

Belmont University

## Belmont Digital Repository

---

DNP Scholarly Projects

School of Nursing

---

Spring 4-16-2023

### Women's Stories of Reaching a Diagnosis of Endometriosis: A Qualitative Study

Susan C. Debolt

*Belmont University*, [susancaitlyn@gmail.com](mailto:susancaitlyn@gmail.com)

Follow this and additional works at: <https://repository.belmont.edu/dnpscholarlyprojects>



Part of the [Nursing Commons](#)

---

#### Recommended Citation

Debolt, Susan C., "Women's Stories of Reaching a Diagnosis of Endometriosis: A Qualitative Study" (2023). *DNP Scholarly Projects*. 80.

<https://repository.belmont.edu/dnpscholarlyprojects/80>

This Scholarly Project is brought to you for free and open access by the School of Nursing at Belmont Digital Repository. It has been accepted for inclusion in DNP Scholarly Projects by an authorized administrator of Belmont Digital Repository. For more information, please contact [repository@belmont.edu](mailto:repository@belmont.edu).

Women's Stories of Reaching a Diagnosis of Endometriosis: A Qualitative Study

Susan Debolt

Belmont University

Project Faculty Advisors: Dr. Steven Busby, PhD, FNP-BC

Faculty Reader/Advisor: Dr. Laura Gray, PhD, MSN, MA

Date of Submission: April, 15th, 2023

## Table of Contents

<b>Abstract.....</b>	<b>4</b>
<b>Introduction and Background.....</b>	<b>5</b>
<b>Problem Statement.....</b>	<b>6</b>
<b>Purpose.....</b>	<b>6</b>
<b>Review of Literature.....</b>	<b>7</b>
<b>Theoretical Model.....</b>	<b>9</b>
<b>Project Design.....</b>	<b>11</b>
Clinical Setting.....	12
Project Population.....	12
Data Collection.....	14
Instrument and Methods.....	14
Data Analysis.....	15
<b>Results.....</b>	<b>16</b>
<b>Discussion.....</b>	<b>27</b>
Implications for Practice.....	33
Strengths.....	35
Limitations.....	35
Future Directions.....	36
<b>Conclusion.....</b>	<b>36</b>
<b>References.....</b>	<b>38</b>
<b>Figure 1.....</b>	<b>49</b>
<b>Table 1.....</b>	<b>50</b>
<b>Table 2.....</b>	<b>52</b>

**Appendix A.....55**  
**Appendix B.....25**  
**Appendix C.....57**

## Abstract

Endometriosis is a chronic gynecological condition affecting 10% of reproductive-aged women worldwide. Women with endometriosis often experience a decreased quality of life compared to women without endometriosis. The average time to diagnosis is greater than six years for adult women and greater than 11 years for adolescents. Yet, there is little research investigating the pre-diagnostic experiences of women with endometriosis. This study aims to inform healthcare providers of patients' pre-diagnostic experiences of endometriosis in an effort to improve patient care. Using one-on-one, semi-structured online interviews and a qualitative design, this study explored six women's pre-diagnostic experiences of endometriosis. The main themes that emerged from the research were, *Seeking*, *Support* and *Finding*. From the theme *Seeking*, the participant's journeys to care and the day-to-day impact of endometriosis were explored. The theme *Support* underlined the advocacy and resilience each participant experienced. The theme *Finding* highlighted what the experience and outcome of having been diagnosed with endometriosis was like experientially for the participants. The participants' experiences revealed a lack of provider knowledge regarding endometriosis, the importance of positive support, and a strong patient-provider relationship. The findings of this study serve to advocate for the enhancement of endometriosis recognition and pre-diagnostic care of patients with endometriosis.

**Keywords:** Endometriosis, Endometriosis pre-diagnostic experience, Diagnostic experience of Endometriosis, Endometriosis Diagnosis

## **Introduction and Background**

Endometriosis is a chronic gynecological condition affecting one in ten women of reproductive age (Zondervan et al., 2020). Women with endometriosis often endure chronic pain (Ballard et al., 2008), have higher than average rates of depression (Gambadauro et al., 2019), and up to 50% experience infertility (Holoch & Lessey, 2010). The suffering endured by these women is often unnecessarily prolonged with an average diagnostic delay of six years or more for adult women and greater than 11 years for adolescents (Lamvu et al., 2020). Patients most commonly present with a myriad of non-specific symptoms, which may contribute to making a timely and accurate diagnosis challenging (Agarwal et al., 2021; Soliman et al., 2017). One integrated review found that women with endometriosis have an overall decreased quality of life and increased perceived stress levels compared to women who do not have endometriosis (Marinho et al., 2018).

Due to a reported high symptom burden and long diagnostic delay, it is important for researchers and clinicians to better understand women's experiences in the pre-diagnostic period. Since 86% of women experience symptoms before being diagnosed with endometriosis (Fuldeore & Soliman, 2017), understanding women's symptom burden may help advocate for timely disease recognition and treatment.

Endometriosis affects not only the patient but also their loved ones (Rea et al., 2020). Partners have been cited as having experienced helplessness, anger, and frustration regarding their inability to comfort patients (Cole et al., 2021). On a national level, patients with undiagnosed endometriosis have a statistically significant increase in healthcare utilization rates compared to patients without endometriosis (Soliman et al., 2018). Furthermore, in 2009, the economic burden of endometriosis was \$69.4 billion in America and was due to productivity loss

and direct healthcare costs (Soliman et al., 2019). The emotional, physical, and financial cost of endometriosis goes beyond the patient and should be a concern to society at large.

### **Problem Statement**

Although studies have been conducted regarding women's experiences of living with endometriosis, few studies have been focused on the pre-diagnostic period. After an extensive literature search, no studies have been located focusing exclusively on U.S. women's experiences during the pre-diagnostic period for endometriosis. Healthcare systems vary around the world regarding access to care, availability of specialists, affordability, and the referral processes for patients who have endometriosis. In addition, cultural stigma around pain and intimate relationships differs by culture. Therefore, research focusing solely on women in the U.S. may offer a better understanding of the pre-diagnosis timeframe in the context of the American healthcare system (Wren & Mercer, 2021).

### **Purpose**

The purpose of this study is to share the pre-diagnostic experiences of women with endometriosis as conveyed by the patients themselves. Analyzing and explicating emerging themes from the narratives of women's pre-diagnostic endometriosis experiences may reveal information that could inform providers and increase patient-centered care. The researcher is hopeful that the results of this study may inform a holistic understanding of women's experiences during the pre-diagnostic period. Clinicians, who are seen as the most influential facilitators in achieving or delaying a diagnosis of endometriosis (Greene et al., 2009), may learn from and utilize this study's results to improve patient care. Furthermore, arming other women with this information may validate and embolden them to seek care.

## Review of Literature

Endometriosis is an estrogen-dependent multifactorial gynecological disorder that affects women of reproductive age (Mear et al., 2019). According to the landmark study by Sampson (1927), the pathophysiology of endometriosis is attributed to retrograde menstruation, which introduces endometrial cells into the pelvic and abdominal cavity. Outside of the uterus, endometrial cells induce inflammation causing lesions, cysts, and nodules to develop (Prentice, 2001). Scarring, and adhesions may result, contributing to severe pelvic pain (Seear, 2009). If endometriosis is left untreated, the progression of disease may eventually lead to infertility (Fuldeore & Soliman, 2017).

Currently, more than four million reproductive-age women have been diagnosed with endometriosis in the United States (Fuldeore & Soliman, 2017). Yet, it is estimated that six in ten cases of endometriosis are undiagnosed (Morassutto et al., 2016), which currently equates to more than six million American women lacking an accurate diagnosis (Agarwal et al., 2019a). Researchers suggest that delays in onset to diagnosis often exist, but no clear benchmark for that time frame has been established.

Common symptoms of endometriosis include pain, infertility, painful menstruation, dyspareunia, abdominal pain, painful bowel movements, and abnormal uterine bleeding (American College of Obstetricians and Gynecologists, 2021). Disease severity is staged at the time of surgery and ranges between five stages where stage one indicates a minimal disease process and stage five indicates a severe process. (American Society for Reproductive Medicine, 1997). Surprisingly, a significant correlation between disease stage and symptom severity has not been found (Denny et al., 2009).



Women with endometriosis commonly acknowledged believing painful menstruation is normal (Agarwal et al., 2021; As-Sani et al., 2019; Ballard et al., 2006; Simpson et al., 2021; Sims et al., 2021; Stratton, 2006). Furthermore, women have stated that U.S. culture led them to believe endometriosis symptoms, such as dysmenorrhea, are normal (Seer, 2009; Sims et al., 2021; Simpson et al., 2021). Research suggests that healthcare providers may normalize the symptoms of endometriosis, confusing patients, and potentially delaying care (Agarwal et al., 2021; As-Sani et al., 2019; Ballard et al., 2006; Denny, 2009; Greene et al., 2009; Stratton, 2006; Simpson et al., 2021; Wren & Mercer, 2021).

Endometriosis patients also commonly report a decrease in quality of life. In one study, a lack of understanding and support from their family and friends contributed to a reported decrease in quality of life (Mastrangelo & Turnbull, 2021). Furthermore, a higher number of endometriosis-related symptoms have been found to correlate with a decreased quality of life (Soliman et al., 2017). Of endometriosis related symptoms, chronic pain, more than any other symptom is noted to produce significant negative effects on women's daily lives (Ballard et al., 2006; Fourquet et al., 2011; Norman et al., 2021; Rea et al., 2020). Mental health disorders such as depression and anxiety are more common among women with endometriosis than women without endometriosis (Niekerk et al., 2022).

Patients often report that social relationships suffer because of the detrimental effect endometriosis symptoms have on their energy levels (Cole et al., 2021; Wren & Mercer, 2021; Grogan et al., 2017). Women also frequently acknowledge that their intimate relationships suffer. The most common cause of tension in intimate relationships was cited to be pain with sexual intercourse (Agarwal et al., 2021; As-Sani et al., 2019; Rea et al., 2020). Finally, women often commented feeling as if they were a burden to their loved ones (Rea et al., 2020; Denny, 2009).

Feelings of being burdensome contributed to women concealing or downplaying their symptoms to family and friends leading to feelings of isolation (Grogan et al., 2017).

### **Theoretical Model**

The Conceptual Model of Health-Related Quality of Life (CHRQoL), Figure 1, served as the conceptual framework for the current study. The CHRQoL is a revision of the Wilson and Cleary model of health-related quality of life and serves to simplify the original model (Ferrans et al., 2005). Taking a holistic approach to defining quality of life, the CHRQoL model includes how the characteristics of an individual and their environment influence their biological function, symptoms, functional status, general health perceptions, and overall quality of life (Ferrans et al., 2005). Characteristics of the individual are relatively unchangeable and include "demographic, developmental, psychological, and biological factors" that serve to influence health outcomes (Ferrans et al., 2005, p. 337). Characteristics of the environment include interpersonal or social influences, such as family, friends, healthcare providers, and one's physical environment (Ferrans et al., 2005). Often, chronic conditions, such as endometriosis, create an impact that expands beyond one's physical self (Bezner, 2015).

The five patient outcomes, in order, include biological function, symptoms, functional status, general health perceptions, and overall quality of life (Ferrans et al., 2005). The outcomes are organized in an ascending linear fashion to demonstrate the progressive influence each has on the next. Biological function is viewed as a continuum of ideal function, and changes in the continuum have a ripple effect on the four additional outcomes. Individual characteristics affect one's biological function through biological vulnerability and resilience. Environmental characteristics affect biological function through physical and social means, such as exposure to endocrine disruptor chemicals (Ferrans et al., 2005; Polak et al., 2021).

Shifting the focus from the cellular level to the person level, symptoms are viewed as "a person's perception of an abnormal physical, emotional, or cognitive state" (Wilson and Cleary, 1995, p. 61). Common symptom dimensions include frequency, intensity, distress, cause, treatment, and consequences (Ferrans et al., 2005). As humans experience sensations, the sensations are cognitively processed with background information of previous similar experiences and information from the environment. A person's experience, evaluation, and interpretation of symptoms integrate characteristics of the individual, such as personality characteristics, and characteristics of the environment, such as interactions with healthcare providers (Ferrans et al., 2005).

According to the CHRQoL, functional status is defined as the optimization of a person's remaining function and includes four dimensions: functional capacity, functional performance, functional capacity utilization, and functional reserve (Ferrans et al., 2005). Functional capacity refers to one's ability to perform optimally in each domain of their life. Functional performance refers to one's ability to perform tasks on a day-to-day basis and is influenced by personal choices, values, and motivation. Capacity utilization refers to the amount of functional capacity that is used daily. The functional reserve is the difference between capacity utilization and functional capacity. When functional capacity declines due to health issues, a person may have to use a higher amount of their capacity utilization or decrease daily activities. Individual characteristics, such as motivation, and environmental characteristics, such as social support, greatly influence an individual's functional status (Ferrans et al., 2005).

General health perceptions are an overall evaluation of one's health (Ferrans et al., 2005). Perceptions are subjective and build on the earlier components of the model. The strongest predictors of general health are physiological processes, symptoms, and functional ability.

Gender differences exist in rating overall health. Women have been found to include life-threatening and nonlife-threatening diseases when rating their health as opposed to men, who are more inclined only to consider life-threatening diseases (Ferrans et al., 2005). The above suggests that women are more likely to include endometriosis, a nonlife-threatening disease, in their overall health quality assessment.

The CHRQoL is a good fit for the present study as it encompasses a multidimensional view of the influences that affect a patient's overall quality of life. Women with endometriosis often experience long diagnostic delays and chronic symptoms (Norman et al., 2021). It is plausible that over time, the effects of chronic endometriosis symptoms begin to seep into other facets of a woman's life, creating a complex dynamic. The CHRQoL allowed the researchers to better anticipate and understand how to frame participants' experiences in a meaningful way.

Two semi-structured participant interview questions were developed utilizing the overarching factors of the model, characteristics of the individual and characteristics of the environment, of the CHRQoL model. Participant responses organically encompassed the four central factors: biological function, symptoms, functional status, and general health perceptions, creating a summation of overall quality of life. Conceptualizing the building blocks of one's quality of life affords a more in-depth understanding of a patient's pre-diagnostic experience and how it plays into their overall perception of the experience. For these reasons, the CHRQoL is a good fit for appreciating the experiences of women and the factors that may influence those experiences.

### **Project Design**

This study employed qualitative methodology which affords the researcher a better understanding of the meaning of a phenomenon. Qualitative descriptive methodology was

utilized to describe the experiences and perceptions regarding topics about which little is known (Sandelowski, 2010). The use of this methodology allows researchers to understand the unique and diverse experiences among participants experiencing endometriosis (Bradshaw et al., 2017). Qualitative descriptive methodology is appropriate for this study as little is known about the perceptions of women experiencing symptoms of endometriosis before a surgical diagnosis is achieved. Through the lived experience of women who have struggled with this disease, it is hoped that specific themes and meaning may emerge that will assist health care providers with understanding and caring for these women. This study received approval for exempt status by the Institutional Review Board at Belmont University.

### **Clinical Setting**

Women who have been surgically diagnosed with endometriosis and who agreed to participate, were interviewed. The transcripts of their interviews served as raw data. All interviews were conducted over the two-way communication platform, Zoom. Video calling has been found to be an economical, convenient, and safe method to interview participants (Hanna, 2012). As of April 2021, 93% of American adults use the internet, suggesting that access to video calling is nearly universal in American culture (Pew Research Center, 2021). Participants had the freedom to participate in the interview from the location of their choosing, yet the principal investigator encouraged participants to choose a private space in which to be interviewed. During the interview, the researchers remained in a private room and wore noise-cancelling headphones to best protect the participant's privacy.

### **Project Population**

The population of this project was exclusive to women with a confirmed diagnosis of endometriosis. Inclusion criteria includes having been assigned the female sex at birth, being 18

through 51 years old, having had a surgically confirmed diagnosis of endometriosis, living in the United States full time, and being English speaking. Exclusion criteria include having had endometriosis related care outside of the United States and having been diagnosed with endometriosis outside of the United States.

Participant recruitment was conducted through a combined approach of convenience, snowball, and purposive sampling. Convenience sampling was conducted by posting recruitment material on endometriosis Facebook support groups. At the conclusion of each interview, the researcher engaged in snowball sampling by asking participants to share the opportunity to be a part of the study with other women who have endometriosis. Additionally, purposive sampling was utilized to recruit participants whom the researcher believed would be a good fit for the study. Participants were deemed a good fit if they met study eligibility requirements and expressed interest in being a part of the study. These participants were supplied with a link to an online description of the study. To mitigate potential feelings of coercion, the researcher asked the potential participants to "consider joining the study" and allowed them ample time to decide.

Because qualitative researchers employ the technique of concept or theme development, the concepts or themes are considered saturated when no new information emerges (Fusch & Ness, 2015). Therefore, the specific number of participants required would not be known and was not pre-determined. In addition, due to the time constraints of the project, true data saturation was not a goal for this project. In addition, in keeping with the philosophical underpinnings of qualitative research, no claims of generalizability will be made (Carminati, 2018; Salkowski, 2010).

## **Data Collection**

The principal investigator recruited participants who had lived experience with endometriosis and conducted one-on-one interviews regarding their day-to-day experiences with undiagnosed endometriosis. The recorded interviews were reviewed by the principal investigator in conjunction with an experienced qualitative research advisor. Data that emerged were analyzed, sorted, and themes were developed. The themes are described based on their unique properties and dimensions.

## **Instrumentation and Methods**

Word for word transcribed participant interviews served as raw data for this project. An interview script was utilized and consisted of an opening statement informing the participant of what to expect during the interview followed by three open-ended questions. The interview script may be viewed in Appendix A. The questions were posed one at a time and participants were allowed as much time as they required to answer each question. The interview questions were crafted using the CHRQoL model's primary influencing themes, the characteristics of an individual and environmental characteristics. Additionally, the third question related to the patient's overall perception of their quality of life. Prior to the initiation of the research, a pilot interview was conducted with a qualitative research expert so that the principal investigator was able to practice interviewing and receive formative feedback from the expert.

Participant recruitment, data collection and data analysis began in late September 2022 and went through December 2022. The research began with the qualitative research expert conducting a bracketing interview with the principal investigator. Complete objectivity may be difficult as qualitative researchers are instruments in research and therefore must attempt to avoid bias by remaining cognizant of their own potential biases (Corbin & Strauss, 2008; Flick,

2009). The principal investigator has over four years of occupational experience working with endometriosis patients in a pelvic pain specialty clinic. Previous knowledge about endometriosis will allow the principal investigator to better understand the content under study. This heightened sensitivity to nuances of meaning is referred to as theoretical sensitivity (Corbin & Strauss, 2008).

Reflexive journaling, also known as field notes, was utilized by the principal investigator at the conclusion of each interview. Corbin and Strauss recommend the use of reflexive journaling as a tool to reflect on the investigator's ideas and perceptions of what transpired during interviews and the thoughts researcher had immediately following each interview (2008). The goal of reflexive journaling is to highlight how the research is shaping and changing the researcher's perceptions of the emerging data (Corbin and Strauss, 2008). When reflexive journaling is utilized, the author is kept keenly aware of the potential for the imposition of bias and allowed to permanently capture thoughts that may impact future interviews or analysis of data (Corbin & Strauss, 2008).

### **Data Analysis**

Line-by-line open coding was carried out in tandem by the principal investigator and the experienced advisor on all transcripts. Multiple coders improve trustworthiness, data quality, and mitigates subjectivity (Church et al., 2019). Codes were sifted and sorted according to their frequency and relevance and named increasingly abstractly as they were developed and subsequently elevated to the status of "theme." Codes do not rise to the level of themes but support them by becoming properties of themes or detailed dimensions of properties (Corbin & Strauss, 2008). Incident-to-incident comparison was used to check for similarities and differences between sets of circumstances conveyed by participants that appeared to be similar.



NVivo software was utilized to transcribe and store data. Memos were recorded in NVivo to record decision-making through each phase of the study, serving to bolster a data audit decision trail (Birks et al., 2008). The principal investigator conducted randomized member checks at the end of the interview process to ensure the accuracy between the researcher's understanding of the data and the patients' intended meaning. Methods of rigor in this study included the pre-study bracketing interview, randomized member checking, the use of an external expert, the assistance of a second reader, and adherence to accepted methods of qualitative research (Johnson et al., 2020).

### **Results**

A total of six women participated in this study. All women identified as Caucasian. Three women (50%) were between the ages of 25 and 34, two women (33.3%) were between the ages of 35 and 44, and one woman (16.7%) was between the ages of 45 and 51. Most participants (66.7%) were from the Southeast region of the United States, and the remaining participants were from the Southwest region (33.3%). For a complete list of the participant's sociodemographic characteristics, please see Table 1.

The qualitative analysis methods of Corbin and Strauss (2015) were used to analyze, sort, and name the data. To sift the voluminous data, where necessary, abstract names were applied to the data. Concept naming was employed in a hierarchical structure, listed here from highest to lowest: theme, category, property, dimension, and sub-dimension. The highest-level concepts are identified as "themes." The term "category" is utilized to denote a high-level concept that is subordinate to a theme. The name "property" outlines a lower-level concept that is used to characterize a category further. The term "dimension" is a low-level concept utilized to offer

specificity to a property. Lastly, the name "sub-dimension" denotes the lowest concept level and is the most descriptive.

Three themes emerged from the data (1) *Seeking*, (2) *Finding*, and (3) *Support*. The theme *Seeking* includes two high-level categories (1) *Journey to Care* and (2) *Day-to-Day Impact*. Three categories emerged out of the theme *Finding*, which includes, in chronological order, (1) *Diagnosis*, (2) *Impact of Diagnosis*, and (3) *Reflection*. The theme *Support* yielded two categories, (1) *Advocacy* and (2) *Resilience*, and was found to exert influence throughout the participant experience until diagnosis.

To determine the importance of the information, the PI used item frequency and relevance in the form of theoretical sensitivity to determine the hierarchy of the ultimate thematic structure (Corbin & Strauss, 2015). All subservient properties and dimensions are identified in detail below. See Appendix C for a depiction of the thematic structure that emerged in this study. In the image, the title "Patient's Pre-Diagnostic Experiences of Endometriosis" was transposed and not actual data. All other headings below the title "Patient's Pre-Diagnostic Experiences of Endometriosis" are actual data. Where appropriate, in vivo code exemplars (participant's exact words) were used as evidence and for emphasis. Please see Table 2 for a summarized list of themes with exemplar in vivo quotes.

### **Seeking**

The first theme to arise from the data, *Seeking*, embodies the barriers, facilitators, and daily impact women face when searching for an explanation for their symptoms. The theme includes two high-level categories (1) *Journey to Care* and (2) *Day-to-Day Impact*. The theme *Support* positively impacts both categories.

### *Journey to Care*

The category *Journey to Care* encapsulates what mental and physical barriers participants stated they encountered. Participants also identified several facilitators that led to a diagnosis and were also listed. Six properties further emerged from the data (1) *Acknowledgement of Seriousness*, (2) *Overcoming Symptom Normalization*, (3) *Information Gathering*, (4) *Self-Treatment*, (5) *Frequent ER Visits*, and (6) *Healthcare Provider*.

The first property, *Acknowledgement of Seriousness*, identified that participants commonly experienced identifying a definite difference between their gynecological symptoms compared to other women's symptoms. The participants frequently described a need for bothersome symptoms to be considered life-altering prior to decisively seeking care. One participant acknowledged, "I came to a point... I was like, actually no, this is not okay, this pain is not okay, or these things that I'm living with are not okay, and that is when I finally sort of switching doctors until I knew I found the right one." Once participants' symptoms had become life-altering, providers were commonly credited with being open to exploring their symptoms further. Another woman said "I am losing things that I love in life" when referring to what led her to seek treatment. Infertility, specifically, drove some participants to push providers to consider the diagnosis of endometriosis. The dimensions (1) *Worsening of Symptoms*, (2) *Provider Acknowledgement*, (3) *Impetus for Treatment Seeking*, and (4) *Infertility* were identified in this category.

In the second property, *Overcoming Symptom Normalization*, the dimensions (1) *Self*, (2) *Provider*, (3) *Peers*, and (4) *Mother* emerged as dimensions. Participants frequently reported the normalization of symptoms. Normalization most often occurred by the participants as they believed their symptoms to be no worse than what other women endured. For example, one

participant stated "I genuinely just felt like I was being a big baby" while discussing how she believed she handled her menstrual symptoms compared to other menstruating women. Providers were stated to be the second most common source of normalization. Another participant explained, "I bled for three and a half months... when I went in, they told me it's perfectly normal, and that's when I started to begin like I felt like I was actually crazy." One woman mentioned that peers were a source of her symptom normalization, "Friends are just being like, come on... take some ibuprofen like, you're fine... I have bad cramps too." Additionally, one participant stated that her mother, despite having surgically diagnosed endometriosis, normalized the participant's symptoms; "My mom was like... periods are painful... you're going to have to deal with that. I'm sorry, you're a woman."

The third property is entitled *Information Gathering*. Multiple women shared that finding information related to endometriosis was difficult. Half of the participants stated they independently searched for information. Overall, participants felt there was limited information about endometriosis readily available, and they carried the burden of seeking it out. Multiple women had not heard of the disease, and one did not know anyone who had experienced it. The dimensions (1) *Individual Research* and (2) *Limited Information* were identified in this property.

To gain symptom relief, participants commonly acknowledged trialing at-home interventions prior to seeking professional care. The name *Self-Treatment* was given to the fourth property. Participants stated they used accessible interventions such as non-steroidal anti-inflammatory medications and heat to relieve their symptoms. Sometimes symptoms were stated to persist, and one participant acknowledged using trial and error to determine what would best relieve her symptoms. The dimensions (1) *Interventions* and (2) *Trial and Error* emerged.

The fifth property is entitled *Frequent ER Visits*. One participant stated that she frequently went to the emergency room due to the severity of her symptoms. She acknowledged that she had lost count of how often she had been to the emergency room to seek care. She would receive a similar workup each time without significant findings and would be discharged without an explanation for her symptoms.

The dimensions that emerged in the sixth category, *Healthcare Provider*, include (1) *Misdiagnosis*, (2) *Diagnostic Barriers*, (3) *Inappropriate Referral*, (4) *Multiple Providers*, and (5) *Specialist*. The dimension, *Specialist* produced the sub-dimensions (1) *Dismissive*, (2) *Not listened to*, and (3) *Diagnostic Facilitator*. The majority of the participants discussed being misdiagnosed before receiving an accurate endometriosis diagnosis. Some participants stated that their providers discouraged them from exploring an endometriosis diagnosis. One participant was referred to an inappropriate specialist for further surgical endometriosis care and was responsible for self-referring to the correct specialist. The concern about having seen multiple providers for endometriosis symptoms prior to receiving a diagnosis was addressed by some women. Participants spoke about specialists, gynecologists, and reproductive endocrinologists, being dismissive toward their symptom concerns. It was also identified that women felt they were not listened to by specialists due to feeling as if the specialists they saw were protocol driven. Multiple women stated that seeking care from a physician with specialized endometriosis training was a facilitator to receiving a diagnosis.

### ***Day-to-Day Impact***

The category, *Day-to-Day Impact*, highlights the influence undiagnosed endometriosis had on participants' daily lives. Five properties emerged (1) *Infertility*, (2) *Symptoms*, (3) *Loss*,

(4) *Difficulty with Common Activities*, and (5) *Quality of Life*. The properties were organized according to their frequency and relevance.

The first property to emerge was *Infertility*. Five dimensions emerged (1) *All-Consuming*, (2) *Depression and Anxiety*, (3) *Exhaustion*, (4) *Physically Difficult*, and (5) *Hope of*. Infertility was discussed by almost all participants and was found to carry significant meaning to the participants. Women discussed making physical and financial sacrifices in the hopes of being able to conceive. Multiple participants felt they were fixated on their infertility leading to disruption of happiness; "Sometimes it would just hit me and then I... walk through that grief again, and I'm like, why can't I just enjoy my life?" Some women further acknowledged depression and anxiety related to infertility. The physical demands of fertility treatments were said to be taxing; "It was just such an arduous journey, and we're like, is this the end of the road? I don't know... I was kind of at the end of the road like I was so worn out." However, participants who desired fertility and had not yet conceived remained hopeful that they would become pregnant with proper endometriosis management.

The second property identified was *Symptoms*. Six dimensions emerged and are listed by their reported frequency (1) *Pain*, (2) *Heavy Periods*, (3) *Gastrointestinal Upset*, (4) *Mood Changes*, and (5) *Infertility*. Symptoms ranged between each participant from mild to severe. In describing the severity of her symptoms, one woman acknowledged that her endometriosis symptoms masked sepsis; "I had sepsis, and I had no idea because I'm in pain all the time, and I didn't know that I was actually so sick." Pain was acknowledged by all participants except one who had no symptoms of endometriosis outside of infertility. Some participants mentioned heavy periods, gastrointestinal upset, mood swings, and infertility were all mentioned at the same

frequency. Anxiety and depression related to undiagnosed endometriosis were cited by one participant to have influenced unpredictable mood changes.

The third property, *Loss*, is further characterized by four dimensions (1) *Sexual Intimacy*, (2) *Fertility*, (3) *Physical Activity*, and (4) *Hope of Occupation*. Some of the participants said that they were not able to engage in sexual intercourse due to pain. Multiple women stated they experienced a loss of sexual intimacy with their husbands; "This just feels like a chore... this isn't even pleasant at this point." Multiple women attributed their loss of fertility to undiagnosed endometriosis. One participant was a college athlete and could not consistently compete due to the symptoms of endometriosis. Another participant explained that she was training to become a professional ballerina, but she believed her endometriosis-related symptoms prevented her from practicing at the frequency required to be successful.

The fourth property to emerge was *Difficulty with Common Activities*. Participants acknowledged needing to decrease physical activities, such as working out, due to their endometriosis symptoms. Some acknowledged that their symptoms made going to school or work difficult; "Some days it was just a real, real struggle to get up and to go to work." They felt as if they had to tap into a deeper power to get through their day when symptoms were severe. Some women found they needed to alter their lives to accompany flairs of symptoms, such as missing out on their otherwise regular activities.

The property, *Quality of Life*, was the sixth and last property to emerge. Participants commonly discussed how undiagnosed endometriosis negatively impacted their lives. Their experiences were not isolated to their physical being but infiltrated into social, occupational, and relational dimensions. When referring to endometriosis-related symptoms, one participant acknowledged, "They did impact my everyday life, my quality of life, I mean, In a major way."

## **Finding**

The second theme to emerge from the data was *Finding*, which represents the reported meaning and impact receiving a diagnosis had on participants. The Theme afforded one high-level category, *Diagnosis*, one medium-level category, *Impact of Diagnosis*, and one low-level category, *Reflection*. The categories were organized based on chronological order.

### ***Diagnosis***

Participants reported mixed feelings toward receiving a medical diagnosis. All participants reported experiencing a perceived delay in diagnosis. At diagnosis, most participants stated they did not have an adequate understanding of the disease after discussion with their clinician. Two properties emerged from *Diagnosis* (1) *Delayed Diagnosis* and (2) *Educational Material*.

The first property, *Delayed Diagnosis*, was unanimously reported and emerged as a perceived delay in receiving an endometriosis diagnosis. The dimension, *Frustration* further emerged and was directed toward the medical system and healthcare providers. Multiple participants felt they could have been diagnosed sooner if they had been better listened to by healthcare providers. Furthermore, some women discussed that diagnostic time could have decreased if healthcare providers had a more robust understanding of endometriosis. When discussing infertility related to endometriosis, one participant stated, "People are spending thousands of dollars and putting their bodies through like a lot of trauma, both physically and emotionally... I would hope that providers would become more informed."

*Educational Material* was the second property to emerge. Four dimensions further arose from the property *Educational Material*, (1) *Appreciation for*, (2) *Not Enough*, (3) *Not Helpful*, (4) *Overwhelming*. The participants said that they were grateful for the information given to



them by their healthcare provider regarding endometriosis but found it laden with medical jargon. Others found that the literature the provider gave them addressed superficial topics leading it to be unhelpful. Outside of their provider's education, they reported that finding credible information was difficult and acknowledged that the internet was the most common place they turned to for information.

### ***Impact of Diagnosis***

Four properties emerged from the category *Impact of Diagnosis*, (1) *Fertility*, (2) *Care Enhancement*, (3) *Validation*, (4) *Peace of Mind*, and (5) *Recognizing Commonality*. Some participants found that having an accurate diagnosis positively impacted them. One participant who had previously struggled with infertility became pregnant shortly after having her first laparoscopic endometriosis excision surgery. Another participant acknowledged that providers understood how to better care for her knowing that she has endometriosis; "I can go to my fertility specialist and say, here's what's been going on, and he can look at that and say, okay, you've had stage one endometriosis, and this is how this will impact our fertility treatment moving forward." Multiple participants described feeling validated, having a name for their symptomology; "Glad to know that I wasn't crazy and that these things are happening in my body like there's a name to them." Another woman acknowledged that having the diagnosis was reassuring; "Just knowing that's what's been going on gave me incredible peace of mind and even now into my fertility journey." Multiple participants were surprised to discover how common endometriosis is despite not knowing about it.

### ***Reflection***

In the category *Reflection*, some participants reflected on their experiences and advice for other women. The dimensions (1) *Medical Self-Advocacy*, and (2) *Advice for Other Women*

emerged. Multiple women said they wish they had better medical self-advocacy; "I did not know how to speak up for myself medically.... I did not know how to have healthy conflict with people that I viewed as authorities like doctors...". Another woman stated, "I wish... I had been more forceful in and in pushing for treatments... I just trusted that my doctors knew, and you know, it felt very isolating." One woman encouraged others not to rationalize their symptoms and seek care if something seems abnormal; "Do not underestimate certain symptoms in your life that need to be explored more deeply... we tend to make excuses or overlook or rationalize and I think it's important to do the due diligence and really see it through." A participant acknowledged that she would use her lived experience of the diagnostic journey to empower her daughters; "I will be an advocate for my girls, and I will teach them to be advocates for their body because of this journey."

### **Support**

The theme, *Support*, was found to exert influence on both themes, *Seeking* and *Finding*. In this body of participants, *Support*, and the subservient components, appeared to bridge seeking and finding a diagnosis. *Support* was embedded in much of the theme of *Seeking*. However, no participant in this sample stated that support was bolstered when receiving a diagnosis. Two categories emerged from the theme *Support*, (1) *Advocacy* and (2) *Resilience*.

### **Advocacy**

The category *Advocacy* yielded two properties (1) *Support Systems* and (2) *Self-Advocacy*. According to the participants, advocacy is found intrinsically and extrinsically, but often occurring in conjunction. Advocacy was a player in facilitating a diagnosis for participants.

The first property, *Support Systems*, highlights the extrinsic support women frequently cited. Women commonly mentioned family as being positive support. Mothers, specifically,

were noted by multiple participants to be a positive influential support system; "My mom... was just constantly supportive, like, okay, like, we're going to figure this out... there's something out there that will help you. We've just got to find it. So, she was just like a voice of positivity." Friends, and further, friends who were specifically healthcare providers, positively impacted participants' journeys. When discussing her symptoms with a nurse who also had endometriosis, one participant explained that "It was like this really weird, beautiful like space... she knew what I was going through," adding, "I felt very comforted in that moment to know that I wasn't alone." One participant stated that a Facebook support group provided a supportive community that she was not able to find elsewhere. The dimensions (1) *Family*, (2) *Friends*, (3) *Women with Endometriosis*, and (4) *Online Support Groups* arose from this property.

The second property, *Self-Advocacy* proved to be relevant and important to the women who discussed it, although it was not as frequently mentioned as extrinsic support systems. Self-advocacy was found to be innate, previously acquired, built during the diagnostic process, or occurred in combination. Some women described the diagnostic process as isolating, and felt they had to accept being their own advocate during their diagnostic journey. One participant explained, "I was just kind of my own researcher and self-advocate." Almost all women stated that medical self-advocacy was uncomfortable, even those who had a profession or background in healthcare.

### ***Resilience***

The Second category, *Resilience* highlights the need to withstand difficulties. Some women described tapping into resilience while other women stated that resilience was created through their pre-diagnostic journey. Although participants commonly discussed the difficulties of endometriosis, one participant speculated that her care journey strengthened her; "Might have

had a positive impact...because I was able to overcome the pain, you know, deal with it, go through life." More commonly, though, women stated they needed to do what they could to get through a day; "You'd have to find ways to dig deep and go on when you are in pain at school; at work, when I was later in life." Resilience was demonstrated by all women and served as an essential trait during their diagnostic journey.

### **Discussion**

The purpose of this study was to summarize and share the pre-diagnostic experiences of women with undiagnosed endometriosis with healthcare providers. The findings of this study may promote endometriosis symptom recognition by providers and improve patient-centered care. The experiences women reported portrayed a difficult journey to reaching an accurate endometriosis diagnosis. The main findings of this study included identifying common diagnostic barriers and facilitators, the day-to-day impact of undiagnosed endometriosis, the importance of support during the diagnostic journey, and participant outcomes after receiving an endometriosis diagnosis. This study's findings are consistent with previous studies regarding a patient's pre-diagnostic experiences.

Multiple barriers, such as symptom normalization and the acknowledgment of symptom severity, often needed to be overcome before women sought medical care. This finding is consistent with Young et al. (2015), a systematic review that synthesized qualitative research on women's experiences with endometriosis. The researchers highlighted the importance of women acknowledging symptom severity before seeking medical care (Young et al., 2015). Sims et al. (2021) found that symptom normalization was common in their study group. Endometriosis symptoms were most frequently normalized by healthcare providers and women's social support systems (Sims et al., 2021). The current study found that normalization by the participant's social

support systems, especially by a maternal figure, directly correlated with the participant's normalization of her symptoms.

Women often stated that clinician-provided educational material was unhelpful, leading to patient-initiated educational searches. Women reported internet support groups as being helpful, particularly Facebook groups. A qualitative study comprised of women from the U.S. and the U.K. found that women stated online support groups afforded a safe space to share their experiences about endometriosis (Shoebottom & Coulson, 2016). However, women questioned the reliability of the information they found in the online groups because the information posted was not validated (Shoebottom & Coulson, 2016).

Few women reported utilizing medical research articles which is consistent with Whelan (2007), who found that women prioritized online support groups and literature written for lay audiences over medical research articles. Medical research articles may be found to be confusing and inaccessible as they are written at a higher reading level, may be too specific, and are often blocked by a paywall. On the other hand, online support groups may be convenient and free to access, and participants may have prior experience navigating the host platform, such as Facebook.

Whelan (2007) also concluded that women subscribed to a knowledge hierarchy with experiential knowledge at the top, research in the middle, and provider opinion at the bottom. All levels of knowledge were utilized by the participants in this study. Still, like Whelan's findings, multiple participants in this study acknowledged that experiential knowledge from oneself and other women with endometriosis was the most reliable form of information. As endometriosis is marked by many subjective symptoms, such as pain, the bond between someone who understands one's situation may promote deep trust and connection. This trust and connection

could lead to a perception of the person being a more reliable source of information than a source who has not had a personal experience with the symptoms.

Women in this study stated they felt that a lack of provider knowledge about endometriosis further delayed receiving a diagnosis. Another qualitative study had similar findings in that a lack of provider knowledge about endometriosis led to normalizing patients' symptoms, perpetuating a diagnostic delay (Márki et al., 2022). This idea is plausible as an inadequate understanding of the symptoms of endometriosis may lead a provider to overlook common symptoms or not consider endometriosis a differential.

Support was integral to each participant's diagnostic journey. The importance of support was similar to the findings of one qualitative study (Wren & Mercer, 2021), which concluded that a key component of a woman's diagnostic journey was an effective support system. The support system was integral to mitigating emotional distress, which improved the participants' quality of life (Wren & Mercer, 2021). Most participants in this study had good social support systems. However, some participants did not have adequate social support and thus had to rely more heavily on self-support. Though mainly focusing on poor support systems, women in previous studies acknowledged positive and negative social support experiences (Mastrangelo & Turnbull, 2022; Grogan et al., 2018). All women demonstrated resilience throughout their diagnostic journey. Women who reported having decreased social support acknowledged leaning on resilience more heavily than those with good social and provider support.

Maternal support was stated to be of particular importance. Family support was mentioned, but multiple participants identified mothers as contributing to good and poor support. This occurrence could be due to the feminine nature of menstruation, making it easier for

daughters to confide in their mothers. Additionally, mothers may have a perceived shared lived experience with symptoms of menstruation and are uniquely trusted by their daughters.

Most participants stated that medical self-advocacy was hard, especially when a perceived unequal power dynamic existed. Participants acknowledged they did not know how to talk to doctors and found it uncomfortable to confide in a provider who dismissed their symptoms. Smith and Huntoon (2014) propose "modesty norms," American gender norms indicating women should be polite, quiet, and modest, may negatively influence self-promotion among U.S. women. Furthermore, Buello (2020) found that women with endometriosis often had trouble describing their pain to providers, potentially leading providers to misunderstand the true meaning of their pain. Additionally, multiple studies found that providers were likely to trivialize symptoms of endometriosis which are often non-specific (Van Der Zanden et al., 2021; As-Sanie et al., 2019; Grundstrom et al., 2018).

Many women's experiences revolved around the negative impact of their endometriosis-related symptoms. For women who had difficulty conceiving, infertility was stated to be the most bothersome symptom. However, for those who were not experiencing infertility, pelvic pain was the most critical negative experience reported. This finding is consistent with Grogan et al. (2018) and Gater et al. (2020), who stated pelvic pain was the most distressing symptom reported among women surveyed. Unlike the current study, Grogan et al. (2018) found that when pain was compared to infertility, pain was more bothersome than infertility for all women included in their study. The high burden of infertility could be a unique finding to this participant group because most participants desired conception or recently struggled to conceive. Women in other studies may not have been ready to conceive or could have had a higher level of overall perceived pain compared to the current group of women.

Endometriosis symptoms were attributed by all participants to have decreased their quality of life. The negative impact of endometriosis on women's quality of life is well documented in the literature (Van Niekerk et al., 2022; Lamvu et al., 2020; Soliman et al., 2017). Furthermore, multiple studies found that endometriosis negatively affected all aspects of participants' daily activities (Rae et al., 2020; Young et al., 2015). Participants in this study lost meaningful functions, such as physical activity, fertility, and sexual intimacy, due to symptoms of endometriosis. During symptom flairs, daily activities were more difficult for participants, and some acknowledged that they sometimes resorted to pushing through to endure a typical day. Depression and anxiety were acknowledged among the participant group. One meta-analysis concluded that women with endometriosis had increased levels of depression compared to women without endometriosis (Gambadauro et al., 2019). Another article concluded that the severity of endometriosis symptoms strongly correlated with the prevalence of depression (Warzecha et al., 2020). The pre-diagnostic period of endometriosis may be an especially vulnerable time for patients with undiagnosed endometriosis as they do not have validation of their symptoms through a diagnosis. Additionally, a decreased quality of life may prove more evident in the pre-diagnostic period, as women could have greater uncertainty and a lack of effective support.

Although there were predominately negative accounts of endometriosis, some participants acknowledged a silver lining of the disease. One participant stated that her diagnostic journey contributed to developing resilience. Others said they eventually found a trusted provider who would listen to them. These providers were most often endometriosis specialists or had advanced knowledge about endometriosis. Lastly, multiple patients stated that their diagnostic journey sparked a desire to be an advocate for other women. Most commonly,



this was fueled by a desire to help other women avoid the suffering they experienced.

Although most endometriosis-related literature focuses on negative patient experiences, one study from the Netherlands assimilated participants' pre-diagnostic journeys to a "double-edged sword" and contained both positive and negative experiences (Grundström et al., 2018). The negative aspect stemmed from the provider's disbelief of symptoms and lack of understanding of endometriosis (Grundström et al., 2018). The positive side acknowledged that some providers made participants feel heard and acknowledged, which boosted their self-esteem (Grundström et al., 2018). The "double-edged sword" effect was found to be true in this study's participants.

The diagnostic delay of endometriosis is well documented in the literature (Fernley, 2021; Wren & Mercer, 2021; Lamvu et al., 2020). All the women in this study acknowledged experiencing a perceived diagnostic delay. The delay contributed to participants voicing the need for greater provider education about endometriosis. Although most participants believed their medical provider contributed to a diagnostic delay, unlike the findings of Wren and Mercer (2021), participants in this study did not lose faith in medical providers but felt the medical system at large had contributed to their diagnostic delay.

According to Hawkey et al. (2022), diagnostic delays were partially attributed to women delaying seeking treatment. The need to acknowledge the seriousness of symptoms and overcome symptom normalization were both identified as barriers that needed to be overcome before a woman sought treatment. It is plausible that this would account for a portion of the diagnostic delay from symptom onset and would align the present study's findings with those of Hawkey et al. (2022). Once patients sought medical treatment, they often cited having their symptoms normalized by at least one provider. This finding is consistent with a growing number

of research articles (Sims et al., 2021; Pettersson & Berterö, 2020). Furthermore, multiple studies found that a major influence of delayed diagnosis was healthcare providers not listening to patients (Cole et al., 2020; Hawkey et al., 2020; Young et al., 2015).

When participants were diagnosed with endometriosis, they found the education provided by healthcare providers unhelpful. This finding is similar to Grogan et al. (2018), who also found that education given to patients by providers needed to be strengthened to promote a better understanding of endometriosis. In addition, Grogan et al. discovered that participants preferred to have tailored advice from their provider and would instead have presented for a sooner follow-up visit to discuss endometriosis versus being given written information at the time of diagnosis (2018).

Participants stated that receiving a diagnosis made them feel validated. The feeling of validation upon diagnosis is consistent with multiple previous studies (Cole et al., 2021; Lamvu et al., 2020; Roomaney et al., 2018; Culley et al., 2013). Women who have had their symptoms normalized were found in this study to feel relief knowing that their pain was factual and not imaginary. Upon diagnosis, participants also acknowledged that they were surprised to discover how common endometriosis is, even though they were naive to the disease. This finding parallels women's reactions in Fernley et al. (2021), where most participants stated they were unfamiliar with endometriosis. Women in both studies expressed bewilderment that a disease affecting one in ten women worldwide would not have more awareness (Fernley et al., 2021).

### ***Implications for Practice***

This study produced multiple practice implications. First, it is important that providers exercise mindfulness in identifying patients without staunch support systems. When a patient

without an adequate support system is identified, the provider should recommend online or in-person support groups, counseling resources and offer additional provider support.

A comprehensive approach should be taken when caring for all women with endometriosis, including the involvement of an interdisciplinary care team. Agarwal et al. (2019b) applied an interdisciplinary model of care to a chronic pain model when caring for women with endometriosis. The researchers used an interdisciplinary team of the following disciplines, with the patient being the key member of the team: nursing staff, physical therapy, gastroenterology, urology, researchers, pain medicine, mental health, integrative medicine, gynecologists, primary care providers, expert surgeons, reproductive endocrinologists, and imaging specialists. After implementation, researchers found patients had improved long-term outcomes (Agarwal et al., 2019b).

Next, we recommend bolstering access to endometriosis education in the clinic setting and online. Providing patients with graduated levels of information may prove useful during various times of the diagnostic process. Education about disease recognition and management needs to be enhanced for primary care providers, gynecologists, and reproductive endocrinologists. One tool healthcare providers could consider using to identify patients at elevated risk for endometriosis is the Painful Periods Screening Tool (PPST) (DiBenedetti et al., 2018). The five-item patient self-report tool was designed to assess the most important symptoms of endometriosis, as stated by a group of surveyed patients with endometriosis (DiBenedetti et al., 2018). Although the tool has not been validated, one recent study conducted at Johns Hopkins University concluded that women felt the tool helped them discuss their pain symptoms with their clinicians and helped to initiate a conversation about their symptoms (Singh et al., 2022). Administering a tool like the PPST may serve as a conversation starter for other women

who may be embarrassed or unfamiliar with how to otherwise initiate a conversation with their medical provider.

## **Strengths, Limitations, and Future Directions**

### ***Strengths***

Multiple strengths were identified in this study. First, the interviews were conducted via the Zoom platform. This afforded flexibility in scheduling interviews and allowed recruitment of participants from other states and regions of the country to be included in the study. Second, the principal investigator was theoretically sensitive to the data as she worked with endometriosis patients for over four years at a large academic medical institution's minimally invasive gynecological surgery department. Next, the researcher does not know of another study, like the current one in the United States, making this study unique to the existing body of endometriosis literature. Lastly, the researchers ensured this study maintained a high level of rigor by using a pre-study bracketing interview, randomized member checking, utilizing an external expert, employing a second reader, using appropriate software for data management, and adhering strictly to qualitative research methods.

### ***Limitations***

Multiple study limitations were identified. First, some participants acknowledged having been diagnosed with other gynecological or gastrointestinal conditions, such as polycystic ovarian syndrome and irritable bowel syndrome. These conditions could produce overlapping symptoms with endometriosis making it challenging to differentiate the impact of endometriosis symptoms versus coinciding conditions. Secondly, the researchers relied on participants' recall of events, and the accuracy of the medical information was not verified through medical chart review. The researchers also relied on the participants to accurately report that they underwent

diagnostic surgery and were diagnosed with endometriosis. Finally, some participant recruitment was conducted using an endometriosis support group on Facebook. Participants who have had a challenging diagnostic experience may utilize specialty support groups and be more vocal about sharing their experiences and engaging in research studies.

### ***Future Directions***

Patients and the medical community may benefit from studies focusing on endometriosis patients of minority races and with varying insurance statuses, including uninsured and underinsured patients. All women interviewed in the current study were of a majority race and reported having insurance coverage during the pre-diagnostic period. Bolstering participant diversity may aid in determining the similarities and differences between the group's pre-diagnostic experiences. Underprivileged women are hypothesized to encounter unique barriers during the pre-diagnostic period that may not be captured in the current study. Identification of potential unique barriers could serve to facilitate better access to care for this group of women.

Furthermore, a future meaningful study may entail comparing the pre-diagnostic experiences of women with a clinical diagnosis of endometriosis with women who have had a surgical diagnosis. The time to diagnosis with a clinical diagnosis is understandably shorter than a surgical one. A shorter diagnosis time may contribute to a higher quality of life than women diagnosed via surgical methods.

### **Conclusion**

In conclusion, the current study aimed to share the pre-diagnostic experiences of women with endometriosis with medical providers. Women from the United States of America comprised the participant population as the researchers sought to capture potential barriers and facilitators that may be unique to a country that does not subscribe to socialized medicine. To the

researcher's best knowledge, there has not been another research study like the present study conducted in the United States, making this study unique. The current study enhances existing qualitative literature involving patients' diagnostic journey to reach an endometriosis diagnosis. It contributes to new knowledge by introducing the importance of support in a patient's diagnostic journey and prioritizes infertility as the most bothersome symptom for women struggling with endometriosis-related infertility. The study added to a small body of literature acknowledging that goodness can be found in a disease with an otherwise large negative symptom burden. There is a continued need for further education regarding endometriosis symptom recognition for healthcare providers. Additionally, perceived diagnostic delays continue to exist in patients with endometriosis. Further research is needed to identify unique barriers and facilitators in women of color and uninsured or underinsured women. Furthermore, research comparing diagnostic experiences of women having received a clinical diagnosis versus a surgical diagnosis of endometriosis would help identify differences in perceived quality of life.

## References

- American College of Obstetricians and Gynecologists. (2021). *Endometriosis*.  
[https://www.acog.org/womenshealth/faqs/endometriosis?utm\\_source=redirect&utm\\_medium=web&utm\\_campaign=otn](https://www.acog.org/womenshealth/faqs/endometriosis?utm_source=redirect&utm_medium=web&utm_campaign=otn)
- American Society for Reproductive Medicine. (1997). Revised American Society for Reproductive Medicine classification of endometriosis: 1996. *Fertility and Sterility*, 67(5), 817-821. [https://doi.org/10.1016/S0015-0282\(97\)81391-X](https://doi.org/10.1016/S0015-0282(97)81391-X)
- Agarwal, S. K., Antunez-Flores, O., Foster, W. G., Hermes, A., Golshan, S., Soliman, A. M., Arnold, A., & Luna, R. (2021). Real-world characteristics of women with endometriosis-related pain entering a multidisciplinary endometriosis program. *BCM Women's Health*, 21(19). <https://doi.org/10.1186/s12905-020-01139-7>
- Agarwal, S. K., Chapron, C., Giudice, L. C., Laufer, M. R., Leyland, N., Missmer, S. A., Singh, S. S., & Taylor, H. S. (2019a). Clinical diagnosis of endometriosis: A call to action. *American Journal of Obstetrics & Gynecology*, 220(4), 354.e1-354.e12.  
<https://doi.org/10.1016/j.ajog.2018.12.039>
- Agarwal, S. K., Foster, W. G., & Groessl, E. J. (2019b). Rethinking endometriosis care: Applying the chronic care model via a multidisciplinary program for the care of women with endometriosis. *International Journal of Women's Health*, 11, 405-410.  
<https://doi.org/10.2147/IJWH.S207373>
- As-Sanie, S., Black, R., Giudice, L. C., Valbrun, T. G., Gupta, J., Jones, B., Laufer, M. R., Milspaw, A. T., Missmer, S. A., Norman, A., Taylor, R. N., Wallace, K., Williams, Z., Yong, P. J., & Nebel, R. A. (2019). Assessing research gaps and unmet needs in

- endometriosis. *American Journal of Obstetrics & Gynecology*, 221(2), 86-94.  
<https://doi.org/10.1016/j.ajog.2019.02.033>
- Austin, Z., & Sutton, J. (2014). Qualitative research: Getting started. *The Canadian Journal of Hospital Pharmacy*, 67(6), 436-440. <https://doi.org/10.4212/cjhp.v6i6.1406>
- Ballard, K., Lowton, K., & Wright, J. (2006). What's the delay? A qualitative study of women's experiences of reaching a diagnosis of endometriosis. *Fertility and Sterility*, 86(5), 1296-1301. <https://doi.org/10.1016/j.fertnstert.2006.04.054>
- Ballard, K., Seaman, H. E., DeVries, C. S., Wright, J. T. (2008). Can symptomatology help in the diagnosis of endometriosis? Findings from a national case-control study- part 1. *BJOG*, 115(11), 1382-1391. <https://doi.org/10.1111/j.1471-0528.2008.01878.x>
- Bernuit, D., Ebert, A. D., & Halis, G. (2011). Female perspectives on endometriosis: Findings from the uterine bleeding and pain women's research study. *Journal of Endometriosis and Pelvic Pain Disorders*, 3(2), <https://doi.org/10.5301/JE.2011.8525>
- Bezner, J. R. (2015). Promoting health and wellness: Implications for physical therapist practice. *Physical Therapy & Rehabilitation Journal*, 95(10), 1433-1444.  
<https://doi.org/10.2522/ptj.20140271>
- Birks, M., Chapman, Y., & Francis, K. (2008). Memoing in qualitative research: Probing data and processes. *Journal of Research in Nursing*, 13(1), 68-75.  
<https://doi.org/10.1177/174498710781254>
- Bradshaw, C., Atkinson, S., & Doody, O. (2017). Employing a qualitative description approach in health care research. *Global Qualitative Nursing Research*, 4.  
<https://doi.org/10.1177/2333393617742282>



- Buello, S. (2020). "I feel like I'm being stabbed by a thousand tiny men": The challenges of communicating endometriosis pain. *Health, 24*(5), 476-492.  
<https://doi.org/10.1177/1363459318817943>
- Carminati, L. (2018). Generalizability in qualitative research: A tale of two traditions. *Qualitative Health Research, 28*(13). 2094-2001.  
<https://doi.org/10.1177/1049732318788379>
- Christ, J. P., Yu, O., Schulze-Rath, R., Grafton, J., Hansen, K., & Reed, S. D. (2021). Incidence, prevalence, and trends in endometriosis diagnosis: A United States population-based study from 2006 to 2015. *American Journal of Obstetrics & Gynecology, 225*(5), P500.E1-500.E9. <https://doi.org/10.1016/j.ajog.2021.06.067>
- Church, S. P., Dunn, M., & Prokopy, L. S. (2019). Benefits to data quality with multiple coders: Two case studies in multi-coder data analysis. *Journal of Rural Social Sciences, 34*(1), Article 2. <https://egrove.olemiss.edu/jrss/vol34/iss1/2>
- Cole, J. M., Grogan, S., & Turley, E. (2021). "The most lonely condition I can imagine": Psychosocial impacts of endometriosis on women's identity. *Feminism & Psychology, 31*(2), 171-191. <https://doi.org/10.1177/0959353520930602>
- Corbin, J., & Strauss, A. (2015). *Basics of Qualitative Research* (4th ed.). Sage Publications.
- Corbin, J., & Strauss, A. (2008). Strategies for qualitative analysis. *Basics of Qualitative Research* (3rd ed., pp.65-86). Sage Publications.
- Critical Appraisal Skills Programme. (2018). CASP qualitative checklist. [https://casp-uk.b-cdn.net/wp-content/uploads/2018/03/CASP-Qualitative-Checklist-2018\\_fillable\\_form.pdf](https://casp-uk.b-cdn.net/wp-content/uploads/2018/03/CASP-Qualitative-Checklist-2018_fillable_form.pdf)
- 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(6), 625-639.  
<https://doi.org/10.1093/humupd/dmt027>
- Denny, E. (2009). "I never know from one day to another how I will feel": Pain and uncertainty in women with endometriosis. *Qualitative Health Research*, 19(7), 985-995.  
<https://doi.org/10.1177/1049732309338725>
- DiBenedetti, D. B., Soliman, A. M., Ervin, C., Evans, E., Coddington, C. C., Agarwal, S. K., Surrey, E. S., & Taylor, H. S. (2018). Development of the Painful Periods Screening Tool for endometriosis. *Postgraduate Medicine*, 130(8), 694-702.  
<https://doi.org/10.1080/00325481.2018.1526623>
- Doyle, L., McCabe, C., Keogh, B., Brady, A., & McCann, M. (2020). An overview of the qualitative descriptive design within nursing research. *Journal of Research in Nursing*, 24(5), 443-455. <https://doi.org/10.1177/1744987119880234>
- Fernley, N. (2021). That one doctor...qualitative thematic analysis of 49 women's written accounts of their endometriosis diagnosis. *Journal of Endometriosis and Pelvic Pain Disorders*, 13(1), 40-52. <https://doi.org/10.1177//2284026520984366>
- Ferrans, C. E., Zerwic, J. J., Wilbur, J. E., & Larson, J. L. (2005). Conceptual model of health-related quality of life. *Journal of Nursing Scholarship*, 37(4), 336-342.  
<https://doi.org/10.1111/j.1547-5069.2005.00058.x>
- Flick, U. (2009). Research Design. *An Introduction to Qualitative Research*. (4th ed., pp. 87-96). Sage Publications.
- Fourquet, J., Baez, Figueroa, M., Iriarte, I., & Flores, I. (2011). Quantification of the impact of endometriosis symptoms on health related quality of life and work productivity. *Fertility and Sterility*, 96(1), 107-112. <https://doi.org/10.1016/j.fertnstert.2011.04.095>

- Fuldeore, M. J., & Soliman, A. M. (2017). Prevalence and symptomatic burden of diagnosed endometriosis in the United States: National estimates from a cross-sectional survey of 59,411 women. *Gynecologic and Obstetric Investigation*, 82(5), 453-461.  
<https://doi.org/10.1159/000452660>
- Fusch, P. I., & Ness, L. R. (2015). Are we there yet? Data saturation in qualitative research. *The Qualitative Report*, 20(9), 1408-1416.
- Galdas, P. (2017). Revisiting bias in qualitative research: Reflections on its relationship with funding and impact. *International Journal of Qualitative Methods*, 16(1), 1-2.  
<https://doi.org/10.1177/1609406917748992>
- Galloway, A. (2005). Non-probability sampling. In Kempf-Leonard, K. (Ed.), *Encyclopedia of Social Measurement*. (pp. 859-864). Elsevier.
- Gambadauro, P., Carli, V., & Hadlaczky, G. (2019). Depressive symptoms among women with endometriosis: A systemic review and meta-analysis. *American Journal of Obstetrics and Gynecology*, 220(3), 230-241. <https://doi.org/10.1016/j.ajog.2018.11.123>
- Gater, A., Taylor, F., Seitz, C., Gerlinger, C., Wichmann, K., & Haberland, C. (2020). Development and content validation of two new patient-reported outcome measures for endometriosis: The Endometriosis Symptom Diary (ESD) and Endometriosis Impact Scale (ESI). *Journal of Patient-Reported Outcomes*, 4(13).  
<https://doi.org/10.1186/s41687-020-0177-3>
- Greene, R., Stratton, P., Cleary, S. D., Ballweg, M. L., & Sinaii, N. (2009). Diagnostic experience among 4,334 women reporting surgically diagnosed endometriosis. *Fertility and Sterility*, 91(1), 32-39. <https://doi.org/10.1016/j.fertnstert.2007.11.020>

- Grogan, S., Turley, E. & Cole, J. (2018). 'So many women suffer in silence': A thematic analysis of women's written accounts of coping with endometriosis. *Psychology & Health, 33*(11), 1364-1378. <https://doi.org/10.1080/08870446.2018.1496252>
- Grundström, H., Alehagen, S., Kjølhede, & Berterö, C. (2018). The double-edged experience of healthcare encounters among women with endometriosis: A qualitative study. *Journal of Clinical Nursing, 27*(1-2), 205-211. <https://doi.org/10.1111/jocn.13872>
- Hanna, P. (2012). Using internet technologies (such as Skype) as research medium: A research note. *Qualitative Research, 12*(2), 239-242. <https://doi.org/10.1177/1468794111426607>
- Holoch, K. & Lessey, B. (2010). Endometriosis and infertility. *Clinical Obstetrics and Gynecology, 53*(2), 429-438. <https://doi.org/10.1097/GRF.0b013e3181db7b71>
- Johnson, J. L., Adkins, D., & Chauvin, S. (2020). A review of the quality indicators of rigor in qualitative research. *American Journal of Pharmaceutical Education, 84*(1), 7120. <https://doi.org/10.5688/ajpe7120>
- Krouwel, M., Jolly, K., & Greenfield, S. (2019). Comparing Skype (video calling) and in-person qualitative interview modes in a study of people with irritable bowel syndrome - an exploratory comparative analysis. *BCM Medical Research Methodology, 19*(1). <https://doi.org/10.1186/s12874-019-0867-9>
- Lamvu, G., Antunes-Flores, O., Orady, M., & Schneider, B. (2020). Pathway to diagnosis and women's perspectives on the impact of endometriosis pain. *Journal of Endometriosis and Pelvic Pain Disorders, 12*(1), 16-20. <https://doi.org/10.1177/228402650903214>
- Márki, G., Vásárhelyi, D., Rigó, A., Kaló, Z., Ács, N., & Bokor, A. (2022). Challenges of and possible solutions for living with endometriosis: A qualitative study. *BMC Women's Health, 22*(20), <https://doi.org/10.1186/s12905-022-01603-6>

- Mastrangelo, M. & Turnbull, D. (2022). The impact of surgically diagnosed symptomatic endometriosis on women's social lives, work and education: An inductive classical content analysis. *Australian & New Zealand Journal of Obstetrics & Gynecology*, 62(2), 274-279. <https://doi.org/10.1111/ajo.13447>
- Marinho, M. C. P., Magalhaes, T. F., Fernandes, L. F. C., Augusto, K. L., Brilhante, A. V. M., & Bezerra, L. R. P. S. (2018). Quality of life in women with endometriosis: An integrative review. *Journal of Women's Health*, 27(3), 399-408. <https://doi.org/10.1089/jwh.2017.6397>
- Mear, L., Herr, M., Fauconnier, A., Pineau, C., & Vialard, F. (2020). Polymorphisms and endometriosis: A systematic review and meta-analyses. *Human Reproduction Update*, 26(1), 73-103. <https://doi.org/10.1093/humupd/dmz034>
- Missmer, S. A., Tu, F. F., Agarwal, S. K., Chapron, C., Soliman, A. M., Chiuve, S., Eichner, S., Flores-Caldera, I., Horne, A. W., Kimbal, A. B., Laufer, M. R., Leyland, N., Sing, S. S., Taylor, H. S., & As-Sanie, S. (2021). Impact of endometriosis on life-course potential: A narrative review. *International Journal of General Medicine*, 1(14), 9-25. <https://doi.org/10.2147/IJGM.S261139>
- Morassutto, C., Monasta, L., Ricci, G., Barbone, F., & Ronfani, L. (2016.). Incidence and estimated prevalence of endometriosis and adenomyosis in northeast Italy: A data linkage study. *Public Library of Science*, 11(4), 1-11. DOI: 10.1371/journal.pone.0154227
- Norman, M., Razmpour, O., & Olsen, J. M. (2021). Women's use of self-care interventions for endometriosis pain in the United States. *Nursing for Women's Health*, 25(5), 346-356. <https://doi.org/20.2026/j.nwh.2021.01.008>

Pettersson, A., & Berterö, C. M. (2020). How women with endometriosis experience health care encounters. *Women's Health Report, 1*(1), 529-542.

<https://doi.org/10.1089/whr.2020.0099>

Pew Research Center (2021). *Internet/broadband fact sheet*.

<https://www.pewresearch.org/internet/fact-sheet/internet-broadband/>

Polak, G., Banaszweska, B., Filip, M., Radwan, M., & Wdowiak, A. (2021). Environmental factors and endometriosis. *International Journal of Environmental Research and Public Health, 18*(21), 11025. <https://doi.org/10.3390/ijerph182111025>

Prentice, A. (2001). Endometriosis. *British Medical Journal, 323*, 93-95.

<https://doi.org/10.1136/bmj.323.7304.93>

Rae, T., Giampaolino, R., Simeone, S., Pucciarelli, G., Alvaro, R., & Guillari, A. (2020). Living with endometriosis: A phenomenological study. *International Journal of Qualitative Studies on Health and Well-being, 15*(1), 1822621.

<https://doi.org/10.1080/17482631.2020.1822621>

Roomaney, R., & Kagee, A. (2018). Salient aspects of quality of life among women diagnosed with endometriosis: A qualitative study. *Journal of Health Psychology, 23*(7), 905-916.

<https://doi.org/10.1177/1359105316643069>

Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research in Nursing & Health, 33*(1), 77-84. <https://doi.org/10.1002/nur.20362>

Sampson, J. A. (1927). Metastatic or embolic endometriosis, due to the menstrual dissemination of endometrial tissue into the venous circulation. *American Journal of Pathology, 3*(2), 93-110.43.

- Seear, K. (2009). The etiquette of endometriosis: Stigmatization, menstrual concealment and the diagnostic delay. *Social Science & Medicine*, 69(8), 1220-1227.  
<https://doi.org/10.1016/j.socscimed.2009.07.023>
- Shoebbotham, A., & Coulson, N. S. (2016). Therapeutic affordances of online support group use in women with endometriosis. *Journal of Medical Internet Research*, 18(5), e109.  
<https://doi.org/10.2196/jmir.5548>
- Sims, O. T., Gupta, J., Missmer, S. A., & Aninye, I. O. (2021). Stigma and endometriosis: A brief overview and recommendations to improve psychosocial well-being and diagnostic delay. *International Journal of Environmental Research and Public Health*, 18(15), 8210.  
<https://doi.org/10.3390/ijerph18158210>
- Singh, B., Berry, J., Volovsky, M., Xu, Y., Soliman, A. M., Thompson, C. B., & Segars, J. H. (2022). The utility and impact of the Painful Periods Screening Tool (PPST) to improve healthcare delivery for people with symptoms of pelvic pain. *Reproductive Sciences*.  
<https://doi.org/10.1007/s43032-022-01119-2>
- Smith, J. L., & Huntoon, M. (2014). Women's bragging rights: Overcoming modesty norms to facilitate women's self-promotion. *Psychology of Women Quarterly*, 38(4), 447-459.  
<https://doi.org/10.1177/0361684313515840>
- Soliman, A. M., Surrey, E., Bonafede, M., Nelson, J. K., & Castelli-Haley, J. (2018). Real-world evaluation of direct and indirect economic burden among endometriosis patients in the United States. *Advances in Therapy*, 35(3), 408-423. <https://doi.org/10.1007/s12325-018-0667-3>
- Soliman, A. M., Surrey, E. S., Bonafede, M., Nelson, J. K., Vora, J. B., Agarwal, S. K. (2019). Healthcare utilization and costs associated with endometriosis among women with

- Medicaid insurance. *Journal of Managed Care and Specialty Pharmacy*, 25(5), 566-572.  
<https://doi.org/10.18553/jmcp.2019.25.5.566>
- Soliman, A. M., Fuldeore, M., Snabes, M. C. (2017). Factors associated with time to endometriosis diagnosis in the United States. *Journal of Women's Health*, 26, 788-797.  
[https://doi: 10.1089/jwh.2016.6003](https://doi:10.1089/jwh.2016.6003)
- Stratton, P. (2006). The tangled web of reasons for the delay in diagnosis of endometriosis in women with chronic pelvic pain: Will the suffering end? *Fertility and Sterility*, 86(5), 1302-1304. <https://doi.org/10.1016/j.fertnstert.2006.06.044>
- Van Der Zanden, M., De Kok, L., Melen, W. L. D. M., Braat, D. D. M., & Nap, A. W. (2021). Strengths and weaknesses in the diagnostic process of endometriosis from the patients' perspective: A focus group study. *Diagnosis*, 8(3), 333-339. <https://doi.org/10.1515/dx-2021-0043>
- Warzecha, D., Szymuski, I., Wielgos, M., & Pietrazak, B. (2020). The impact of endometriosis on the quality of life and the incidence of depression- A cohort study. *International Journal of Environmental Research and Public Health*, 17(10), 3641.  
<https://doi.org/10.3390.ijerph17103641>
- Whelan, E. (2007). 'No one agrees except for those of us who have it': Endometriosis patients as an epistemological community. *Sociology of Health & Illness*, 29(7), 957-982.  
<https://doi.org/10.1111/j1467-9566.2007.01024.x>
- Wilson, I. B., & Cleary, P. D. Linking clinical variables with health-related quality of life. A conceptual model of patient outcomes. *JAMA*, 273(1), 59-65.  
<https://doi.org/10.1001/jama.1995.03520250075037>



Wren, G., & Mercer, J. (2021). Dismissal, distrust, and dismay: A phenomenological exploration of young women's diagnostic experiences with endometriosis and subsequent support.

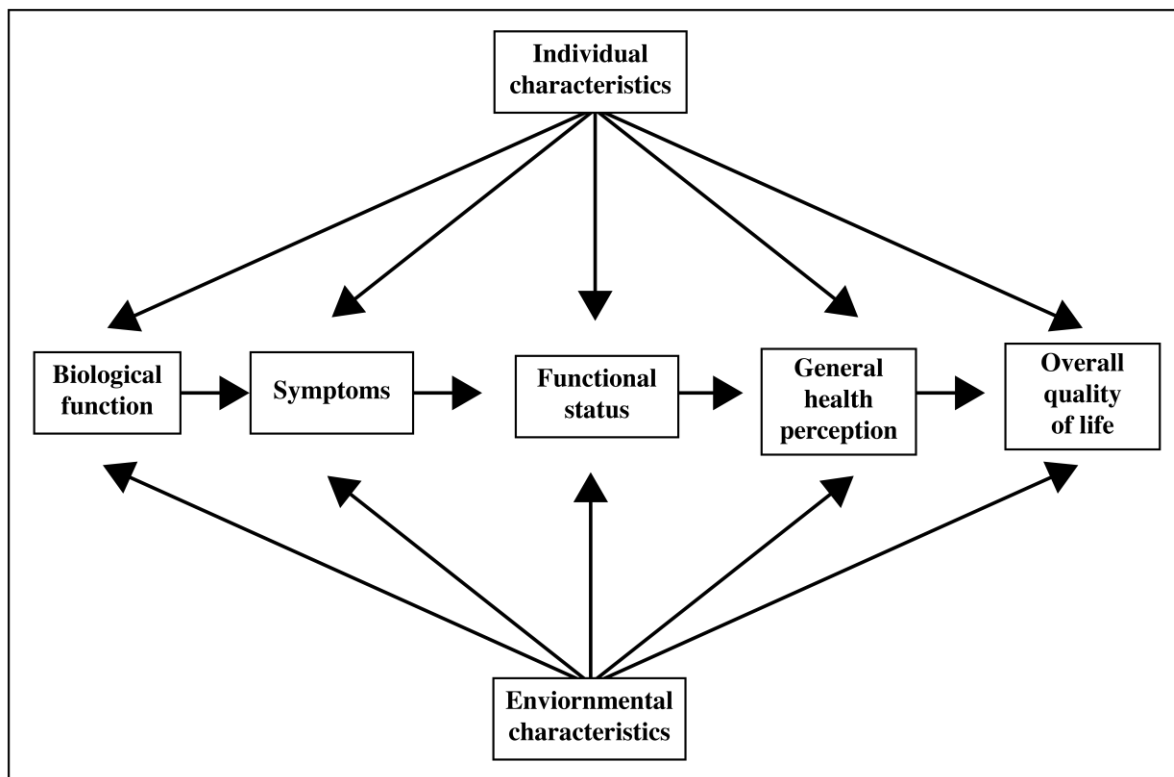
*Journal of Health Psychology*. <https://doi.org/10.1177/13591053211059387>

Young, K., Fisher, J., & Kirkman, M. (2015). Women's experiences of endometriosis: A systemic review and synthesis of qualitative research. *Journal of Family Planning & Reproductive Health Care*, 41, 225-234. <https://doi.org/10.1136/jfprhc-2013-100853>

Zondervan, K. T., Becker, C. M., & Missmer, S. A. (2020). Endometriosis. *The New England Journal of Medicine*, 382, 1244-1256. <https://doi.org/10.1056/NEJMra1810764>

**Figure 1**

*Conceptual Model of Health-Related Quality of Life*



**Table 1***Sociodemographic Characteristics of the Participants*

Sample Characteristics	<i>n</i>	%
Age		
25-34	3	50
35-44	2	33.3
45-51	1	16.7
What is your race		
Caucasian	6	100
Marital status		
Single	1	16.7
Married	5	83.3
Annual household income		
Less than \$25,000	1	16.7
\$25,000 - \$50,000	0	0
\$50,000 - \$100,000	2	33.3
\$100,000 - \$200,000	1	16.7
More than \$200,00	2	33.3
Education level		
Bachelor's degree	2	33.3
Master's degree	4	66.7
Region of residence		
Southeast	4	66.7

Southwest	2	33.3
Had health insurance coverage while seeking care		
Yes	6	100
Amount of healthcare coverage		
Complete	6	100
Insurance type		
Private	4	66.7
Government funded	1	16.7
Other	1	16.7

---

*Note.*  $N = 6$

**Table 2***Results Table*

Theme	Category	Property	Dimension	Exemplar
<b>Seeking</b>	Journey to Care	Acknowledgement of Seriousness	Worsening of Symptoms	"I came to a point... I was like, actually no, this is not okay, this pain is not okay or these things that I'm living with are not okay and that is when I finally sort of switching doctors until I knew I found the right one."
			Impetus for Treatment Seeking	"I am losing things that I love in life."
		Overcoming Symptom Normalization	Self	"I genuinely just felt like I was being a big baby."
			Provider	"I bled for three and a half months... when I went in, they told me It's perfectly normal, and that's when I started to begin, like I felt like I was actually crazy."
			Peers	"Friends are just being like, come on... take some ibuprofen like, you're fine... I have bad cramps too."
			Mother	"My mom was like... periods are painful... you're going to have to deal with that. I'm sorry, you're a woman."
	Day-to-Day Impact	Infertility	All-Consuming	"Sometimes it would just hit me and then I... walk through that grief again and I'm like, why can't I just enjoy my life?"
			Exhaustion	"It was just such an arduous journey. And we're like, Is this the end of the road? I don't know... I was kind of at the end of the road like I was so worn out."
		Symptoms	Pain	"I had sepsis, and I had no idea because I'm in pain all the time, and I didn't know that I was actually so sick"

		Loss	Sexual Intimacy	"This just feels like a chore... this isn't even pleasant at this point."
		Difficulty with Common Activities		"Some days it was just a real, real struggle to get up and to go to work"
		Quality of life		"They did impact my everyday life, my quality of life, I mean, In a major way."
<b>Finding</b>	Diagnosis	Delayed Diagnosis		"People are spending thousands of dollars and putting their bodies through like a lot of trauma, both physically and emotionally... I would hope that providers would become more informed."
	Impact of Diagnosis	Care Enhancement		"I can go to my fertility specialist and say, here's what's been going on, and he can look at that and say, okay, you've had stage one endometriosis, and this is how this will impact our fertility treatment moving forward."
		Validation		"Glad to know that I wasn't crazy and that these things are happening in my body like there's a name to them."
		Peace of Mind		"Just knowing that's what's been going on gave me incredible peace of mind and even now into my fertility journey."
	Reflection	Medical Self-Advocacy		"I did not know how to speak up for myself medically. Um, I Did not know how to have healthy conflict with people that I viewed as authorities like doctors..."
		Medical Self-Advocacy		"I wish... that I had been more forceful in and in pushing for treatments... I just trusted that my doctors knew, and you know, it felt very isolating."
		Advice		"Do not underestimate certain symptoms in your life that need to be explored more deeply... we tend to make excuses or overlook or rationalize and I think it's important to do the due diligence and really see it through."

		Advice for Other Women		"I will be an advocate for my girls, and I will teach them to be advocates for their body because of this journey."
<b>Support</b>	Advocacy	Support-Systems	Family	"My mom... was just constantly supportive, like, okay, like, we're going to figure this out... there's something out there that will help you. We've just got to find it. So, she was just like a voice of positivity."
			Women with Endometriosis	"It was like this really weird, beautiful like space... she knew what I was going through."
				"I felt very comforted in that moment to know that I wasn't alone."
		Self-Advocacy		"I was just kind of my own researcher and self-advocate."
	Resilience			"Might have had a positive impact...because I was able to overcome the pain, you know, deal with it, go through life"
				"You'd have to find. Ways to dig deep and go on when you are in pain at school. At work when I was later in life."

## **Appendix A**

### *Interviewer Questions*

1. How long was the time frame from the onset of your symptoms to when you received a surgical diagnosis of endometriosis? When did you notice your symptoms becoming markedly worse?
2. Beginning from the start of your symptoms to when you were diagnosed, please walk me through the impact that undiagnosed endometriosis had on your day-to-day life.
3. Please tell me how your life circumstances helped or hindered reaching a diagnosis of endometriosis. By circumstances I mean your support system, daily roles you take on, your physical environment, your work situation, your attitudes and beliefs about yourself, your provider relationships, and anything else you may think of.



## Appendix B

### *Research Consent Form*

**BELMONT UNIVERSITY**  
RESEARCH PROJECT INFORMATION SHEET

**Women's Stories About the Journey to a Diagnosis of Endometriosis**

Principal Investigator: Susan C. Debolt  
Faculty Advisor: Dr. Steven Busby

You are invited to participate in a research study about investigating the pre-diagnostic experiences of women with endometriosis.

If you agree to be part of this project, you will be asked to attend a 15-30-minute interview held via the internet platform Zoom. During the interview you will be asked open-ended questions about your experiences related to achieving a diagnosis of endometriosis. After the interview you may be asked to review the researcher's interpretation of the interview for accuracy of overall meanings.

Benefits of the research include provide relatable stories, increase global knowledge about U.S. women's experiences of living with undiagnosed endometriosis. Findings may enhance current evidence for the need to further decrease a known endometriosis diagnostic delay and validate the importance of pelvic pain specialists.

Risks and discomforts are potential emotional disturbance from reflecting on previous life struggles related to this diagnosis.

It is your choice whether or not to participate in this study. Even if you decide to participate now, you may change your mind and stop at any time with no negative consequences. The care that you receive from your provider will in no way be impacted by your participation, or lack thereof.

We will protect the confidentiality of your research records by requiring two individual passcodes to access all sensitive data. Sensitive data may only be accessed by study authors and all documents containing sensitive information will be encrypted.

Information collected may be shared with other researchers involved in this project. We will not share any information that could identify you with others outside of the research team. If results of this study are published or presented, individual names and other personally identifiable information will not be used.

If you have questions about this research study, please contact Susan Debolt at [susan.debolt@bruins.belmont.edu](mailto:susan.debolt@bruins.belmont.edu). If you have questions about your rights as a research participant, or wish to obtain information, ask questions, or discuss any concerns about this study with someone other than the researcher(s), please contact Phil Johnston, PharmD, Vice Provost for Academic Affairs: (615) 460-6964 or [phil.johnston@belmont.edu](mailto:phil.johnston@belmont.edu).

**Name of Participant (Please print):** \_\_\_\_\_

**Signature of Participant:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Signature of Investigator:** \_\_\_\_\_ **Date:** \_\_\_\_\_

## Appendix C

### Thematic Structure

