A Mixed Methods Study of Endometriosis: Patient Experience and Provider Awareness

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Background

- Endometriosis is a disease in which the tissue that normally lines the inside of the uterus grows outside of it.
- It is one of the most prevalent disease in gynecologic practice.
- It affects an estimated 1 in 10 women; worldwide 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

1. A survey was used to determine what respondents (providers who treat patients with endometriosis) believed the true prevalence of endometriosis was.
2. Interviews were used to:
   a) Assess providers’ awareness & knowledge of the disease.
   b) Assess patient experience for those diagnosed with the disease.

Participants

- For the provider-facing portion of the study, physicians and nurse practitioners across several subspecialties 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 subspecialties, 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)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
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<td>24</td>
</tr>
<tr>
<td></td>
<td>Female</td>
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<tr>
<td>Age Range</td>
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</tr>
<tr>
<td></td>
<td>50+</td>
<td>7</td>
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<td>Race/Ethnicity</td>
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<tr>
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<tr>
<td></td>
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<td>3</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>33</td>
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<tr>
<td>Diagnosis</td>
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<td>53</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>0</td>
</tr>
<tr>
<td>Awareness</td>
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<td>53</td>
</tr>
<tr>
<td></td>
<td>No</td>
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</tbody>
</table>

Limitations

- Homogenous 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.

Table 2. Participant characteristics (n=12)

<table>
<thead>
<tr>
<th>Characteristic</th>
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<th>Percentage</th>
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</thead>
<tbody>
<tr>
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<td>5</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>7</td>
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<tr>
<td></td>
<td>30-39</td>
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<tr>
<td>Race/Ethnicity</td>
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<td></td>
<td>Other</td>
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<tr>
<td>Diagnosis</td>
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<tr>
<td></td>
<td>No</td>
<td>0</td>
</tr>
<tr>
<td>Awareness</td>
<td>Yes</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>No</td>
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</tr>
</tbody>
</table>

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.

Lack of confidence in healthcare 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 pushed under the rug and no one listens to you and for most of these, OB/GYN’s are to blame because I have to bear you and I mean I was in their office, not for attention but because they didn’t get it. I couldn’t function, I needed help. And I have to go to that point is discouraging. And I’m not that a point where I’m 23 I’m not married, I have no children, I can never have children, and I really do blame a lot of this on all of the doctors.”

Feelings of dispossession

- “We need better treatment options, because right now it’s just a guessing game. There needs to be something that can diagnose it sooner and that’s less invasive than surgery. It will be nice when a day comes that where surgery isn’t the only option.”

Limited treatment options

- “I blame the doctors, I blame the hospitals, I blame the insurance. I just deal with it, we all have pain and some people need to deal with it more than others. Women are treated in the medical world as patients who are being dramatic. ‘Oh, take your Advil, no problem,’ etc. ‘Women are supposed to have a period, why is it suddenly a problem?’”

Core competencies

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

Acknowledgements

- Amy Leader, PhD for serving as my chair and for her time, expertise, and guidance.
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Endometriosis Prevalence

<table>
<thead>
<tr>
<th>Category</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other</td>
<td>8</td>
<td>15.6%</td>
</tr>
<tr>
<td>Family Medicine</td>
<td>4</td>
<td>7.6%</td>
</tr>
<tr>
<td>Primary Care</td>
<td>48</td>
<td>89.4%</td>
</tr>
<tr>
<td>Other</td>
<td>10</td>
<td>19.2%</td>
</tr>
</tbody>
</table>

Research findings:

- Limited treatment options
- Misperception of the actual prevalence of the disease
- Variable understanding of those providers tasked with treating the disease.

Analysis

- Comparing providers’ prevalence estimates of endometriosis to their subspecialties, number of years in practice, and gender.
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Feelings of dispossession

- “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 to know how women are treated in the medical world as patients who are being chronic. 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 it.’ So I definitely delayed treatment myself because I didn’t want to be ‘overdramatic’ about anything.”

Limited treatment options

- “We need better treatment options, because right now it’s just a guessing game. There needs to be something that can diagnose it sooner and that’s less invasive than surgery. It will be nice when a day comes that where surgery isn’t the only option.”

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