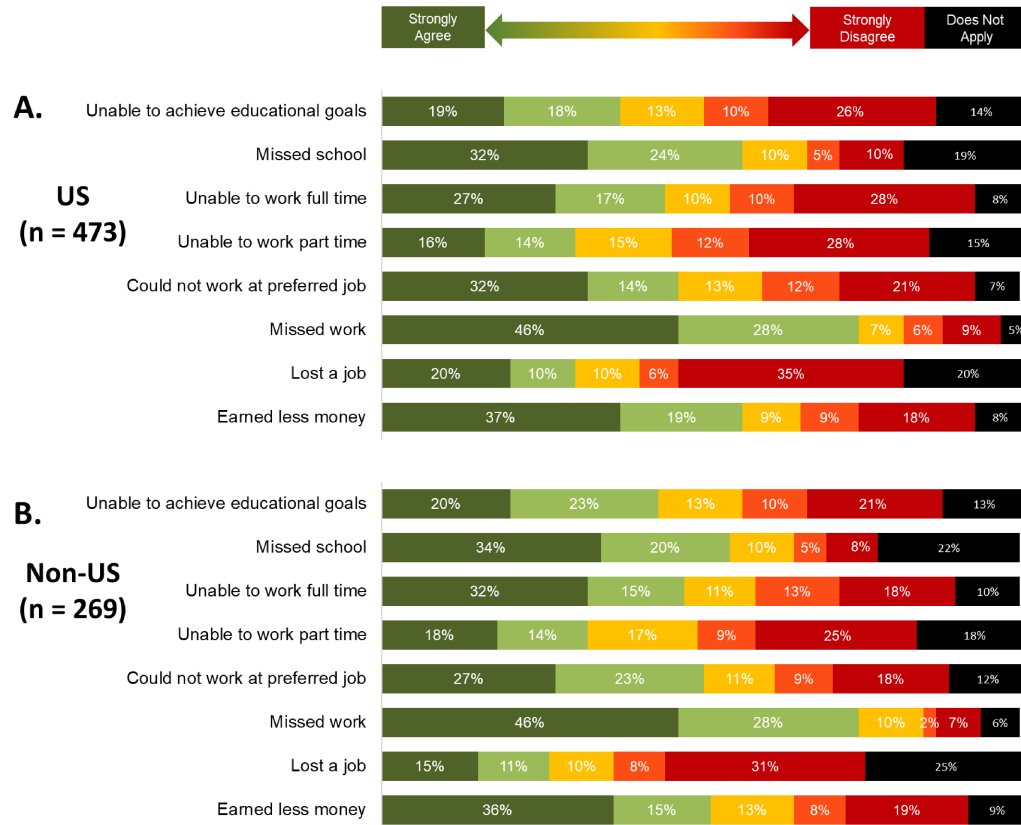
S1C	Pelvic pain apart from period	Painful periods	Pelvic pain during period	Depression or anxiety	Painful sexual intercourse	Heavy period- related bleeding	Other endometriosi s-related pain	Taken prescription for symptoms	Multiple surgeries	Infertility	Other symptoms or conditions
Total, n (%) (N = 743)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

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

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

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

Supplemental 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 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.