

Background

- Endometriosis is a disease in which the tissue that normally lines the inside of the uterus instead grows outside of it
- It is one of the most prevalent disease in gynecologic practice
 - It affects an estimated 1 in 10 women; world-wide this number is 176-200 million women
- Pelvic pain and infertility are the main symptoms, but other symptoms include but are not limited to
 - Painful menstrual cramps, diarrhea, painful intercourse, heavy menstrual cycles, constipation, urinary incontinence
- There is no known cause, cure, or test (blood, urine, saliva, or otherwise) that can test for it
 - Only method for definitive diagnosis is surgery
- In the U.S., it takes ~10 years from symptom onset to receive an accurate diagnosis of endometriosis

Study Purpose

- To assess perceptions and awareness of endometriosis among providers and evaluate the patient experience in conjunction with current practice, in order to identify any common themes contributing to the overall public health burden associated with the disease

Methods

Mixed methods study

- A survey was used to determine what respondents (providers who treat patients with endometriosis) believed the true prevalence of endometriosis was
- Interviews were used to
 - Discern providers' awareness & knowledge of the disease
 - Assess patient experience for those diagnosed with the disease

Participants

- For the **provider-facing portion** of the study, physicians and nurse practitioners across several sub-specialties at Thomas Jefferson University Hospitals were surveyed and interviewed
- For the **patient-facing portion** of the study, female patients with a confirmed diagnosis of endometriosis were recruited for interviews

Design and Analysis

- All quantitative analyses were conducted using SPSS
 - Analysis of the survey data included calculating means and frequencies of each survey item
 - Comparing providers' prevalence estimates of endometriosis to their sub-specialties, number of years in practice, and gender
- Interviews were all conducted via telephone and audio recorded on an iPhone
 - Transcribed verbatim and hand-coded
 - Identified major recurring themes

Results

Table 1. Provider characteristics & knowledge (n=53)

Category	Frequency	Percentage
Race		
White	35	66.0%
Black or AA	3	5.7%
Asian	11	20.8%
Hispanic	3	5.7%
Other	1	1.9%
Sex		
Male	20	37.7%
Female	33	62.3%
Age Range		
20-29	22	41.5%
30-39	22	41.5%
40-49	5	9.4%
50-59	2	3.8%
60 +	2	3.8%
Clinician Specialty		
Family Medicine	21	39.6%
Internal Medicine	3	5.7%
OB/GYN	11	20.8%
Gastroenterology	8	15.1%
Other	10	18.9%
Licensure		
M.D.	51	96.2%
N.P.	2	3.8%
Years in Practice		
0-5	44	83.0%
6-10	5	9.4%
11-15	1	1.9%
16-20	1	1.9%
20+	2	3.8%
Time in Direct Pt. Care		
<50%	3	5.7%
51-75%	10	18.9%
76-100%	40	75.5%
Endometriosis Prevalence		
Correct Response (1 in 10)	6	11.3%
All Other Responses	47	88.7%

Table 2. Participant characteristics (n=12)

Category	Frequency/ Mean	Percentage/ SD
Race/Ethnicity		
Caucasian	11	90%
Hispanic	1	10%
Sex		
Female	12	100%
Age Range		
20-47	36	5.847
Insurance Status		
Employer	4	33%
Spouse	1	8%
Medicaid/ACA/Private	3	25%
Parents	1	8%
Other (did not specify)	3	25%
Region of U.S.		
Northeast	5	41%
Southeast	3	25%
Mid-West	3	25%
West Coast	1	8%
Family Hx of Endo		
Confirmed	2	16%
Suspected	5	41%
Unsure	2	16%
None aware of	3	25%
# of Surgeries		
1	6	50%
2	2	16%
3	2	16%
4	2	16%

Lack of Confidence in health care system

"I do not feel that I have trust, unfortunately, in any doctors because of the path that I've been on and because I feel like this disease is so pushed under the rug and no one listens to you and for most of these OB/GYN's to be women and to not hear you... I mean I've cried in their office, not for attention but because they didn't get it, I couldn't function, I needed help. And to have to get to that point is discouraging. And to have to get to the point where I'm 37 and I'm not married, I have no children, I can never have children, and I really do blame a lot of this disease on all of that".

Feelings of dismissiveness

"In general being a woman that goes to the doctor, I feel that all the time my 'stuff' is being shoved under the rug, and, 'it's no big deal, don't worry about it, take your Advil, no problem, etc.'. And it's just really frustrating in general how women are treated in the medical world as patients who are being dramatic. A lot of doctors were kind of just telling me that it wasn't as bad as I thought it was and I was honestly afraid of having a surgery only to be told, 'it's not endometriosis, just deal with it, we all have cramps'. So I definitely delayed treatment myself because I didn't want to be 'overdramatic' about anything".

Lack of awareness

"It really does make me so happy to hear that research is being done and awareness is being brought to the disease because I was not diagnosed for so long and it has affected my life. I'm not able to have children right now because of my endometriosis and I don't know if I'm going to be able to, and I blame the doctors, I do. I don't really know if it's their fault, but I wish there was more awareness about the disease because maybe I would have had a chance to get pregnant if I was diagnosed even a couple years sooner. So anything I can do to help to bring awareness, I'm going to do".

Limited treatment options

"We need better treatment options, because right now it's just a guessing game. There needs to be something that can diagnosis it sooner and that's less invasive [than surgery]; it will be nice when a day comes where surgery isn't the only option".

Discussion

- The purpose of this study was to contribute to the understanding of the different factors of this disease's overall public health burden
- A unique component of this study was the analysis of the provider experience juxtaposed with the patient experience
- One of the biggest takeaways from our study was the lack of awareness and the misperception of the actual prevalence of the disease
 - Of the providers queried (n=53) only 11% of respondents (n=6) got the correct response**

Future Research

- This study serves as a solid basis on which to
 - Develop larger-scale studies similar in nature
 - Act as a platform for future research
 - Serve as resource for moving the field forward
- Topics for exploration include
 - The association between the experience of those with the disease and awareness of those providers tasked with treating it
 - The variability of symptoms, factors, and influences contributing to the overall understanding of the disease
- The findings of our study can be utilized to
 - Develop and implement necessary interventions to assist patients and clinicians
 - Decrease the risk of long-term negative health outcomes associated with the disease

Limitations

- Homogenous patient sample
 - All but one of the participants (n=11) were Caucasian
- Inter-Coder Reliability
 - On account of limited availability, there was only one individual responsible for the coding of the interview transcripts

CORE COMPETENCIES

- Analytical & Assessment Skills
- Communication Skills
- Public Health Sciences Skills

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