

INTRODUCTION/OBJECTIVES

Despite its 10% prevalence rate among females and roughly 50% comorbidity rate with infertility, endometriosis is an understudied, underfunded, and misunderstood disease.

Endometriosis is an estrogen-dependent chronic inflammatory disease in which tissue similar to the lining of the uterus grows outside the uterus, contributing to internal bleeding, scarring, adhesions, and anatomical distortion.



Qualitative works have consistently demonstrated that these patients feel unheard in many ways, including by clinicians.

These perceptions frequently manifest as not having pain sufficiently acknowledged and acted upon by clinicians.

As part of a larger research project, this survey therefore examined multiple markers of patient engagement with the survey, which functioned as a forum to feel heard.

METHODS

The survey with which patient engagement was examined was an anonymous online survey (20-30 mins.) examining the relationship between the patient-clinician relationship and patient online community use among patients with endometriosis as well as patients' physical and mental health.

Data collection occurred over the course of 3.5 months.

No compensation was included, but participants were able to enter into a raffle for 1 of 3 \$25 Amazon gift cards.

METHODS

Endometriosis organizations posted the below advertisement to their social media site(s):

Women with Endometriosis Needed for Research Study

Rutgers University is seeking volunteers to participate in a brief (20-30 minutes) and anonymous online survey on endometriosis, the patient-physician relationship, and the use of patient online communities. Subjects will have the opportunity to enter their email in a draw for a chance to win one of three \$25 Amazon gift cards.

To participate in this study, you must:

- Have a diagnosis of endometriosis
- Be at least 18 years of age

If you meet these criteria and would like to participate, please access the survey at: [\[Link to website goes here\]](#)

For more information, please contact Allyson at: allyson.bontempo@rutgers.edu
School of Communication and Information, Rutgers University
4 Huntington Street, New Brunswick, NJ 08901

RESULTS

Data were collected from 1,391 patients with self-reported endometriosis, 72% (n = 997) of whom completed the survey (M age = 33.9 years, 83.7% white).

Patients from 45+ countries, including the US, participated.

33% (n = 326) of patients signed up to receive survey results.

Among completers, 45% (n = 448) went on to complete an optional field at the end that asked them if there was anything else they thought the researchers should know.

Mean word length was 69.7 (SD = 83.5, range = 2-669).

In open-ended comments, 21 patients thanked the authors for doing this research, and frequently equated the researchers doing this research as caring about and trying to help them.

(see below)

DISCUSSION/IMPLICATIONS

This survey demonstrated multiple markers of engagement with the survey, as this survey served as a forum for participants to share their frustrations with both the disease and their experiences of not feeling heard.

There is much evidence that merely communicating one's health experiences carries positive psychological and physiological effects, which supports these findings.

These markers of engagement are consistent with extant work illustrating that patients do not feel heard and highlight a need for patient-centered communication training with an emphasis on consultation and diagnosis, especially for OB/GYNs.

Such training may allow patients the opportunity to communicate their experiences and feel heard by clinicians as they emotionally cope with the disease.

SELECTED REFERENCES

Eskenazi, B., & Warner, M. L. (1997). Epidemiology of endometriosis. *Obstetrics and Gynecology Clinics of North America*, 24, 235-238.

Culley, L., Law, C., Hudson, N., Denny, E., Mitchell, H., Baumgarten, M., & Raine-Fenning, N. (2013). The social and psychological impact of endometriosis on women's lives: A critical narrative review. *Human Reproduction Update*, 19, 625-639.

ACKNOWLEDGMENTS



"Thank you for asking these questions. Thank you for caring."

"Please keep researching endo and its widespread effects. Thank you for your research!!!"

"Your survey gives me hope....Thank you!"

"Thank you for choosing to do your work on this awful disease."

"Thank you for doing this survey :)"

"Thank you for taking the time to survey us and care about us! <3"

"Thank you for seeking truthful research from sufferers."

"Thank you doing this and helping women who suffer."

"Thank you for doing this research. Genuinely, thank you."

"Thanks for taking the time to study endo!"

"Thank you for doing research. We need you. We are an invisible, drowning population."