

Supplemental Material

Patient-Physician Interactions Regarding Dyspareunia with Endometriosis: Online Survey Results

Kathryn Witzeman,¹ Oscar Antunez Flores,² Roberta I. Renzelli-Cain,³ Brett Worly,⁴ Janelle K. Moulder,⁵ Jorge F. Carrillo,⁶ Beth Schneider⁷

¹Department of Obstetrics and Gynecology, Denver Health Medical Center, Denver, Colorado; ²AbbVie Inc., North Chicago, Illinois; ³Department of Obstetrics and Gynecology, West Virginia University, Morgantown, West Virginia; ⁴ Department of Obstetrics and Gynecology, The Ohio State University, Columbus, Ohio; ⁵ Department of Obstetrics and Gynecology, Wake Forest University School of Medicine, Winston-Salem, North Carolina; ⁶ Department of Obstetrics and Gynecology, University of Central Florida, Orlando, Florida; ⁷MyHealthTeams, San Francisco, California

MyEndometriosisTeam Survey – Dyspareunia

Introduction

Pain while having sexual intercourse (the medical term is dyspareunia) is a symptom experienced by many women with endometriosis. In this 8-minute survey, we are going to ask a series of questions about pain you may experience during sexual intercourse. These questions will help us better understand the experience and, importantly, the needs of women living with dyspareunia. We understand that some of the questions may be somewhat uncomfortable. Your thoughtful feedback will help build awareness and understanding of the impact of this painful condition.

Your participation is completely voluntary, and please rest assured that your responses are anonymous and cannot be tied back to you. 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 a woman, 19 years of age or older, 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. What is your age?

Under 19 (Terminate)

19-29

30-39

40-49

50-55

56 or older (Terminate)

S2. Which one of the following best describes your condition?

Stage 1 endometriosis

Stage 2 endometriosis

Stage 3 endometriosis

Stage 4 endometriosis

I have endometriosis, but not sure what stage

I do not have endometriosis (Terminate)

S3. In which country do you currently live?

United States (excluding Puerto Rico)

Australia

Canada

Ireland

Netherlands

New Zealand

South Africa

United Kingdom

Other

S4. For how many years have you been living with endometriosis related pain? (drop down window)

S5. As a reminder, we are going to ask a series of questions about pain you may experience during sexual intercourse (the medical term for this is dyspareunia). We understand that some of the questions may be somewhat uncomfortable. Please rest assured that your responses are completely anonymous.

S6. During the past 2 years, have you had any pain during sexual intercourse or in the 24 hours after having sex?

Yes, I have felt pain

No, I have not felt pain (Terminate)

I have not been sexually active in the past 2 years (Terminate)

Section 2 – Brief Pain History (context setting)

1. Pain caused by endometriosis can be experienced in a number of ways. This survey is specifically focused on painful sexual intercourse. How often have you typically had pelvic pain during or in the 24 hours after sexual intercourse? By 'pelvic pain' we are referring to any type of pain (cramping or stabbing feeling, etc.) in the lower part of your belly.

Always (every time)

Usually (more than half of the time)

Often (a quarter to half of the time)

Occasionally (less than a quarter of the time)

Never

2. Please rate how severe your pelvic pain has been at its worst for the past 2 years during sexual intercourse using a scale from 0 to 10 where 0=no pain and 10=worst imaginable pain.

3. Was sexual intercourse painful as soon as you became sexually active or was there a time when you were able to have pain-free sex?

Yes, I started having painful sex right away and I always feel some type of pain

Yes, I started having painful sex right away, but it comes and goes

No, I did not have painful sex at first

4. During the past 2 years, how long has the pain from sexual intercourse typically lasted?

During sex only

For a few hours after sex

For about 24 hours after having sex

For a few days or more after sex

Section 3: Understanding Impact on Quality of Life

5. As you think about the past 2 years, how much do you agree or disagree with the following statements? (Rotate order)

(Please select one box for each row) Strongly disagree Some-what Disagree Neutral Some-what

Agree Strongly agree

I have avoided sexual intercourse due to the pain 1 2 3 4 5

I have had sexual intercourse to please my spouse or partner even when I would prefer not to

1 2 3 4 5

Pain related to sexual intercourse has led me to avoid being involved in intimate relationships

1 2 3 4 5

Pain related to sexual intercourse has made it challenging for me to start a family 1 2

3 4 5

Pain related to sexual intercourse has had an impact on my relationship with my spouse or significant other 1 2 3 4 5

I find sexual intercourse to be unpleasant or unfulfilling due to the pain 1 2 3
4 5

6. Which, if any of these, do you feel or experience as a result of painful sexual intercourse (dyspareunia)? Check all that apply. (Rotate order)

I feel...

Low self esteem

Inadequate

Unsexy

Unfeminine

Insecure

Guilty

Embarrassed

Unfulfilled

Depressed

Anxious

Alone

Worried that my spouse or partner will leave me or will feel unfilled

Worried that I will never be able to have children

Worried that I won't be able to find a partner or spouse

None of these

7. With whom have you discussed the fact that you have painful sexual intercourse (dyspareunia)? Check all that apply. (Rotate order)

Spouse or partner

Parents

Doctor

Nurse practitioner

Family member other than parents or spouse

Friends

Teachers

Co-workers

Other (please describe)

No one

(Ask Q8 if spouse or partner chosen at Q7)

8. How understanding has your spouse or partner been about the pain you experience during sexual intercourse?

Extremely understanding

Very understanding

Somewhat understanding

Not very understanding

Not at all understanding

Section 4: Understanding Intensity of Pain

9. How would you describe the pain you have felt during sexual intercourse? Check all that apply. (Rotate order)

Aching

Burning

Throbbing

Stabbing

Ripping sensation

Stinging

Dullness

Cramping

Other (please describe)

10. Are there times of the month in which sexual intercourse is typically more painful than at other times? (Check all that apply)

During my period^[SEP]

A few days before my period

A few days after my period

At mid cycle (around ovulation)

It's painful all month long

None of these

Do not have a period

11. When you have had sexual intercourse, where have you typically felt the pain? (select all that apply)

At the entrance of your vagina

Deep inside your vagina

Abdomen/pelvis

Back

Other location (please describe)

None of these

12. When have you most often felt the onset of pain?

Before starting sex

Upon entry

During deep vaginal penetration

After sex

13. During the past 2 years, how often have you had to stop sexual intercourse because the pain is too severe?

Always (every time)

Usually (more than half of the time)

Often (a quarter to half of the time)

Occasionally (less than a quarter of the time)

Never

14. During the past 2 years, how often have you refused or avoided sexual intercourse with your spouse or partner due to the pain?

Always (every time)

Usually (more than half of the time)

Often (a quarter to half of the time)

Occasionally (less than a quarter of the time)

Never

Section 5: HCP Discussions

15. Which, if any, of the following healthcare professionals (HCPs) have you discussed painful sexual intercourse with? Check all that apply. (rotate order)

Primary care physician
Family practitioner
Internal medicine specialist
Gynecologist
Fertility specialist
Pediatrician
Pain management specialist
Emergency room doctor
Nurse practitioner
OB-GYN
Other (please specify)
None

(Ask Q16 if “none” not selected at Q15)

16. As part of the process of identifying the source of the pain due to sexual intercourse, did your HCP ever conduct a pelvic exam? (A pelvic exam is when your doctor performs an external and internal examination of your pelvic area to look for any abnormalities.)

Yes

No

Not sure

(Ask Q17 if “none” not selected at Q15)

17. Did your HCP ever mention that the pain you feel during sexual intercourse may be the medical condition called dyspareunia?

Yes

No

Not sure

(Ask Q18 if “none” not selected at Q15)

18. Did your HCP discuss whether painful sexual intercourse (dyspareunia) was linked to a certain type of endometriosis?

Yes, “Superficial”

Yes, “Endometrioma”

Yes, “Deep infiltrating endometriosis”

Yes, but I don’t recall the type

No

Not sure

(Ask Q19 if “none” selected at Q15)

19. Why have you not discussed painful sexual intercourse with an HCP? Check all that apply. (rotate order)

Embarrassed / uncomfortable discussing it

I don’t believe the HCP would be able to help me

My HCP is not understanding

I didn’t think there was anything that could help lessen the pain

It is not the most important symptom for me to discuss

My HCP is a male

Other (please describe)

20. What would make you feel more comfortable discussing painful sexual intercourse with your HCP? Check all that apply. (Rotate order)

Having a description card or journal that I could fill out and hand to my HCP that describes the pain

Seeing a female HCP instead of a male HCP

The HCP shares examples of similar experiences of other women (for example suggesting positions that are less painful based on experiences from other patients)

The HCP is the one to initiate the conversation on painful sexual intercourse (for example, asks whether you have had any pain during sex rather than waiting for you to bring up)

Being able to communicate with my doctor via a phone app or email instead of in person

Other (please describe)

Nothing

(Ask Q21 if “none” is not selected at Q15)

21. What advice or treatment has your HCP recommended to help ease the pain during sexual intercourse? Check all that apply. (Rotate order)

Over the counter pain medication not specific to sexual intercourse (for example, ibuprofen or aspirin)

Prescription pain medication not specific to sexual intercourse (for example, opioids)

Surgical procedure (for example, removal of endometriosis lesions)

Pelvic floor exercise tips

Different sexual positions

Physical therapy

Change in diet

Osphena (ospemifene)

Intrarosa (prasterone)

Medication to lessen dyspareunia other than Osphena or Intratosa (please describe)

Anti-depressants

Use a lubricant

Mental health counseling (to cope with pain or deal with relationship challenges)

Other (please describe)

None

(Skip if “none” mentioned at Q21)

22. Which of your HCP’s advice or treatment, if any, did you try? Check all that apply.
(Rotate order)

Over the counter pain medication not specific to sexual intercourse (e.g., ibuprofen or aspirin)

Prescription pain medication not specific to sexual intercourse (e.g., opioids)

Surgical procedure (e.g., removal of endometriosis lesions)

Pelvic floor exercise tips

Different sexual positions

Physical therapy

Change in diet

Osphena (ospemifene)

Intrarosa (prasterone)

Medication to lessen dyspareunia other than Osphena or Intratosa (please describe)

Anti-depressants

Use a lubricant

Mental health counseling (to cope with pain or deal with relationship challenges)

Other (please describe)

None

Q23. Of the lifestyle changes, treatments or therapies you may have tried, which were the top 3 that you feel have been most effective at addressing painful intercourse?

Over the counter pain medication not specific to sexual intercourse (e.g., ibuprofen or aspirin)

Prescription pain medication not specific to sexual intercourse (e.g., opioids)

Surgical procedure (e.g., removal of endometriosis lesions)

Pelvic floor exercise tips

Different sexual positions

Physical therapy

Change in diet

Osphena (ospemifene)

Intrarosa (prasterone)

Medication to lessen dyspareunia other than Osphena or Intratosa (please describe)

Anti-depressants

Use a lubricant

Mental health counseling (to cope with pain or deal with relationship challenges)

Other (please describe)

None

24. Finally, what advice or tips or questions do you have for other women who experience pain during sexual intercourse? (open-end)

Thank you for participating in this survey. We look forward to sharing the results with the MyEndometriosisTeam community.