

THE NEED FOR ENDOMETRIOSIS AWARENESS: A CASE STUDY OF COLLEGE
STUDENTS AND MEDICAL PROFESSIONALS

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SPRING 2023

A thesis submitted to the Honors Program at Southern New Hampshire University to complete
HON 401, and as part of the requirements for graduation from the Honors Program

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ABSTRACT

Endometriosis is an estrogen-dependent chronic illness in which tissue similar to the endometrium develops outside of the uterine cavity. This disease affects an estimated 10-15% of individuals with a uterus at reproductive age and yet it takes an average of 7.5 years for an individual to receive an accurate diagnosis. This delay in diagnosis, along with recent studies on endometriosis, suggest a severe lack of education on endometriosis within both the medical community and the general public. There is literature that suggests there is a strong need for more education and awareness of endometriosis in the global medical community. However, there is a lack of literature that addresses the knowledge of college-age individuals in the United States on endometriosis. This thesis consists of a focus group at Southern New Hampshire University that determined the knowledge of college-age individuals on endometriosis, the menstrual cycle and reproductive health. This thesis found that there is a need for more education on topics relating to endometriosis, the menstrual cycle and reproductive health. General practitioners, specifically pediatricians need to develop more knowledge on these topics and be willing to share their information with their patients in order to educate them and ultimately reduce the length of diagnostic delay of endometriosis and other diseases characterized by reproductive issues.

Keywords: Endometriosis, Menstrual Cycle, Uterus, Period, Diagnostic Delay, Knowledge, General Practitioners, Focus Group

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ACKNOWLEDGEMENTS

The author would like to thank and acknowledge that the completion of this thesis would not be possible without the help, support and superior mentorship of Dr. Katie Duryea. The author would also like to thank Dr. Michele Goldsmith for her guidance in developing the research methods within this thesis. The author would also like to thank all the focus group participants for providing their honest thoughts and opinions and sharing their experiences during the focus group.

Chapter 1

Introduction to Endometriosis

Invisible diseases commonly refer to diseases without visible signs of sickness, however, endometriosis is an invisible disease in medical, political and social contexts. An estimated 10% of individuals with a uterus at reproductive age have endometriosis, an estrogen-dependent chronic illness in which tissue similar to endometrial tissue develops outside of the uterine cavity. Similarly to the endometrium that lines the uterus, this tissue responds to hormonal changes within the body and will bleed outside the uterine cavity in response to hormone production, usually associated with the menstrual cycle. Since this tissue has developed in an area of the body without an exit, it continues to grow on the organs, causing inflammation and swelling, leading to the formation of scar tissue. This causes many physical symptoms to arise, such as severe dyspareunia, dysmenorrhea, abdominal cramps, infertility, chronic pelvic pain, cyclic menstrual pain, abdominal bloating, dyschezia and nausea. Individuals with endometriosis can have multiple of these symptoms but not all individuals with endometriosis will experience the same symptoms or experience those symptoms with the same frequency and intensity. Oftentimes people can have endometriosis and exhibit no symptoms. There are different types of endometriosis that correlate with more specific sets of symptoms and different stages of endometriosis also correlate with more specific sets of symptoms. However, when examining the literature and studies surrounding endometriosis, different sources list varying symptoms of endometriosis. The same symptoms are not listed in every piece of literature on endometriosis. This inconsistency aligns with the idea that there is a lack of education surrounding this disease.

On average it takes 7.5 years after the onset of symptoms for individuals with endometriosis to receive an accurate diagnosis (Agarwal, 2019). This delay in diagnosis, along with recent studies on endometriosis, suggest a severe lack of education on endometriosis within both the medical community and the general public (Kotowska et al., 2021; Roullier et al., 2021). There is literature which suggests there is a strong need for more education and awareness of endometriosis in the global medical community (Kotowska et al., 2021; Rogers et al., 2013; Roullier et al., 2021; Tsamantioti & Mahdy, 2022). However, there is a lack of literature that addresses the knowledge of college-age individuals in the United States on endometriosis. This thesis seeks to close that knowledge gap and determine the level of knowledge college-age individuals in the United States possess in regard to endometriosis.

Theories of Endometriosis

The cause of endometriosis is not known, but there are several medical theories including the Theory of Samson or retrograde menstruation, Mayer's theory and the lymphatic and vascular metastasis theory (Rogers et al., 2013; Smolarz et al., 2021; Tsamantioti & Mahdy, 2022).

The Theory of Samson is the most commonly accepted theory. It states that during menstruation, endometrial foci are released through the fallopian tubes and into the peritoneal cavity instead of being released from the body. This is commonly referred to as retrograde menstruation. Studies suggest that 80% of individuals with open fallopian tubes experience some level of retrograde menstruation, while endometriosis only occurs within a small group of those individuals. This leads people to believe that retrograde menstruation cannot be the sole cause of endometriosis (Smolarz et al., 2021; Tsamantioti & Mahdy, 2022).

Mayer's theory states that peritoneal cells are transformed into Muller-type cells under the influence of hormones. Muller-type cells are glial cells that are usually found in the retina and help to maintain structural and functional stability of other cells. This theory takes into account that the parietal peritoneum epithelium can differentiate into endometrial tissue, most likely under the stimuli of cytokines among other factors. This theory would align with the occurrence of endometriosis in biological females without a uterus (Smolarz et al., 2021).

The lymphatic and vascular metastasis theory states that tissue similar to the endometrium can enter the lymphatics and vasculature and then travel throughout the body. This theory would account for the process by which tissue travels throughout the body cavity and would explain why it is sometimes found near the eyes, brain and feet (Smolarz et al., 2021; Tsamantioti & Mahdy, 2022).

Other theories regarding endometriosis include the idea that those with this disease are immune-compromised in that they are unable to prevent the adhesion of endometrial lesions within the peritoneal cavity. As previously mentioned, research suggests that 80% of individuals with open fallopian tubes experience some level of retrograde menstruation. This could indicate that those with endometriosis are unable to clear endometrial lesions before they spread out and attach to different areas in the body, given they may be immuno-compromised. This theory is supported by studies that have determined a reduced cell activity of the Natural Killer cells in individuals with endometriosis. Natural Killer cells are the main group of cells in the immune system responsible for natural cytotoxicity (Smolarz et al., 2021).

Potential Risk Factors for Endometriosis

There are thought to be many genetic and environmental factors when it comes to endometriosis. Many studies have shown that genetic conditions are linked to this disease and

current studies are working to determine biomarkers and genes that would signify the formation of endometriosis within the body (Parasar et al., 2017; Rogers et al., 2013; Smolarz et al., 2021; Tsamantioti & Mahdy, 2022).

Multiple studies have found that individuals with endometriosis tend to share certain characteristics. One of these observations is that individuals who undergo menarche at an age below 11 years old are more likely to have endometriosis than those who undergo menarche after age 11. Other factors that indicate an individual may have endometriosis include a shorter duration of menstrual periods, less than 27 days, and heavy menstrual bleeding. It is also worth noting that the average individual with endometriosis has a low BMI, is Caucasian, and is between the ages of 25 and 29 (Alimi et al., 2018; Parasar et al., 2017; Rogers et al., 2013; Smolarz et al., 2021; Tsamantioti & Mahdy, 2022).

Diagnosis and Treatment

Endometriosis is not a disease that can be easily diagnosed. The most common way to diagnose endometriosis is through laparoscopic surgery. This surgery essentially cuts out the endometrial lesions, preventing the tissue from further growing within the peritoneal cavity. Endometriosis can also be diagnosed through an ultrasound examination if there are endometrial cysts on certain organs like the ovaries, however, if the tissue is not present in that area then the ultrasound will not indicate if an individual has endometriosis. Depending on where the endometrial tissue is, other medical examinations can be done, such as cystoscopies, colonoscopies and transrectal ultrasound examinations (Alimi et al., 2018; Kotowska et al., 2021; Parasar et al., 2017; Rogers et al., 2013; Roullier et al., 2021; Smolarz et al., 2021; Tsamantioti & Mahdy, 2022).

Treatments for endometriosis often include laparoscopic surgery, non-steroidal anti-inflammatory drugs (NSAIDs), contraceptives and herbal or natural remedies. Individuals with endometriosis tend to rely on a combination of these treatments to reduce pain symptoms and control endometrial growth within the body. NSAIDs control the inflammation caused by endometrial tissue. Different forms of contraceptives or birth control are commonly used to help control the growth of the tissue through hormones. These contraceptives release different types of hormones to inhibit the growth of tissue and make the body act as if it were pregnant.

Herbal and natural remedies often act as anti-inflammatories and are primarily used to alleviate pain. Individuals with endometriosis often need to alter their diet and lifestyle to prevent a relapse from occurring. A relapse can occur if tissue begins to grow in the uterine cavity again, after a surgery has been performed to remove tissue from the uterine cavity. Common changes in diet can include cutting out soy products, as soy mimics estrogen in the body, a limited intake of red-meat due to the proteins it contains, and the addition of more fresh fruits and vegetables that contain iron and natural antioxidants (Alimi et al., 2018; Parasar et al., 2017; Roullier et al., 2021; Smolarz et al., 2021; Tsamantioti & Mahdy, 2022).

Chapter 2**Current State of Knowledge on Endometriosis**

Over the past 10 years there have been many studies conducted on endometriosis, the knowledge individuals have on endometriosis and why endometriosis has such a long diagnostic delay. The majority of these studies are not conducted in the United States and do not solely address the knowledge of college-age populations.

Recent studies have examined the knowledge that different populations have on endometriosis, in an effort to create a baseline of knowledge around endometriosis and determine what can be done to increase the level of knowledge of endometriosis. Many studies sought to discover what resources people use to learn more about endometriosis and reproductive health. Responses among studies that looked at populations of individuals ranging in age from 19-24 years, included: the internet, television and the classroom. The classroom option included formal education on the topic and also conversation among peers in the classroom (Khan et al., 2022). This study determined that the proportion of individuals ages 19-24, who went to their family and friends as a resource when talking about the menstrual cycle and reproductive health was remarkably low. This can potentially be due to a lack of social or family communication about these topics as they may be viewed as taboo or uncomfortable (Khan et al., 2022). A study from the United Kingdom determined that 14% of adolescents with a uterus could describe endometriosis, while the other 86% lacked knowledge on endometriosis but were willing to learn more about it (Randhawa et al., 2021). It is important to note that during adolescence, individuals are more affected by contextual influences, so understanding the knowledge this population has on endometriosis will allow for the informed creation of better methods to provide individuals

with this information (Gupta et al., 2018). These studies, along with many others, indicate that young people with a uterus do not have enough knowledge or education on endometriosis.

Knowledge on endometriosis and reproductive health is something that general practitioners and medical professionals are formally taught and trained to evaluate patients on. However, a study conducted in France on the knowledge of general practitioners on endometriosis determined that only 25% of general practitioners believed they had enough knowledge on endometriosis for their routine clinical practice (Roullier et al., 2021). This study also determined that 74.5% of general practitioners believed they did not know enough about endometriosis and that most general practitioners are poorly aware of some of the main signs and symptoms, including dysmenorrhea and dyspareunia (Roullier et al., 2021).

There is a lack of knowledge on endometriosis within the general population and the population of general practitioners. This is one of the main factors that influences the long diagnostic delay of endometriosis. Studies have determined that diagnostic delay of endometriosis factors include: trivialization of symptoms, low levels of knowledge among medical professionals, medical professionals ignoring endometriosis symptoms and prescribing ineffective treatments, as well as the societal stigma around the menstrual cycle (Rouillier et al., 2021; Wróbel et al., 2022). One study noted that one of the main factors that add to the diagnostic delay of endometriosis is the reluctance and late reporting of endometriosis symptoms to a medical provider (Wróbel et al., 2022). Participants in many studies share that they are reluctant to visit and consult with obstetricians or gynecologists when experiencing pain during menstruation for a variety of different reasons. Some participants did not believe there was a need for medical treatment, they could treat their symptoms with over the counter drugs, they were hesitant of going in for an appointment and that they believed the pain would go away over

time (Khan et al., 2022). Other participants have had past experiences with medical professionals in which their symptoms have been minimized, normalized or dismissed. In some cases they have been inappropriately referred to other medical professionals or received at least one misdiagnosis (Gupta et al., 2018). A study in Sweden asked a group of individuals with surgically-confirmed endometriosis about their experiences with misdiagnoses. Out of 758 participants, 75.2% shared they had been misdiagnosed at least once by medical professionals and of those 75.2%, 49.5% that were misdiagnosed, were diagnosed with a mental health affliction (Wróbel et al., 2022). Another factor that can influence an individual's willingness to talk about topics relating to the menstrual cycle is interactions with partners, family members, friends and other social interactions. Based on the aforementioned social interactions, many participants believe periods are often associated with weakness and considered taboo since they are characterized as a female health issue. These interactions are exacerbated by societal stigmas around the menstrual cycle and reproductive health for those with uteruses and can create self-doubt within individuals which can turn into isolation due to a societal lack of understanding the menstrual cycle and reproductive health. At the adolescent level, this self-doubt, coupled with feelings of shame and embarrassment, can inhibit future help-seeking. This can cause adolescents with a uterus to develop a distrust for their healthcare providers and believe they will not respect them or treat their health issues seriously (Gupta et al., 2018). The age of the patient is another factor that delays diagnosis. If the patient is an adolescent and sharing their symptoms in search for a diagnosis, they are more likely to not be listened to or taken seriously. Conversely, those who have symptoms characteristic of endometriosis and want to become pregnant are more likely to be diagnosed with endometriosis due to the fertility issues associated with this disease (Wróbel et al., 2022).

Chapter 3

Methodology

This study used both qualitative and quantitative methods, with a survey and focus group designed to determine the knowledge of college-age individuals that possess a uterus, on endometriosis and reproductive healthcare pertaining to those with a uterus. The focus group took place on Tuesday, February 21, 2023 from 12:00 –1:30PM on the Southern New Hampshire University Manchester Campus in the Green Center, Conference Room 122.

In order to select participants for the focus group, a Google Forms survey with questions that ask about the participant's ability to attend the focus group at the required date and time, was created and advertised as a QR code on a flyer created in Canva (See Appendix A for survey questions) (See Appendix B for flyer). Although efforts were made to hang physical flyers up around the Southern New Hampshire University Manchester Campus, the flyers were unable to be physically distributed and were posted on the social media platform Instagram instead. Additional efforts were made to post the flyer on Southern New Hampshire University social media accounts but were unsuccessful. The facilitator of the group distributed the flyer digitally through Instagram and other individuals viewed the flyer and shared it on their personal social media accounts. Individuals could scan the QR code using their phones if they intended to be a part of the focus group, could click a link attached to the digital flyer, or contact the focus group facilitator through the email listed on the flyer. The goal was to have 13 people sign up for the focus group and then close the survey, however, due to the failure of flyers to be physically posted around campus or virtually shared through Southern New Hampshire University social media, there was little participation and only 6 individuals out of the 7 that filled out the survey were eligible to attend the focus group.

On Tuesday, February 21, 2023 the focus group gathered at the Green Center Conference Room 122 on the Southern New Hampshire University Manchester Campus. The facilitator distributed an informed consent form for each participant to fill out (See Appendix C for copy of informed consent form). After all consent forms were filled out and collected, the facilitator shared a link for a Google Forms survey with all participants. This survey contained demographic questions and questions that established a baseline of the knowledge participants have on endometriosis (See Appendix D for survey questions). Participants were allowed up to 10 minutes to fill out the survey and were then informed their voices would be recorded during the focus group before the facilitator started a voice recorder app on an iPhone.

The facilitator then asked the group a list of five questions, in numerical order (See Appendix E for focus group questions). Every participant was allowed ample time to answer each question before moving onto the next question. Questions were asked at the facilitator's pace based on the interactions within the group. Once the group had answered all the questions and the conversation had died out, the facilitator thanked everyone for coming and turned off the voice recorder (See Appendix F for a redacted version of the transcript). Once the group had left the facilitator scanned each of the informed consent forms and sent them via email to each participant.

The facilitator uploaded the voice recording of the focus group to the computer program Rev which is a speech-to-text service that allows audio and video files to be transcribed into text. After the audio file was added to the program and had been transcribed, the facilitator listened to the audio file while reading the transcription to ensure it was accurate and make any necessary edits. Once the transcription was accurate, the facilitator saved it as a word document. The facilitator then went through the transcription, examining the data and redacting names of

participants and conversations that were not related to the focus group questions or overall focus group topics.

Chapter 4**Questions and Responses****Google Form:****Focus Group Demographics**

The focus group participants were asked to fill out a Google Forms survey containing 3 demographic questions and 3 questions relating to general knowledge on endometriosis (See Appendix G for graphs and charts).

Demographic Questions

The first question asked the age of participants in the focus group. 1/6 participants were 19 years old, 3/6 participants were 20 years old, 1/6 participants were 21 years old, and 1/6 participants were 22 years old. The second question asked what gender the participants identified as. 5/6 participants identified as female and 1/6 participants selected the “?” option. The third question asked participants to specify their ethnicity. 5/6 participants identified as Caucasian and 1/6 participants identified as African-American.

Focus Group Topic Questions

The first question asked the participants if they were familiar with the term endometriosis. 3/6 participants selected: “Yes, I am confident I know what that is”. 2/6 participants selected: “Kind of, I know people who have it and have heard of it before”. 1/6 participants selected: “Not really, I have heard the word but don’t know what it means”. The second question asked the participants how many people with a uterus do they think are affected by endometriosis. 3/6 participants selected 5-10% and 3/6 participants selected 10-15%. The third question asked the participants how long do they think it takes for an individual to be diagnosed with endometriosis after exhibiting symptoms (average diagnostic delay)? 2/6

participants selected 2-4 years, 1/6 participants selected 4-6 years, 2/6 participants selected 8-10 years and 1/6 participants selected “Longer than 10 years”.

Focus Group Questions

Question One

The focus group was asked: When receiving care from a general practitioner do you feel that there is a level of gynecological care? Are you asked about your period, uterus, vagina etc. ?

In response to this question 1/6 participants confidently responded yes. This participant went on to elaborate and state that they have a fairly close relationship with their pediatrician, and they believe that impacted their answer. Conversation in response to this question led to the determination that no participants in the focus group see a general practitioner consistently and all participants are in the process of switching from pediatricians to general practitioners. Other conversation in response to this question determined that 4/6 participants are not currently on birth control and 2 of those participants have been on some type of hormonal birth control in the past. 2 participants shared that they have tried multiple different types of hormonal birth control. This conversation contained many instances of questions and seeming confusion as participants asked each other about different types of birth control, the reasons for being prescribed birth control and what makes up birth control. No confident answers were provided by any participants. One participant stated, “I don’t know what I’m putting in my body”. Conversations about pediatricians continued and 5/6 participants stated the last person they went to for primary medical care was an individual who identified as a woman.

Question Two

The focus group was asked: Where does the knowledge you have about your menstrual cycle and sexual health come from? The doctors, you and your experiences, school, family members, the internet etc.?

In response to this question 4/6 participants stated their doctor was not the person who provided them with the knowledge they have on their period. Many participants talked about books they read or had someone read to them in grade school and middle school. 3/6 participants mentioned *The American Girl Doll Book: "The Care and Keeping of You: The Body Book for Girls"* as being one of the main resources they used while being introduced to the menstrual cycle and sexual health. One participant mentioned they also gained their introductory knowledge on the menstrual cycle and sexual health from a book but did not mention the title or author. 3/6 participants explicitly mentioned that their mothers provided them with their knowledge on the menstrual cycle and sexual health. 2/6 participants said school provided them with this knowledge. 3/6 participants said their knowledge came from the internet. 2/6 participants said their knowledge came from their friends and 1/6 participants said their knowledge came from their own experiences. Participants provided multiple answers or resources in response to the question asked. One participant mentioned they felt their doctor only talked about the menstrual cycle and sexual health when they asked about it. The participant stated: "I'd asked clarification questions, but that was when I was old enough and comfortable enough to be able to do that". Another participant stated: "But I never felt comfortable talking to my mom about it [the menstrual cycle and sexual health]. And my mom came into my doctor's appointments for a very long time, so I never felt comfortable talking to my doctor about it".

Question Three

The focus group was asked: Is there a societal stigma around the menstrual cycle and periods? Do you think that affects medical care?

One participant shared that she had recently done a project in a class at Southern New Hampshire University in which she presented on period poverty and the price of a period. She stated that her male professor made comments about the presentation being “out there and edgy” and “gutsy”. In referencing the presentation after she had presented, he referred to it as “the end of a sentence”. During the presentation the male professor also asked if females use one tampon per day. As the focus group conversation continued this participant stated: “So it’s horrifying to see that my presentation on how much period products cost was the most education they have ever received in their 18 years, 20 years of life”. She also stated: “And I felt pressured to have to preface the presentation to be like, this isn’t a kill all men presentation. This is a conversation between you and I because it’s a universal issue”. The same participant went on to talk about the lack of knowledge and education that men have on the topics of birth control and reproductive healthcare. She stated: “Also they, I think most men think that the only option for birth control is a pill.... It’s like people don’t know about these things and women’s healthcare is just so ignored, so frustrating”. Another participant shared their experience with birth control and medical care. They went on birth control at age 13 to combat severe acne and their mother started questioning them about whether or not they were sexually active. This participant stated that there is a societal stigma around the menstrual cycle and said: “I think it influences your medical care severely”. Then went on to say that their mother was not educated on the uses of hormonal birth control other than sex, presumably due to the associated societal stigma and then they stated: “And it impacted whether or not I got medical care”. The participant went on to

share that their mother had a hysterectomy, but they were unaware until recently, which upset them because it can affect their medical care. The participant stated: “But literally, these things are not talked about and it can impact our medical care as individuals”. They also shared an experience in which they started developing cysts from their birth control and it was causing them to bleed during sex. Ultimately, they quit hormonal birth control about a month before the focus group because of those health issues. This participant also shared that at one point they made an appointment to get an Intrauterine Device (IUD) but were not able to attend the appointment because they were terrified and did not believe there was any treatment for the pain the insertion would cause. As conversations continued one participant stated: “We’re not taught in schools. Our doctors didn’t really talk to us about it. I didn’t feel comfortable talking to my mom about it”.

During this question section, the facilitator asked the group to go around and share the age or grade each participant was in when they experienced their first period. 2/6 participants were 11 years old, 2/6 participants were in the fifth grade, 1/6 participants were 14 years old and 1/6 participants were in the eighth grade when they experienced their first period. Conversation about this topic continued and 2/6 participants told stories about hiding their periods when they first experienced it and 2/6 participants told stories about how they did not know what was happening when they experienced their first period. One participant shared that they waited to tell their mother that they had experienced their first period until they knew their father was not home because they were afraid he was going to hear it. Another participant shared: “My cousin though, when she got it [her period], she was told not, she’s not allowed to tell her dad. So her dad is just like, she’s a senior in high school now, just is unaware”. Another participant

responded: "I was told that about birth control. Like don't tell your dad about birth control, when I wasn't on it for, doesn't matter what the reason was".

Question Four

The focus group was asked: When you need medical advice when it comes to gynecological care/menstrual cycle/periods what is your go-to resource?

4/6 participants shared that their friends or romantic partners are their go-to resource. 1/6 participants shared that the internet is their go-to resource. 1/6 participants shared that their mother is their go-to resource. One participant shared that they seek out medical advice from others as a last resort. This participant stated: "But usually just either if it's a physical problem or a mental problem, I wait, I like to wait till it gets really, really, really bad and then I think I'm dying and then I tell somebody". Another participant shared an experience about a medical issue they had that turned out to be a severe UTI. They shared that the first resource they went to was the internet, then the second resource was a doctor. They further stated that they waited two and a half hours to be seen by the doctor when they were in an immense amount of pain and had a fever. A different participant shared that she had a 16 hour wait at a hospital after being in incredible pain and once she was seen, the doctors performed a CAT scan which did not yield any issues and so they told her nothing was wrong and sent her home without giving her any medication. Ultimately, she found out that the pain was a result of cysts rupturing within her body. This was determined multiple weeks later after being sent to the primary care doctor and then sent to an OBGYN who performed an internal ultrasound. Another participant shared that they had an experience in which something similar to a massive pimple with purple coloration appeared on her vagina and caused her a great deal of pain. She mentioned that she waited until it hurt really bad to then tell her mother about it. She scheduled an appointment with the doctor

but before she was able to be seen, the pimple-like growth burst. She went to the doctor and they told her that it was relatively common. When she asked the doctor if they knew why it was there, they responded: no. Then over the next six months, this happened to the participant three more times and she ended up going on antibiotics multiple times. She remembered it being very painful every time.

Another participant shared that she felt her medical providers blamed the actions of other medical providers for negative health issues. She talked about an experience where her gynecologist prescribed her a hormonal birth control at the same time that her psychiatrist prescribed her Zoloft. When she started gaining weight continuously, she became concerned and talked to her medical providers, she said they would blame each other and focus on assigning blame instead of trying to help resolve her medical issues. She went on to talk about how she gave up taking birth control and refused any hormonal birth control implants like an IUD or Nexplanon and her doctor was not very receptive to her refusal. The participant stated: “And it’s unfortunately, I think a lot of people feel bulldozed by their medical providers, but that was a boundary that I had to set and she was not happy about it and I was like, so sorry you have to work a little bit harder. That’s not something I’m willing to do”.

A different participant continued the conversation by sharing her thoughts and opinions about receiving medical care. She stated: “I’m going to be transparent and say that I am terrified to be pregnant because I have seen way too many scary videos of the healthcare system not treating African women the same or giving them the same care as people who are white, Caucasian, or even present that way, even if they’re not”. One participant responded by saying she doesn’t want to have kids or be pregnant because of “how much of a toll it takes on your body with the lack of knowledge so many doctors have”. Another participant responded to that

statement, agreeing that they no longer want to have children because of how scary they perceive pregnancy to be.

As the conversation continued, another participant shared an experience that their friend had recently gone through. The participant has a black, cisgender female friend who had a cyst on her breast that ruptured in October of 2021 and went to the local emergency room and was told there was nothing to worry about and that nothing was cancerous. But in December of 2021 this friend was diagnosed with breast cancer and because she was not given medical treatment for so long, she had to have surgery and ended up in a coma. It was not clear from the participant's story whether the coma was medically induced or natural. When the participant asked her friend if she thought being a person of color influenced her medical treatment, the participant responded that her friend had stated: "I would hate to think that way, but at some point it's part of the equation. It's a part of the system".

Another participant responded to this experience with a similar experience that her sister had gone through. The participant's black, cisgender female sister went to the emergency room one day due to issues with her lungs and by the time they took her into a room she had to be put into a medically induced coma because she could no longer breathe on her own. In telling this story, the participant stated: "She had to be put on a ventilator. So, it was scary. And that's the kind of shit that I hate going to the doctor's for, which is why I wait, and I prolong going to the doctors until it gets to the point where it's so bad".

Question Five

The focus group was asked: Is there anything else you would like to say about healthcare for individuals with uteruses or your own healthcare experiences relating to gynecological healthcare or other diseases including endometriosis?

One participant responded to the question by saying they know about endometriosis because their gynecologist suspects they have it, but they do not have a good understanding of the disease. This participant went on to share that she had an experience where she was experiencing contractions and then passed a very large piece of tissue, which is what led her gynecologist to believe she may have endometriosis.

3/6 participants spent the first minute after this question trying to develop a definition of endometriosis and take guesses at what it is. 2/6 participants brought up polycystic ovary syndrome (PCOS). As the conversation continued one participant made a statement in regards to doctors: "I just want them to do better. That's a consensus with everyone, but I just want them to do better because it's known that the type of care and treatment that men get is different than the type of treatment that women get". Multiple people responded to that statement with their own statements about doctors not being trained enough or having enough knowledge. One participant stated: "Unfortunately when people want to be doctors, majority of them are looking at the fucking salary that they're getting". Another participant stated: "They're looking at the money that they're going to get after they do all this medical shit. Which is probably why they don't know shit and they don't care enough to know shit. You might have one or two here and there that actually care about what they're doing and the service that they provide and they care for their patients and stuff like that but when it comes down to it, it's about making money and being able to support yourself".

As the conversation continued, one participant stated: "When psychiatrists or counselors... prescribe medication, they tell women that they're supposed to take it on a regular schedule and that men can just take it whenever they want". The participant did not know if

their statement was correct or incorrect, but they had heard this information recently and wanted to share it with the group.

The topic of insurance also came up during this conversation. One participant shared that their friend who is immunocompromised and has PCOS had to marry someone in order to receive reliable health insurance so they can continue affording to see medical professionals.

3/6 participants shared that they were told by medical professionals when they were 14 or 15 years old that they may not have children or that they may have fertility issues. These participants all agreed that the medical professionals did not elaborate or talk more about the potential issues and said the doctors responded to them with statement similar to: “we’ll address it at a later point” or “when we cross that road”.

As the conversation was wrapping up, participants began talking about how sex education may be location dependent. One participant shared the following statement: “In New Hampshire, there’s a divisive concepts law.... They’re not allowed to talk about anything that’s divisive. So, parts of sex ed and talking, especially about queer theory, is just not an option”. This participant went on to share a personal experience: “In New Hampshire they said to a room of eighth graders, hey, if you’re going to have sex, don’t wear condoms because you’re choosing to possibly have children with that person”. This participant did not further specify where this experience took place or in what context it took place.

Chapter 5

Discussion

Pediatricians and Gynecological Care

As determined through the focus group, 5/6 participants shared that they do not feel there is a level of gynecological care or that they are asked about their period, uterus, vagina etc. when receiving care from a general practitioner. Considering 5/6 participants shared that the last person they went to for primary medical care was an individual who identified as a woman, it is not likely that the lack of gynecological care, provided by a general practitioner, stems from the general practitioner identifying as a male. General practitioners who identify as females may be regarded as having more knowledge around periods and gynecological care for those with a uterus as it is often assumed they experience the menstrual cycle. However, in this focus group that is not the case and this connection cannot be assumed. It is important to note that all participants in the focus group have seen a pediatrician for the majority of their life and are just beginning to transition to seeing general practitioners. But considering all participants reached menarche by the time were 14 years old, their pediatrician should have a great deal of knowledge on periods and gynecological care as the majority of their biological female patients will reach menarche while under their care.

Birth Control

The confusion surrounding birth control within the focus group can be attributed to the lack of education provided by medical professionals to their patients. If an individual is

prescribed a medication, the focus group determined there should be an understanding of what the medication is and how it will affect the body of the individual for whom it's being prescribed. At one time or another, 4/6 participants have been on some type of birth control. Considering that all participants are over the age of 18 years old, it can be assumed that they were prescribed birth control while under the care of their pediatrician. It is important to note that the pediatrician may not be the medical professional who prescribed the birth control but that the individual is still under the care of the pediatrician. Since the individuals are taking birth control while seeing a pediatrician, the pediatrician should be able to provide education on what the pill is made up of, how it works and how it will benefit or negatively impact the patient. This lack of clarity could account for the confusion amongst the participants of the focus group and if this finding reflects the attitude of the greater population that is prescribed birth control, could highlight an area of improvement in communication between medical professionals and patients. A further area of study could examine the knowledge of pediatricians on birth control which could help determine whether the communication breakdown is taking place between pediatricians and their patients or if there is a greater need for educating pediatricians on the topic of birth control.

When further discussing birth control, one participant shared that they were prescribed birth control at age 13 to combat severe acne and their mother had a negative reaction. The participant attributed this reaction to a societal stigma around the menstrual cycle and birth control and went on to talk about how they believed this stigma affected their medical care. This participant believes that there is a direct link between the societal stigma around the menstrual cycle and their ability to receive medical care. Although the societal stigma around the menstrual

cycle may not have directly affected their access to medical care and ability to communicate with a medical professional; as a minor, their medical care was controlled to an extent by their legal guardians, who were affected by this societal stigma. This participant went on to talk about how they believe their mother felt ashamed of having a period and being a biological woman due to the stigma around the menstrual cycle and reproductive health as it pertains to individuals with a uterus. The participant shared that their mother had a hysterectomy due to endometriosis, but the participant was unaware until recently, and only became aware due to a joke their mother had made about having a uterus. The participant felt strongly that they should have been aware of their mother's endometriosis diagnosis and hysterectomy because they believe it affects their health due to the genetic factors associated with endometriosis.

Knowledge and Resources

When talking about where the knowledge participants have about the menstrual cycle and sexual health comes from, 4/6 participants mentioned their knowledge came from a book. Since the majority of participants received their knowledge from books, it is important to continue updating books that discuss the menstrual cycle and sexual health as the knowledge in these areas keeps evolving. A further area of study could specifically look at the resources individuals get their knowledge on the menstrual cycle and sexual health from and examine if those resources have changed over time. Furthering exploring if different generations get their knowledge from different sources and if those resources are consistently reliable.

Participants were asked about their "go-to resource" when it comes to medical advice on gynecological care/menstrual care/periods and not one participant shared that a medical professional was their "go-to resource". This can make individuals susceptible to misinformation

about the menstrual cycle and reproductive health. It is important to examine why individuals do not seek out medical professionals as their primary resource when they should have the greatest quantity and quality of knowledge on these topics. Further areas of study could examine the relationships between medical professionals and patients to determine why medical professionals are not the first resource individuals go to for medical advice. These studies could determine that factors such as negative experiences with medical professionals, long waits at doctors' offices and emergency rooms, high insurance co-pays or lack of insurance have a great impact on this finding.

Societal Knowledge

When discussing a presentation that a participant had created for a class, it was mentioned that the male professor refused to say the word "period" as it pertains to the menstrual cycle and instead referred to it as "the end of a sentence". This language can be interpreted as this professor being uncomfortable with talking about the menstrual cycle and periods as a whole which can negatively impact his students. His language and attitude towards the subject of periods and reproductive health does not appear to be very positive and open, but instead it comes off as shameful and embarrassed. This can negatively impact students that identify as males or those who have not experienced a period, as they are learning this language from someone who traditionally teaches them and who they presumably hold in a high regard. This can also negatively impact students that identify as females or those who have experienced a period, as the language surrounding this topic does not directly address periods and the menstrual cycle but instead presumably comes from a place of shame, potentially causing students to be shameful about their period and embarrassed to talk about it in an educational setting. A further

area of study could examine how the language around the menstrual cycle impacts the relationship people with uteruses have with their body or their willingness to talk about their reproductive health and the menstrual cycle.

While talking about this presentation, the participant also mentioned that the male professor asked if females used one tampon per day. She also talked about how frustrating it was to be under the impression that her presentation on the cost of period products was the most education that the male students or students who have not experienced a period, have had during their lifetime. These statements can be attributed to the lack of education that people who identify as males or those who have not experienced a period, may receive. Further areas of study could examine the knowledge of those who identify as males, or those who have not experienced a period, on the menstrual cycle and period products. It is important to note that the male professor and male students are not at fault for their lack of knowledge on menstrual products. They have not had the opportunity to receive education on this topic which can reflect on many different institutions for not providing information on topics pertaining to the menstrual cycle and reproductive health, to every person.

Discussion around the presentation also focused on how the participant felt that she needed to preface the presentation and explain that it was supposed to be informative and not divisive. She did not want the male students or students who have not experienced a period, to feel that she was attacking them in presenting on the cost of period products. This idea of feeling that students who do not experience a period would be upset at learning about period products could reflect a societal theme of toxic masculinity. Meaning that male students or students who do not experience a period would feel uncomfortable in learning about the menstrual cycle and

reproductive health and feel as though they do not need to know about these topics because of their gender identity.

Societal Stigma

During the focus group it was determined that 2/6 participants hid their periods from others when they first experienced it. This can be attributed to the societal stigma around the menstrual cycle and reproductive health and feelings of shame and embarrassment that are often associated with the menstrual cycle. Additionally, 2/6 participants did not know what was happening when they experienced their first period. This can be attributed to the lack of education on the topics of the menstrual cycle and reproductive health and can be used to support the idea that more information on and education about these topics is needed. Further areas of study could examine the resources that people within today's society commonly expect to learn about the body and biological systems from. Then action can be taken to either educate the resource, assuming it is a group of people like medical professionals, or update the resource, assuming it's a book or website.

The focus group participants talked about experiences and discussions they've had within their family dynamics about topics relating to the menstrual cycle and birth control. One participant shared that they waited until they knew their father was not home to tell their mother they had experienced their first period. Another participant shared that her cousin was told by her mother that she could not tell her father she had her period. A different participant also shared that their mother told them not to tell their father that they were prescribed birth control. These experiences can be attributed to the societal stigma around the menstrual cycle and reproductive health as it relates to talking to people who identify as males or those who do not experience the

menstrual cycle. Based on the findings from this focus group, it is possible that individuals from different generations have different views on the acceptableness of talking about topics relating to the menstrual cycle to individuals who identify as males or who do not experience the menstrual cycle. Further studies could examine the idea of different attitudes or views that individuals have from different generations on talking about the menstrual cycle and reproductive health to those who identify as males or who do not experience the menstrual cycle.

Medical Experiences

Participants in the focus group shared many experiences relating to medical care they received from medical professionals. One participant shared an experience where she went to the emergency room and had a wait of 16 hours and after being admitted was told there was nothing wrong with her. This participant found out a few weeks later that the pain was a result of cysts rupturing within her body. This experience shows insight into why many people believe that medical professionals do not take the pain of people with uteruses as seriously as they do people without uteruses who have never identified as a woman.

A common theme throughout the focus group was the participants not seeking out help from medical professionals until their pain reached a level that was intolerable. Many experiences were shared that highlighted this idea. This theme could be attributed to a societal belief that medical professionals do not take the pain of people with uteruses as seriously as they do people without uteruses who have never identified as a woman. The participants in the focus group did not want to be seen as weak or asking for help because they may not have wanted their pain to be dismissed or seen as fitting into the stereotype of those who identify as women having a low pain tolerance. A further area of study could examine how often people who identify as

men see a medical professional versus how often people who identify as women see a medical professional for the same type of injuries, symptoms or diseases.

Pregnancy

The topic of pregnancy also came up in the focus group. Three participants shared statements relating to their fear of becoming pregnant. One participant attributed her fear to videos of the healthcare system treating pregnant people of color differently than white pregnant people. Another participant attributed her fear to the lack of knowledge she believes so many medical professionals have, and another participant shared that she is scared of pregnancy. These findings may reflect the doubts these participants have about their current medical care and general practitioners they have received care from during their lifetime and how pregnancy is being portrayed within today's society through videos, television shows, movies, books, etc. Further studies could examine the attitudes and thoughts of people who are able to become pregnant on pregnancy and how those attitudes and thoughts have been shaped over their lifetimes based on the type of media they consume.

Intersectionality

The topic of intersectionality as it relates to healthcare for individuals with a uterus was also brought up during the focus group. One participant shared that her black, cisgender female friend was diagnosed with breast cancer after a prolonged period of time and after being told by a medical professional that a cyst on her breast was not cancerous. After a conversation with her friend, the participant shared that she and her friend believed that being a person of color influenced her medical treatment. Although this thesis does not specifically address the difference in medical treatment among individuals of different races and ethnicities, it is

important to note that the intersection of many identities along with the identity of being a person with a uterus can affect medical care as it relates to reproductive health. There are many different aspects of identity that need to be furthered researched as it pertains to treatment for people who have a uterus and experience the menstrual cycle.

Conclusion

This focus group helps support the idea that general practitioners are not providing enough knowledge on the menstrual cycle and reproductive health to their patients. Every participant in the focus group reached menarche while still attending their pediatrician and only 1/6 participants believed there was a level of gynecological care and that they were asked about their period, uterus, vagina, etc. This participant believed that their answer was influenced by their outside relationship with their pediatrician since they were family friends. This thesis did not examine why general practitioners are not providing enough knowledge on the menstrual cycle and reproductive health to their patients, but potential reasons could be the lack of training they receive on these topics or societal stigma around these topics. Another participant shared they felt their doctor only talked about the menstrual cycle and reproductive health when the patient asked questions. Patients at the age of menarche are most often minors and may not have the education and/or ability to advocate for themselves and their health. Relying on patients to talk about a very common biological function that they will most likely experience while seeing a pediatrician is not good practice. Since it is so common the pediatrician should ask questions about the menstrual cycle, initiating the conversation and allowing the patient to feel comfortable talking about it to them in the future.

Conversations within this focus group also helps support the idea that a general practitioner is not the person who provides individuals the knowledge they have on the menstrual cycle and reproductive health. This is potentially concerning as general practitioners should have the most factual information pertaining to these topics and consuming information about these

topics from other resources can lead to a spread of misinformation. This misinformation could negatively impact the medical care individuals with uteruses experience and has the potential to exacerbate the societal stigma around these topics.

The idea that there is a societal stigma surrounding the menstrual cycle and reproductive health for individuals with a uterus is also supported by this focus group. It also supports the idea that this stigma can affect access to reproductive care, ability to talk openly about the menstrual cycle with other individuals and ability to talk openly about the menstrual cycle with individuals who identify as males or who have never experienced the menstrual cycle.

This focus group also supports the idea that there is a lack of trust and support within the relationships that individuals have with medical professionals. Not one participant shared that the first resource they go to is a medical professional and multiple participants shared concerns that medical professionals are only in their fields for their salaries. Participants also shared that they felt medical professionals did not want to elaborate or talk more about potential health issues regarding the menstrual cycle and reproductive health.

As it relates to endometriosis and care for individuals with endometriosis and other diseases that are characterized as reproductive diseases, this thesis helps determine that there is a lack of knowledge and education among the general practitioner population, especially pediatricians, in regard to the menstrual cycle and reproductive health. This lack of knowledge and education negatively impacts patients and their ability to trust medical professionals and receive proper medical care. If pediatricians do not have enough knowledge to educate their patients on basic issues and topics pertaining to the menstrual cycle and reproductive health, then

it is unrealistic to think they have enough knowledge to propose an endometriosis diagnosis to their patients.

Appendix A

Participant Eligibility Questions

- 1) Are you able to participate in a focus group from 12:00-1:30PM on Tuesday, February 21, 2023?
 - i) Yes
 - ii) No
- 2) Are you over the age of 18 or will be over the age of 18 by February 21, 2023?
 - i) Yes
 - ii) No
- 3) Are you currently enrolled as a student at Southern New Hampshire University?
 - i) Yes
 - ii) No
- 4) Do you have a uterus, or have you ever had a uterus?
 - i) Yes
 - ii) No

Appendix B

Focus Group Flyer

Do You Have a Uterus?

Join a focus group to talk about experiences you've had relating to your medical care!

**Where: Green Center
Conference Room 122**

**When: 12:00-1:30PM,
Tuesday, Feb. 21**

This focus group is a part of an Honors Program Senior Thesis project.

Free pizza!

Scan here to see if you can participate!



Email rachael.harris@snhu.edu for more information



Honors Program

Individuals with disabilities requiring accommodations should contact the Accessibility Center at (603)-644-3118 or cac@snhu.edu

Appendix C

Copy of Informed Consent Form

Informed Consent Form for The Need for Endometriosis Awareness: A Case Study of College Students and Medical Professionals

You are being invited to participate in a research project conducted by Rachael Harris, who is an undergraduate student at Southern New Hampshire University.

You are invited to participate in a research study about the challenges regarding gynecological healthcare for individuals with uteruses.

You will be asked to actively participate in a focus group of 9-13 individuals to talk about gynecological healthcare, that will take about a half-hour to an hour-and-a-half of your time. There will be five questions that will ask about your personal experiences with gynecological healthcare, the menstrual cycle and societal stigma around these topics.

The potential risks associated with this study include talking about your personal experiences with gynecological healthcare with other people which may cause some individuals to feel uncomfortable. The project is expected to benefit you by providing a space to talk about a topic that is usually not talked about in a group setting. It may help to validate your personal experiences and allow you to learn more about yourself.

If you have decided to participate in this project, please understand that your participation is voluntary and that you have the right to withdraw your consent or discontinue participation at any time with no penalty. You also have the right to refuse to answer any question(s) for any reason with no penalty.

In addition, your individual privacy will be maintained in all publications or presentations resulting from this study. This focus group will be recorded using a voice recording app on an iPhone. Once the data from the study group is analyzed, then the recording will be deleted from the iPhone and no longer be saved on any device. This study will be completed by March 15, 2023 and all recordings will be deleted by that date. Subjects' names will not be used in the final research document, however if deemed necessary, individuals may be referred to as "Participant A, Participant B..." within the final research document.

If you have any questions regarding this project, you may contact the researcher at rachael.harris@snhu.edu. If you have questions regarding your rights as research participant or any concerns regarding this project, you may report them – confidentially, if you wish – to the University Campus Institutional Review Board Chairperson, Dr. Leslie Campbell, at IRB@snhu.edu.

A copy of this consent form will be provided to you.

I understand the above information and voluntarily consent to participate in the research.

Signature of Participant: _____ Date: _____

IRB Approval Number: _____ IRB Expiration Date: _____

Appendix D

Demographic Survey Questions

1) Age

- i) 18
- ii) 19
- iii) 20
- iv) 21
- v) 22
- vi) 23
- vii) 24
- viii) Over 24

2) What gender do you identify as?

- i) Male
- ii) Female
- iii) Non-Binary
- iv) Prefer Not To Say
- v) Other: (fill in)

3) Please specify your ethnicity (you may click more than one)

- i) Caucasian
- ii) African-American
- iii) Latino or Hispanic
- iv) Asian

- v) Native American
 - vi) Native Hawaiian or Pacific Islander
 - vii) Prefer Not To Say
 - viii) Other: (fill in)
- 4) Are you familiar with the term endometriosis?
- i) Yes, I am confident I know what that is
 - ii) Kind of, I know people who have it and have heard of it before
 - iii) Not really, I have heard the word but don't know what it means
 - iv) No, I have never heard this word in my life
- 5) On average, how many people with a uterus do you think are affected by endometriosis?
- i) 0-5%
 - ii) 5-10%
 - iii) 10-15%
 - iv) 15-20%
- 6) On average, how long do you think it takes for an individual to be diagnosed with endometriosis after exhibiting symptoms (average diagnostic delay)?
- i) Less than 1 year-2 years
 - ii) 2-4 years
 - iii) 4-6 years
 - iv) 6-8 years
 - v) 8-10 years
 - vi) Longer than 10 years

Appendix E

Focus Group Questions

- 1) When receiving care from a general practitioner do you feel that there is a level of gynecological care? Are you asked about your period, uterus, vagina etc. ?
- 2) Where does the knowledge you have about your menstrual cycle and sexual health come from? The doctors, you and your experiences, school, family members, the internet etc.?
- 3) Is there a societal stigma around the menstrual cycle and periods, do you think that affects medical care?
- 4) When you need medical advice when it comes to gynecological care/menstrual cycle/periods what is your go-to resource?
- 5) Is there anything else you would like to say about healthcare for individuals with uteruses or your own healthcare experiences relating to gynecological care, or diseases, including endometriosis?

Appendix F

Redacted Version of Transcript

Facilitator (00:02:47):

So if you do decide at any point during the conversation that you need to step out or that you just do not want to participate anymore, no worries at all. You are free to go and do that. Just at some point have a conversation with me saying like, Hey, I don't want that anymore. I withdraw my consent and I'll take care of that. If a day or two goes by and you're like, mm, I'd like to withdraw my consent now, you can do that as well. Yeah. And with that, we are going to start the conversation. So like I said, there are five questions. I'm going to ask a question and then we can have a discussion about it. Go around whatever's more comfortable. If you don't want to answer, you don't have to answer. And yeah, if conversation comes up that's not related to the question, that's also totally fine. This is just free flowing discussion. So the first question is, when receiving care from a general practitioner, do you feel that there is a level of gynecological care? Are you asked about your period, uterus, vagina, et cetera?

Participant C (00:04:03):

Yes.

Participant D (00:04:07):

No, I don't experience that.

Participant A (00:04:16):

I mean, my yearly physical, she just asked if it's normal and that's the end of it.

Participant E (00:04:24):

Yeah, I would agree. I said I would say I have a similar experience to that.

Participant F (00:04:29):

I go to a pediatrician still because I

Participant E (00:04:31):

Same

Participant A (00:04:31):

Same

Participant D (00:04:31):

Same

Participant C (00:04:31):

Same

Participant F (00:04:32):

Good for all of us. I think that might be part of it, to be completely honest with you. But I have a pediatrician that I actually have a fair, fairly close relationship with and I think that makes it easier for me to talk about those things. And they'll ask if you're sexually active. And for me, they actually do ask whether or not my partners are what their gender identity is. And then they'll also ask when your last period is, which I think is a tough question because I never remember. And then they're like, okay, what is it? And then that's one thing that they ask. And then they also ask if you might be pregnant, which they don't frequently offer a pregnancy test with that.

Participant D (00:05:14):

Yeah.

Participant F (00:05:15):

And then you also have to pay for it.

Participant D (00:05:16):

Right.

Participant F (00:05:17):

So there's that.

Participant D (00:05:18):

I'm realizing this last time I went to the doctor, so literally in December I cut birth control. I was on birth control for the first three years of my period, and I cut it cold Turkey along with another medication in May, April and she didn't ask anything about it. I wasn't asked about my cycle or anything. I'm realizing that's probably an issue, a problem to be addressed. But normally there's at least one question. But yeah, nothing

Facilitator (00:05:51):

Real quick, I just want to go back. Did everyone say that they still see a pediatrician?

Participant F (00:05:57):

Yeah.

Participant C (00:05:57):

Yeah,

Participant D (00:05:58):

I do.

Participant E (00:06:00):

Well, I haven't been to the doctor in a while.

Participant F (00:06:02):

My next appointment will not be with a pediatrician.

Participant E (00:06:03):

Yeah. I got a physical last year for work through the Elliot, so that's the last time I went to a doctor. So I don't know, but I think I'm not going to going Forward.

Participant F (00:06:14):

And this is just primary care?

Participant C (00:06:15):

you can't once you're 21.

Facilitator (00:06:17):

Yes

Participant E (00:06:17):

Yeah, yeah.

Participant F (00:06:20):

Depending on the state probably,

Participant E (00:06:22):

I thought it was 24

Participant A (00:06:22):

yeah, cause I can have one more appointment with my pediatrician,

Participant D (00:06:25):

I can go through college. Yeah.

Participant A (00:06:28):

Yeah. I'm through college.

Participant E (00:06:28):

Yeah.

Participant C (00:06:30):

<laugh> I can't

Facilitator (00:06:33):

Another quick question, not one of the five but if you feel comfortable, just go around in a circle and say if you are on a type of birth control, what you might be on, whether it's the pill, whether you have an IUD, et cetera. We could start here.

Participant A (00:06:50):

No birth control

Participant D (00:06:52):

no birth control,

Participant F (00:06:54):

no birth control. But I cut it last month.

Participant E (00:06:57):

No birth control.

Participant C (00:06:58):

I am on birth control, but I forget to take it like every other day. So it's

Facilitator (00:07:03):

It an oral Pill?

Participant C (00:07:04):

Yeah, it's a pill.

Facilitator (00:07:04):

Okay. And, were you on a pill?

Participant F (00:07:06):

I was on the pill for five years.

Facilitator (00:07:07):

Okay. And

Participant D (00:07:08):

Are we Oh, we have a long journey.

Participant F (00:07:10):

Yeah.

(00:07:11):

I was on several pills as well.

Participant D (00:07:12):

Yeah.

Facilitator (00:07:13):

Okay.

Participant D (00:07:13):

Several different types of pills. And then I was on, I would sometimes would take two pills at once. And then I was also on Depo-Provera, which is a quarterly shot. I believe. It can go in your butt or in your arm. I put it in my arm.

Participant C (00:07:33):

Good choice.

Participant D (00:07:34):

I, so I did depo with a pill.

Facilitator (00:07:37):

Okay. Thank you. All right.

(00:07:42):

Anything anyone else wants to really add about that or No,

Participant D (00:07:46):

It's a lot of hormones. <laugh>, like that's a lot to put into your body for so long.

Participant F (00:07:51):

And I took hormonal birth control. Just specify that specifically.

Participant D (00:07:55):

Same.

Participant C (00:07:56):

I don't know what I'm putting in my body, <everyone laughs> but it makes my cramps not as bad, and that's that's all I need. So

Participant F (00:08:01):

who prescribed you that?

Participant C (00:08:03):

My pediatrician.

Participant D (00:08:05):

They can do that?

Participant F (00:08:05):

I was also prescribed by my pediatrician.

Participant D (00:08:08):

I was referred to a gynecologist.

Participant F (00:08:10):

Oh, really?

Participant D (00:08:10):

Yes.

Participant F (00:08:11):

That's not really covered by insurance for me. So I had to go through my pediatrician.

Facilitator (00:08:16):

Another quick question. We can go around again if you don't know, you don't have to answer. But currently or in the past, because I know for myself, I've had multiple different primary care doctors.

You, because it was like the office is my primary care, so I could see a different person each time. The majority of the time. Do you normally see someone who identifies as a man or a woman taking care of you?

Participant A (00:08:43):

A woman.

Participant D (00:08:45):

A woman

Participant F (00:08:46):

It was a man for a while, but now it's a woman.

Participant E (00:08:49):

Yeah, so for me, it was a woman. And the reason I haven't gone to the doctor in the past year is because my doctor retired. I think it was maybe two years ago. And I went once and I had like uh what? When they're in school, I don't know, whatever that is.

Participant F (00:09:07):

A resident?

Participant E (00:09:07):

Yeah, a resident. And it was one man and one woman. But when I went to the Elliot like add-on place to get my physical for work, it was a woman.

Participant C (00:09:19):

Mine's a woman.

Participant A (00:09:24):

So my second question is where does the knowledge you have about your menstrual cycle and sexual health come from? So you have a variety of answers that you could just elaborate on, but some

given answers are the doctors, you and your experiences, school, family member, family members, the internet, et cetera.

Participant C (00:09:48):

Well, I dropped my ring. Okay. My mom told me about periods when I was in first grade because my sister was in fourth grade, so she was probably going to soon. And my mom was like, I'll just get it done now. But then also <laugh> the American Girl Doll book for,

Participant A (00:10:08):

oh my God yeah. <everyone laughs>

Participant C (00:10:08):

Yeah, that thing for sure. And school, I guess, but I already knew at that point. So

Participant E (00:10:19):

Yeah, I guess I would say mainly my mom and probably school. I can't actually actively remember learning about it, but I just assumed that I did like in middle school. And then probably in high school too.

Participant F (00:10:32):

I also got the American girl doll book, I did not learn much from my mom. I learned it mostly through the internet and interactions with friends who conveniently got their periods before I did. And then I taught my sister what I knew.

Participant D (00:10:51):

Yeah. I didn't have the book. <everyone laughs>

(00:10:56):

My mom,

(00:10:57):

I had my mom like

(00:10:58):

Read a different book to me

(00:11:01):

But I didn't get my period until, God, sophomore year of high school. So I just knew from friends and the internet obviously. But otherwise, yeah, school was probably the least helpful.

Participant A (00:11:16):

I also had the American girl doll book <everyone laughs> probably mostly through just my own experience and the internet.

(00:11:26):

Yeah.

Facilitator (00:11:32):

So just going off of that, a lot of people have said varying things, but I didn't really hear anyone specify their doctor, would everyone kind of <everyone laughs>

(00:11:42):

Agree with that? That their doctor was not the person who kind of gave them the knowledge on that.

Participant A (00:11:49):

Correct.

Participant E (00:11:49):

Yeah.

Participant F (00:11:50):

Correct.

Participant C (00:11:50):

Yeah.

Participant F (00:11:51):

I'd asked clarification questions, but that was when I was old enough and comfortable enough to be able to do that

Participant C (00:11:57):

Yeah once I already started.

Participant F (00:11:58):

And that was three or four years in at that point, so,

Participant D (00:12:03):

and their answers are never helpful. It's always lose weight or maybe it's your period. Like okay,

Participant F (00:12:10):

Like thanks. Cool. <laughter>

Participant A (00:12:13):

And like, I never got information from, well, I guess I had a talk with my mom at some point, but I blacked out during it, so I don't remember it. <laughter> But I never felt comfortable talking to my mom about it. And my mom came into my doctor's appointments for a very long time so I never felt comfortable talking to my doctor about it.

Participant D (00:12:33):

recently just told me that my mom doesn't have to come into my doctor's appoints <laughter> and I am 19 years old.

Participant C (00:12:43):

My doctor doesn't allow my mom in anymore. Cause I am afraid of doctors, so I want her there.

Participant D (00:13:16):

Yeah. I was like, I'm going to the doctor in December. And like, your mom's going with you? And I was like, yeah. She was like, she doesn't have to. And I was like, really?

Participant A (00:13:25):

The only perk of her going with me was that she'd make the appointments.

Participant D (00:13:28):

Yeah, yeah, yeah. Well, I made the appointment too.

Participant A (00:13:31):

Oh,

Participant F (00:13:33):

exactly.

Participant C (00:13:35):

Does your doctor not ask if you want your mom or not?

Participant D (00:13:38):

I don't know. It's a quick in and out situation, obviously. I wasn't really asked much.

*A new participant joins in the focus group at this time

Facilitator (00:15:24):

So I'm just going to read them and if you have an answer and then that conversation sparks great.

If not, we'll move on.

Participant B (00:15:32):

Alright

Facilitator (00:15:32):

So our first question, whoa <laugh>, was when receiving care from a general practitioner, do you feel that there is a level of gynecological care? Are you asked about your period, uterus, vagina, et cetera?

Participant B (00:15:50):

Yeah, well, kind of, my gynecologist is more like, you still having sex with the same person?

Yeah. Cool. Open up in and out without <laughter> like, I'm sorry, I'm very blunt, but that's usually it. It's

literally in and out. And then go see the phlebotomist for your blood test, your blood draw and then you're all set to go. And then she prescribes me the birth control and that's it. If I have an issue with my birth control and stuff like that, and I ask her, we talk about it, it does seem that she's rushed in a sense. She's like, I don't know, trying to get me out as fast as she can. Not really sitting there listening to me. So

Participant A (00:16:36):

Like it's just a question she has to ask?

Participant B (00:16:38):

Yeah. Yeah. Like are you okay with your birth control? And I'm like, I mean, yes. But then there's moments where I'm not whatever. But then she's like, oh, that's normal. Bye. <laughter> I'm like, okay,

Participant F (00:16:48):

cool.

Participant B (00:16:49):

Thank you.

Participant A (00:16:50):

Thanks for the help.

Participant D (00:16:50):

Rad.

Participant B (00:16:51):

That's awesome. And that's it. Yeah. So yes and no, I don't know. I haven't really had an issue like down there anyways. Actually, I have I lied. <laughter> Oh my God, I'm so sorry. I do have ovarian cysts, so that was like fucking hell going back and forth because then she sent me to my primary who also didn't do shit. And then he sent me back to her and it was just back and forth of going back and forth and doing so many freaking ultrasounds just for them to tell me that it's normal for me to feel that way. And

then for them to tell me, oh, by the way, you also have fibroids in your uterus, so you might not have kids.

Bye. And I was like. Okay.

(00:17:43):

Yeah. Awesome. Cool.

Facilitator (00:17:46):

So you mentioned you're on birth control. Are you still on birth control?

Participant B (00:17:51):

Yes.

Facilitator (00:17:51):

And if so, what type?

Participant B (00:17:53):

The pill.

Facilitator (00:17:53):

Okay.

Participant B (00:17:54):

Yeah.

Facilitator (00:17:54):

Awesome.

(00:17:55):

And then for your primary doctor, do you ever feel like they ask you about

Participant B (00:18:00):

Oh no.

Facilitator (00:18:00):

Okay.

Participant B (00:18:01):

No.

Facilitator (00:18:02):

And then is your primary doctor normally like a man or a woman?

Participant B (00:18:07):

Oh, he was a male.

Facilitator (00:18:07):

Okay.

Participant B (00:18:08):

But I'm getting a new one so.

Facilitator (00:18:09):

Okay.

(00:18:10):

That's very common here.

Participant F (00:18:12):

Yeah.

Facilitator (00:18:12):

Everyone's seeing new doctors. And then our second question that we just asked was, where does the knowledge you have about your menstrual cycle and sexual health come from? Some examples could be the doctors, you and your experiences, school family members, the internet, et cetera.

Participant B (00:18:32):

When I first got my period, my older sister told me I was dying and I only had a week to live. So
<laughter>

Participant F (00:18:39):

That's funny.

Participant B (00:18:39):

My knowledge comes from my mom because she was the one to talk me down and tell me that I indeed was not dying and what was happening, what was normal, which I literally hate that word now because it's so used when they're like, it's normal, but I'm like, but it doesn't feel normal when you're going through an extra sexual crisis at 11. Or even normal when you're going to the doctors and you're like, this doesn't feel normal. Listen to me. I know my body.

Participant D (00:19:06):

And then years later you find out

Participant B (00:19:08):

Exactly. It's not normal. I'm just like, whatever. But I hate that word. But yeah, it comes from my mom. And the first time I went to the gyno, I was so scared. Nobody prepared me for that one. And even the doctor that I had was like, didn't talk me through it. She was just like, you're going to feel a small like piece of pressure. And I was like, that was not small. At least not for me. For anybody else who's used to it, whatever, that's fine. But for me, it was not. And I was terrified and I was shaking, and she was like, you have to relax. And I'm like, I can't. <laughter> I'm literally having an anxiety attack at the table, like I cannot relax.

Participant D (00:19:51):

Did they not brief you for an exam before?

Participant B (00:19:53):

No. She was like,

Participant D (00:19:55):

That's so traumatic.

Participant B (00:19:56):

Well, she was like, this is what's going to go inside of you, and then I'm going to talk you through it. And I was like, oh, okay. So she's going to talk me through it. And then she didn't, she was like, you're just going to feel some pressure. And I was like, okay, you didn't even tell me you were doing it. You didn't count to three, you didn't do anything. And I'm just sitting here or laying there like ow, ow. Please stop. Please stop. Please stop. And she's not stopping. She's like, relax. You have to relax.

Participant D (00:20:21):

Can I ask how old you were?

Participant B (00:20:22):

I was 18.

Participant D (00:20:24):

They're allowed to do that? Like when I visited a gynecologist for several years, and I never had an exam. Like I don't

Participant F (00:20:32):

It depends, I think partially if you're sexually active.

Participant B (00:20:34):

Yeah. Okay. I was 18.

Participant D (00:20:36):

Okay, that's fair.

Participant B (00:20:39):

But I'm also, okay, TMI but I'm also gay and I never had anything up there either at 18.

Participant D (00:20:44):

Okay.

Participant B (00:20:44):

Like other than a tampon. And even the tampon hurt. And now I know why, because of the fibroids. But even the tampon hurt. And I was like, listen, I don't usually put stuff up there and it fucking hurts when I normally do, so you have to walk me through this and this thing I'm looking at it and I'm like, it's huge. It's a metal thing. <laughter> It's big, it fucking hurt. And she was just like, you're fine, breathe. And I'm like, I'm not fine. So I ended up crying and I was like, okay, I guess this is what it is. And then I walked out and I told my mom and she was like, it shouldn't have hurt that bad. And I'm like, well, it did. <laughter> I dunno what to say. It did. I mean, years later I find out that I have fibroids, but still it did. I don't know.

Participant A (00:21:29):

Do you still have the same doctor?

Participant B (00:21:32):

Yeah, but I haven't been able to get a new one because of my insurance. So I got to take it where I get it.

Participant A (00:21:40):

Yeah, absolutely.

Facilitator (00:21:45):

And then just one follow up to that. So you mentioned your mom and your sister, but did any knowledge come from doctors at all or not really? No? Okay.

Participant B (00:21:55):

Nope.

Participant F (00:21:59):

Did you get the American Girl Doll Book?

Participant B (00:22:01):

No. No.

Participant F (00:22:03):

Just wondering.

Participant B (00:22:04):

No.

Facilitator (00:22:05):

All right. Now we're all up to speed. So we're cool. And there's only three questions left so we're rocking. All right. Our third question is, is there a societal stigma around the menstrual cycle in periods? Do you think that affects medical care?

Participant D (00:22:23):

Can I go first?

Facilitator (00:22:24):

Go for it.

Participant D (00:22:25):

I recently had a class where I could do a project on anything, and I decided to do my project on the price of a period. And my professor's response was positive, but also a little disappointing because he was like, oh my God, this is so out there and edgy. And he was like, when he referenced the presentation again in class a couple days ago, he was like, I really appreciated all your presentations. And then he was like, I think it's really gutsy that some of you did presentations on outside topics. And then he referred to my presentation as "the end of a sentence", and I was like, you're a man in your mid thirties. You can't say period.

Participant F (00:23:15):

That's so embarrassing.

Participant D (00:23:15):

It's so embarrassing.

Participant E (00:23:16):

<laughter> That is so silly, what the heck.

Participant D (00:23:20):

So when I was presenting, it was also very clear that men think the, so the flow level means the size of your vagina. <laughter>

Participant C (00:23:34):

Yeah. I saw that.

Participant D (00:23:38):

<laughter> They also don't know anything about how they work. My professor was like, so you use it one per day? And I was like, no, that creates sepsis. <laughter> You will die. <laughter> And maybe they all did. I don't think any of them had heard of endometriosis or knew about the implications of Roe v. Wade and how that's affected insurance and healthcare and the price of birth control, which is so jarring because these are people who can vote and have political opinions. And unfortunately, I think a lot of men have a conservative opinion about Roe v. Wade and abortion. And none of them know anything about it. And they are also sexually active. So it's horrifying to see that my presentation on how much period products cost was the most education they have ever received in their 18 years, 20 years of life. And it was a 10 minute presentation about period poverty.

Participant D (00:24:59):

Yeah, and there was maybe four guys in the presentation. And I felt pressured to have to preface the presentation to be like, this isn't a kill all men presentation. This is a conversation between you and I because it's a universal issue. But I think society makes everything so segregated in the sense of, oh, men can't go down that aisle. It's like, yeah, they can and they should. And it was very eyeopening and some

ways liberating, but also incredibly frustrating. And then the other day to see that clearly it didn't do much if you can't even say the word period. And you're in mid thirties, that's come on.

Participant A (00:25:38):

Can't even talk about it.

Participant D (00:25:39):

Yeah.

Participant A (00:25:39):

Even though 50% of the population experiences them.

Participant D (00:25:41):

Yeah. Also they, I think most men think that the only option for birth control is a pill. And all the girls were in the conversation, were talking about how their experience with IUDs and how it can pinch the nerve that stimulates labor. It's like people don't know about these things and women's healthcare is just so ignored, so frustrating.

Participant E (00:26:06):

Yeah. I think, I'm sorry,

Participant B (00:26:08):

Go ahead.

Participant E (00:26:08):

Yeah, I think that is really interesting. A question about this question, are you talking specifically about American society?

Participant D (00:26:13):

Oh, this is true.

Facilitator (00:26:14):

That's up for your interpretation. You can talk about specifically American society if you want to, or other societies if you see a difference.

Participant E (00:26:22):

Okay. I guess I only know American society, but I think going off of what you're saying, that presentation sounds really interesting. And I have a dad, I have a brother. I live with two guys right now. So I think, I don't talk to my roommates about my period personally but I've, I've talked to my dad about it before. He's bought me menstrual products. I don't know, I would definitely assume my dad doesn't probably know a lot of information about the topics we're talking about today. But if I did tell him about it, he would probably be receptive. Obviously, if I did have an issue, I would go to my mom first, but I wouldn't shy away about talking to my dad about it at some point, I guess. But I think there is definitely opportunities for education in that aspect of this society for sure.

Participant C (00:27:11):

Going off of that, my parents are divorced. So when I'm at my dad's, because I grew up like that since I got my period, basically they were divorced. So like he has been buying us, me and my sister our menstrual products and everything. So he is very open to talk about it. But I know that's not true for most dads. I think it's specific to the situation

Participant B (00:27:36):

Going off of that my parents are also divorced. So my dad did buy me a lot of products growing up, especially because my mom was gone and it was just me, him and my siblings for a while. And then when my brother was old enough to drive, he started doing the same thing. So I know some of the men in my family can have the conversation. But then I also, if we talk about society, do you guys ever see that TikTok trend where girls would put on clear face mask and talk about, it's fake, obviously, but talk about how it's their time of the month that they're shedding into a new like skin <resounding yeah from group>.

And they were like, oh my God, that's actually how it works. I died at that. But I was also like, are you stupid?

Participant D (00:28:21):

Or when men find out, I know that you can pee with a pad on

Participant B (00:28:23):

Or like with the tampon in, or when they find out how big it is, cause you put it through, I'm like, oh my God. But can we also fault them? Cause growing up, they didn't even have,

Participant D (00:28:36):

It's a weird line because it's also not our responsibility to educate them

Participant B (00:28:38):

to teach them. Exactly. It's not I mean, if you have a girlfriend, boyfriend, whatever, he can ask or you can talk about it. But most men don't grow up learning it because their moms are like, that's for girls only. You don't need to know that.

Participant D (00:28:56):

And we don't learn about it in school. We only learn about like

Participant B (00:29:00):

Sex.

Participant D (00:29:01):

Yeah for hetero-normative relationships

Participant B (00:29:04):

Yeah

Participant D (00:29:04):

And it's all about

Participant B (00:29:06):

You get condoms.

Participant F (00:29:07):

Yeah

Participant D (00:29:07):

Yeah.

Participant B (00:29:07):

Yeah there's no, thank you. Yeah. There's no like, I'm gay. I've known I was gay since I was nine. I'm sitting there like looking at a dick and I'm like, no,

Participant D (00:29:15):

literally

Participant B (00:29:15):

what?

Participant D (00:29:16):

We only learn about the penis. Like it's crazy

Participant B (00:29:19):

That's disgusting. <laughter> Like I'm gonna scream. And then there's just condoms and like then it's all the girl's responsibility to be on birth control and make sure that she doesn't get pregnant. What the fuck? <laughter>.

Participant D (00:29:36):

Because if you're pregnant, you'll die.

Participant B (00:29:37):

You'll die.

Participant C (00:29:38):

Yeah.

Participant B (00:29:40):

Whatever.

Participant F (00:29:41):

I think it influences your medical care severely. Because as a child when I was growing up, when I was struggling with a lot of health issues, especially relating to my severe acne, I went on birth control to stop that. And eventually it did work. But when I had to talk to my mom about it, she was like, are you having sex?

Participant D (00:30:02):

Yeah.

Participant F (00:30:02):

And I don't know what age people start having sex, but I was 13 when I asked my mom that question and she was like, accusing me. Sex is, it's not a sex positive household, but separate from that, there's other things that birth control

Participant A (00:30:16):

Right

Participant F (00:30:16):

impacts.

Participant D (00:30:17):

So many things

Participant F (00:30:17):

So obviously the education isn't there. And it impacted whether or not I got medical care. And then same thing, my mom is also ashamed at the fact she had a hysterectomy. And I didn't know that until I was 18 years old.

(00:30:31):

I also didn't know she had fertility issues. And these can impact me specifically because she has endometriosis. And I didn't know that at all. Didn't know what it was until I was 18, because she was joking about buying duct tape for a scar. But literally, these things are not talked about and it can impact our medical care as individuals. And even then, I think what we were talking about with birth control, especially with how it impacts relationships, I have a partner who is a man with a penis. And I think that my birth control type is actually influenced by that. And again, it rests on the woman, which is like

Participant D (00:31:11):

mm-hmm.

Participant F (00:31:12):

Horrendous.

Participant B (00:31:13):

mm-hmm.

Participant F (00:31:13):

Because I explained to him for months how awful it is because I was getting cysts from my birth control. Cause I had to change it because I, TMI was bleeding during sex. And then I started getting cysts when I switched birth controls. And I was like, this is awful. So that's why I quit it cold Turkey a month ago.

(00:31:33):

And then it's hard to have those conversations, even though I feel fairly sex positive and able to talk about these things. But also getting an IUD I made an appointment for couldn't get an I didn't go because I was so scared about how painful it was going to be. I made the appointment and I spent \$80 to not show up because I was just terrified because there's no treatment for pain, pain for that other than that. That's what, and then there's the trend going around where they were talking about how, again, gross, but the actual IUD will poke the guy,

Participant B (00:32:12):

The guy, yeah.

Participant D (00:32:13):

God forbid.

Participant F (00:32:15):

That's what I said to him. <laughter>

Participant D (00:32:16):

Cope, I don't know what to tell you.

Participant B (00:32:18):

And that's all he knows in his mind. He's like, it's going to hurt me, so don't do it.

Participant F (00:32:23):

Yeah. Also like collapsing onto the floor whenever I go to the Yeah.

Participant B (00:32:27):

Yeah.

Participant A (00:32:27):

I have a friend who was having sex and her IUD got dislodged because he hit it and he was fine, but

Participant B (00:32:34):

she was not

Participant A (00:32:34):

No she was not.

Participant B (00:32:34):

but oh, he was.

Participant A (00:32:37):

Hey, he came.

Participant B (00:32:38):

Yeah. That's what I was going to say, he finished.

Participant C (00:32:39):

Yeah.

Participant F (00:32:40):

A vasectomy is reversible.

Participant C (00:32:42):

Yeah.

Participant F (00:32:42):

Just a thought.

Participant C (00:32:44):

I just read that they're going to the second phase of a male birth control.

Participant F (00:32:51):

Slay

Participant D (00:32:51):

Do you know how many men are going to be like my body, my choice.

Participant B (00:32:53):

My choice. <laughter>

Participant D (00:32:55):

Fuck off, like respectfully. That's crazy.

Participant C (00:32:57):

Yeah.

Participant E (00:32:58):

I think it is interesting though what you guys were saying. What impact does social media have? Like is it lack of education versus misinformation?

Participant D (00:33:07):

A hundred percent misinformation. Again, I was in my sophomore seminar class and we were doing presentations, and somebody was presenting about Roe v. Wade, they called it the 17th amendment. First of all, incorrect. <laughter> They also said that vasectomies are irreversible.

Participant E (00:33:25):

Did someone tell them it wasn't true?

Participant D (00:33:27):

No.

Participant B (00:33:27):

Scares me

Participant D (00:33:27):

And the professor was sitting there nodding along and I was like,

Participant B (00:33:31):

Scares me.

Participant D (00:33:31):

are you kidding me?

Participant B (00:33:32):

I'm terrified.

Participant D (00:33:32):

You are spreading false information.

Participant E (00:33:33):

Was your professor a man?

Participant D (00:33:35):

Yes.

Participant F (00:33:35):

This is also the one who also says end of the sentence. Right?

Participant E (00:33:37):

Oh

Participant D (00:33:38):

No this is a different one.

Participant F (00:33:44):

So these are college educated like

Participant D (00:33:46):

Yes.

Participant B (00:33:47):

That scares me.

Participant D (00:33:47):

And the scariest part is they had viable sources. There are sources saying these things where people are getting information from. You can find anything to support.

Participant E (00:33:57):

Well yeah you can find any information to support anything online. Really.

Participant D (00:34:00):

It's so unfortunate. I hope so much. I wish I had said something, but then again, it's not my responsibility. If you're presenting on that, you should have accurate information.

Participant F (00:34:09):

And there's also like the knowledge like some people don't know that if you can still get pregnant, if a vasectomy happens,

Participant B (00:34:15):

Yeah

Participant F (00:34:15):

some people don't know that.

Participant D (00:34:16):

Yes.

Participant F (00:34:16):

And then will go and have sex and then get pregnant

Participant B (00:34:19):

and then they're like, oh my God

Participant D (00:34:20):

One of my friends is a vasectomy baby. <laughter>.

Participant F (00:34:22):

Yeah these things are like, they aren't informed on that and that influences our medical decisions

Participant B (00:34:27):

Just because it's a one point whatever chance does not mean it's not a chance. Still there. It's still there.

Participant D (00:34:34):

Also, I feel like you need to hold men and shake them in order for them to feel some level of empathy. It's so hard. It's so hard. Like why <laughter>

Participant B (00:34:45):

It's a select few of men that care.

Participant D (00:34:48):

Yes, exactly. It's not all men, but <laughter>

Participant F (00:34:51):

I think that's <laughter>

Participant D (00:34:53):

whatever.

Participant F (00:34:53):

I was just thinking how some women who haven't experienced that also can feel that way. And I think it's partially due to a lack of education. My mom, she didn't feel sharing that information was important to me, even though I'm genetically related to her. But those types of things partially falls on just us as a society as a whole. We got to hold each other accountable.

Participant A (00:35:17):

Well, I think that all ties to the stigma, right? We're not taught in schools. Our doctors didn't really talk to us about it. I didn't feel comfortable talking to my mom about it. And even with my friends

middle school, less in high school and definitely not in college, but we wouldn't talk about it. It was a off, a touchy subject.

Participant F (00:35:35):

Yeah.

Participant A (00:35:37):

But like we all had it.

Participant B (00:35:38):

Yeah. I have seen videos though recently that kind of warm my heart where they have period parties in middle school. I don't know if you guys have seen those <multiple "yees"> period parties. I'm like I kinda wanted one. <laughter> I didn't want to I think I was dying for the whole week, whatever.

Participant E (00:35:54):

Yeah.

Participant F (00:35:54):

That's scary

Participant B (00:35:55):

I wanted a party.

Participant C (00:35:56):

I had mine pretty early and my best friend, they're now nonbinary, but at the time that they were afraid because I said I had my period and they had a dream that I was getting on the bus and blood was pouring out. <laughter>

Participant B (00:36:14):

Noo

Participant C (00:36:14):

Yeah, I was like 11 and they told me that and I was like, oh my God.

Facilitator (00:36:46):

And then another quick question, not a guided question, but if we could all just go around and if you know your, the age grade, if not also grade, maybe grade but age or grade of your first period. Maybe

Participant A (00:37:02):

Fifth or sixth grade, I think fifth

Participant D (00:37:06):

14. The summer before my sophomore year of high school.

Participant F (00:37:10):

December 28th, 2015. <laughter>.

Participant E (00:37:12):

Mine was on St. Patrick's Day. <laughter>

Participant B (00:37:16):

11.

Participant E (00:37:17):

I was in fifth grade. However old that is.

Participant C (00:37:20):

I, yeah, 11 and mine, I got mine the week before we had the educational video on periods.
<laughter> I already knew about it. Thankfully.

Participant A (00:37:28):

Mine was January 8th. We were celebrating my mom's birthday.

Facilitator (00:37:32):

And, how old were you?

Participant F (00:37:33):

I was in eighth grade, whatever that is.

Facilitator (00:37:35):

Awesome. Cool.

Participant F (00:37:37):

Thank you. Not necessarily late, it's just like a development.

Participant D (00:37:45):

Yeah, for sure.

Facilitator (00:37:46):

Is there anything that anyone else wants to add to that question? I know I might have cut it off there, so I apologize.

Participant C (00:37:52):

I'll say that when I started my period, for whatever reason, I hid it for like five days.

Participant A (00:37:59):

Yes, thank you I got my period on January 8th. The day we were celebrating my mom's birthday. I didn't tell anybody until my sister found underwear in the shower.

Participant C (00:38:08):

Oh. I wasn't going to tell anybody except I had to go to the doctor. So they like check and I was like, oh my God, they're going to see the pad. So I told my mom at the doctor's office and then she was embarrassed because she was like, did I not make you feel comfortable to tell me?

Participant A (00:38:22):

The guilting

Participant C (00:38:22):

And I was like, no. I don't know why I did.

Participant E (00:38:25):

Yeah

Participant C (00:38:25):

I didn't want anyone to know.

Participant E (00:38:26):

I was scared to tell my mom, but I don't know why. But I just was,

Participant C (00:38:31):

Yeah

Participant E (00:38:31):

but I did tell her. I was just maybe confused. I don't really know what was happening.

Participant C (00:38:36):

My mom caught me crying so

Participant E (00:38:39):

Yeah. <laughter>

Participant D (00:38:39):

Did anyone else think it was maybe something else and not apparent <laugh> like

Participant B (00:38:44):

Yeah, because I didn't know what it was. I just knew it was bleeding and my sister was the only one that was home.

Participant D (00:38:49):

Well, it's not like red.

Participant F (00:38:50):

Yeah, the blood color.

Participant D (00:38:52):

Yeah. I was like, did I like poop myself? <laughter> I was, I had gotten home from lifting and I was like, did I strain a little too much? And I was like, no,

Participant C (00:39:02):

I think mine was pretty red, to be honest.

Participant E (00:39:03):

Yeah I would have to agree.

Participant C (00:39:03):

Yeah

Participant F (00:39:05):

I told my mom before I got my period that I got my period, because we don't have a great relationship. So I told her in advance, so I would get products purchased for me because I'm the oldest, so I was prepared.

Participant D (00:39:17):

So smart, so smart.

Participant F (00:39:19):

But it's not, but I wasn't okay talking about it.

Participant A (00:39:21):

Yeah.

Participant F (00:39:21):

I had to wait until I was randomly in the middle of the day when I knew my dad wasn't home because I was afraid he was going to hear it. And then it was a transactional, it was six months before I got my period. But I feel like we're all afraid to talk to people about it, especially if we didn't know. Even if we knew what it was. It's still weird.

Participant C (00:39:38):

Yeah

Participant F (00:39:39):

I don't know why

Participant A (00:39:41):

My friends, I'll talk to talk them about it all day long, but if I have to talk to my mom about it.

Participant F (00:39:45):

Yeah.

Participant A (00:39:46):

No. Thanks. I'm good.

Participant B (00:39:47):

It's just how you grew up.

Participant D (00:39:48):

Yeah.

Participant A (00:39:48):

Yeah.

Participant F (00:39:48):

Yeah

Participant B (00:39:49):

I don't have a great relationship with my mom either, so I don't talk to her about literally anything anymore. So

Participant F (00:39:55):

Yeah.

Participant D (00:39:55):

My cousin though, when she got it, she was told not, she's not allowed to tell her dad. So her dad is just like, she's a senior in high school now, just is unaware.

Participant F (00:40:10):

I was told that about birth control. Like don't tell your dad around birth control when I wasn't on it for, doesn't matter what the reason was.

Participant A (00:40:18):

Right.

Participant B (00:40:18):

Wow.

Participant F (00:40:21):

That's so weird.

Participant D (00:40:22):

It's really odd.

Participant B (00:40:24):

So messed up.

Participant D (00:40:25):

It's almost like I'm his child as well.

Participant F (00:40:27):

Yeah.

Participant D (00:40:27):

I know. It's a weird, yeah.

Participant E (00:40:29):

Yeah. Even though I go to my mom first, my dad always finds out, you know like it's not a secret.

Participant C (00:40:34):

Yeah.

Participant B (00:40:37):

Why work so hard then? I dunno. That's just weird.

Participant C (00:40:40):

Yeah.

Facilitator (00:40:45):

Okay,

(00:40:48):

So our, fourth question is, so we already kind of talked about where does your knowledge come from, but this question is a little different and it's when you need medical advice, when it comes to gynecological care, menstrual cycle periods, what is your go-to resource?

Participant A (00:41:09):

You <laughter>.

(00:41:13):

Like if I'm panicking about something, I talk to you and then probably. So my friends and my partner.

Participant D (00:41:19):

No, literally

Participant B (00:41:20):

my best friend.

Participant D (00:41:21):

Yeah.

Participant C (00:41:22):

I look it up <laughter>. Or, okay,

Participant B (00:41:25):

Nah, google scares me <laughter>.

Participant C (00:41:25):

I'll tell someone.

Participant A (00:41:26):

Yeah

Participant D (00:41:28):

It'll tell you you're dying.

Participant B (00:41:29):

Yeah, I actually will have a panic attack, <laughter> so no, so like no.

Participant C (00:41:33):

If I see I'm dying then I'm like, oh, I'm not going to talk to my doctor about it then.

Participant E (00:41:36):

Yeah.

Participant F (00:41:38):

Yeah. They're like, you're either dying or pregnant, guess. <laughter> Figure it out.

Participant E (00:41:41):

Yeah.

Participant A (00:41:42):

Flip a coin.

Participant E (00:41:42):

I usually tell one of my friends and then I call my mom panicking and then she's like, you need to calm down. <laughter> But usually just either if it's a physical problem or a mental problem, I wait, I

like to wait till it gets really, really, really bad <laughter> and then I think I'm dying and then I tell somebody.

Participant C (00:41:57):

<laughter> Healthy.

Participant E (00:41:59):

Exactly. Yeah.

Participant B (00:42:01):

Lot of healthy people in this room.

Participant E (00:42:02):

Yeah. <laughter>

Participant D (00:42:06):

Yeah. My mom has a very normal, stereotypical regular period, so she is probably the least informed. So I don't talk to her about, unless it's an extremity that I need to see a doctor for. It's not a lot, but I'll talk to her. But yeah, but like and I talk about it all the time.

Participant E (00:42:28):

And then my mom was like, why did you wait to tell me? And I'm like, I don't know.

Participant F (00:42:34):

This is just so funny. Now that you ask these things, they sound so stupid. So one time I was driving and almost passed out because I had a severe UTI <laughs> and was like, it'll go away <laughter>. And I had to take meds for two months for it.

Participant D (00:42:57):

How long did you let it go?

Participant F (00:42:59):

So then I <laughter>, but I had been googling it and I was at point in my life when I was commuting here, so I didn't know anyone. I didn't have a ton of close people, so I just had to go to the doctor and be like, yo, what is wrong with me? Literally dying in the waiting room with a fever. I could have had a liver infection or a kidney infection. So like.

Participant B (00:43:25):

How long did it take them for you to, how long did it take for them to put you in a room and see you and stuff?

Participant F (00:43:32):

I had a two and a half hour wait, wait. And I paid 120 bucks to go and then I had to pay for meds.

Participant B (00:43:40):

Yeah. I had a 16 hour wait for my, yeah, I was dying. One of my cysts was rupturing.

Participant F (00:43:47):

Yeah, you were just in the waiting room?

Participant B (00:43:48):

and I was in the waiting room with a fever and a headache and I kept going up, literally limping up by myself and I was limping and I was like, can someone please see me? I don't even care at this point. Give me pain meds. And they were like, we can't give you pain meds because you might have to pee in a cup, so you just have to wait. I'm sorry. I sat in the waiting room for 16 hours. I didn't eat anything. I didn't do anything. And I finally got seen at two in the morning. They took me down for a CAT scan. They didn't even give me meds. And I was still, my ovaries were literally dying. And then I slept a little bit and I think I woke up and the doctor was like, you're good to go. You're all set. Your CAT scan came back normal. And they let me go. So I walked out of there and I got home, took some painkillers, went to bed, and that was that.

Participant F (00:44:37):

How did you get to the point that you decided to go there?

Participant B (00:44:40):

So it was before I found out that I had cysts because I just thought it was appendicitis. I'm not going to lie to you. That's what I thought it was because it was my right side. I literally was, my appendix is bursting. I don't know what's happening, but that's what I convinced myself. And it was the night before or the day before I was in bed all day. I had maybe one sandwich to eat or something. And then my ex-girlfriend was like, you need to go to the doctors. She wasn't anywhere near me, but she was like, you need to go see someone or at least tell someone to drive you or something. And nobody was home. My parents were gone and stuff. I did call my mom crying and I was like, mom I'm dying. And she was like, go to the doctors if you can make it, go to the doctors. And they're both nurses, so they were like, okay, clearly something's wrong, like go. And they're Kenyan, so they're never ever going to, unless they can fix it, which they love to do. They're never going to tell me to go to the doctors. So my mom reinforcing me to go to the doctors actually made me panic more. Cause I was like, she actually believes I'm dying. <laughter> I was like, oh my god. And then I got there and it was 11 or something in the morning and I didn't get seen until like two in the morning.

Participant F (00:45:56):

So it was a lot of exterior people telling you something is wrong,

Participant B (00:45:59):

Yeah.

Participant F (00:45:59):

even though you knew something was wrong, you were like, it's fine, I'll be fine.

Participant B (00:46:02):

Yeah, so I convinced myself that I was fine. I didn't bring water, I didn't bring anything, but I convinced myself it was fine until the point it was nine o'clock at night that I really was curling up in a ball on the hospital floor. I didn't even care at that point because I was just, I was literally still in my pajamas. I just woke up that morning and I was in pain, I don't know. And I just laid there until someone called my name and then I was like, okay, I guess it's time to get up. And they didn't help me up, they just let me walk. They didn't give me a wheelchair, nothing. I was like, okay.

Participant A (00:46:32):

That's wild.

Participant D (00:46:32):

That's horrendous. I'm so sorry.

Participant B (00:46:35):

It's alright, oh, they actually skipped me. I should probably add that part. I checked in, they had a shift change and they skipped me. So I was there for an even longer than I should have been. Yeah.

Participant C (00:46:45):

I was going to say, if you came in thinking you had appendicitis, I feel like that's something that they usually check out early

Participant D (00:46:51):

Yeah and they still like you were like, I think my appendix is bursting and they let you go for 16 hours?

Participant B (00:46:57):

Yeah and

Participant D (00:46:57):

That's crazy

Participant B (00:46:57):

They were like, we'll do a CAT scan when you're in, we can't give you meds. And I was like, okay. And I've never gone to that hospital ever again. <murmurs in agreement>

Participant E (00:47:05):

I just remembered. I always forget about things. I just like to bury things in my brain. But I just remembered senior year in high school, 2020, RIP <laughter>. I developed this, I don't know, I honestly can't remember what it was, but I was in so much pain. It was like, okay, TMI, ya know, it felt like a massive pimple on my vagina, but it hurt so bad. I was in so much pain. It was purple and obviously I waited till it hurt so bad to tell my mom about it.

Participant B (00:47:36):

Naturally.

Participant E (00:47:36):

And why did you wait? I, I was scared. I had never felt anything like this before it, I was in so much pain and I told my mom about it and she called an doctor for me, bless her soul. Honestly, I wasn't going to do it. <laughter> And she called the doctor for me. And so we made an appointment and it was like right when I was graduating high school, walking in a parking lot to graduate high school.

(00:48:00):

And that day, whatever it was, it burst and it was the most red blood I've ever seen in my entire life. I have never seen a color like that before. And I can't remember if I went to the doctor before, I think I went to the doctor after it burst and they were like, I don't, sorry, I can't remember what it was called, but I was like, do you know why it's there? And they were like, no,

Participant F (00:48:21):

Cool.

Participant E (00:48:23):

they told me what it was and they were like, sometimes it just happens to people. And then it happened to me three times in a span of six months, but it never, they kind of told me what to do, so it never got as bad as the first time, but they were just like, yeah, it just happens sometimes. And it happened to me three times and it was so painful and then I had to take antibiotics for two times it happened.

Participant C (00:48:48):

Was that your normal doctor or a gynecologist?

Participant E (00:48:50):

It was my normal doctor, UVM. UVM pediatrics, <laughter>.

Participant D (00:48:54):

Nice.

Participant E (00:48:55):

But yeah, it was so painful and they were just like, yeah, it just happens to some people and they were like, it might get infected, so here are some antibiotics. And I had a shirt that was the same color as my antibiotics. So yeah, that was cool. But

Participant A (00:49:08):

They go to school for so many years and they just don't know what things are.

Participant B (00:49:12):

Right? They pay so much money.

Participant D (00:49:13):

Yeah. Aren't you not supposed to take antibiotics for a long time? I feel like after you have so many rounds of antibiotics, they're not as effective.

Participant E (00:49:23):

Well, I only took them for two weeks and then it's probably a couple months later that the other thing, it happened again, but then the third time they were like, don't take them. So that could have been part of it.

Participant B (00:49:33):

When I had my double ear infection, which I know is not what we're talking about, but antibiotics can affect your GI system if you take them when you're not supposed to. And they were like, okay, well you clearly need them, so you have to take them with probiotics. You can't just take antibiotics without probiotics. So I had a jar of my gummy probiotics, to go with it.

Participant F (00:49:53):

What's really scary about when I was diagnosed or when I got the antibiotics is they didn't ask anything or they didn't consider any other medication I was taking. So I was on birth control and I read somewhere that it interacts birth control, but I don't know. I was on two different psychiatric medications. So that was a fun time. I dissociated for two months straight, to be completely honest with you. So the care that they're going to provide for women or people with uteruses is just wild to me. How about we consider, I know I went to urgent care, but they still, it's the urgent care that's in my doctor's office, so <laughter> they have my records and it's just, it shouldn't be my responsibility to be like, Hey, yeah, am I going to have a manic episode and break because I have a UTI? Those types of things are just something that are not considered ever even uterus or not whatever you're being prescribed, which is scary.

Participant D (00:50:54):

Yeah. I think

Participant B (00:50:55):

Sorry, go ahead.

Participant D (00:50:58):

The reason I cut medication cold turkey in May was because for a year I was gaining four to five pounds every month. And eventually that obviously becomes concerning and unhealthy and I was talking to my, and it's all over the phone. None of these people want you to meet them in person anymore. I was meeting with my gynecologist over the phone for 10 minutes every six months. Same with my psychiatrist. I was on Zoloft and they were blaming each other saying that it's the Zoloft making me gain weight. No, it's the birth control making me gain weight. So when you're in that head space of, obviously we don't live in a society where gaining weight is not, there isn't any association of emotion with it, obviously there's a shame factor of it and you feel more depressed or more hatred towards yourself.

(00:51:55):

It's like, what are you going to do? So I just cut cold turkey and was like, let's hope for the best. And until you're not on those medications anymore or you've done the research, whatever, 4, 3, 4 years later, you don't understand the long-term effects that those things have on your body. And it's like it's really upsetting if you think about it for too long where you're not, it's just any hormonal issue or any period issue. Oh, let's try birth control. There's nothing else we can do before putting a foreign substance into my body? Which is why I refuse to the IUDs or the Nexplanon because I'm like, nothing has ever worked for me before. I'm not going to trust that just because this is a permanent fix that it's going to. And it's unfortunately, I think a lot of people feel bulldozed by their medical providers, but that was a boundary that I had to set and she was not happy about it and I was like, so sorry. You have to work a little bit harder. That's not something I'm willing to do.

Participant B (00:52:58):

Yeah.

Participant D (00:52:59):

Yeah.

Participant B (00:53:14):

My sister was the same way. She cut off her birth control because they were like, try this, try this, try that, try that. And she was like, her weight was fluctuating and all this other stuff, but I'm going to be transparent and say that I am terrified to be pregnant and to be I don't know anything as an African woman because I have seen way too many scary videos of the healthcare system, not treating African women the same or giving the same care as people who are white, Caucasian or even present that way, even if they're not. But it's just terrifying, especially because I also know that for certain diseases and certain illnesses, more and more prone to get them than white people. So it's like I'm terrified, but I also want kids, but I also can't have kids or might not have kids. So like I don't know. <laughter>

(00:54:14):

I'm just scared in general to grow up in this society because I'm scared of the day that I don't know. I go to the hospital and like, I have a baby and then I'm still bleeding and they're like, it's normal. And then I end up dying. Because I'm like, I bleed out or something or there's a tear if I get, I don't know if I get a C-section, they like nick something and they're like it's normal. Bleeding after is normal and then I go into septic shock.

Participant D (00:54:49):

Yeah that's

Participant B (00:54:51):

Like, that's the kind of shit I think about in the middle of the night. I'm like,

Participant D (00:54:54):

It is

Participant B (00:54:54):

I want kids, but how badly do I want kids? And then I can't, I don't have the money to adopt because it's so expensive and then,

Participant C (00:55:02):

Which is crazy

Participant B (00:55:03):

Yeah but even if I want to be pregnant, it's still going to cost me like 20 grand because I have to go with IVF because I'm gay or sperm donor, whatever. It's still going to cost me something either way. So which way is safer, which way is better? I do want to be pregnant, but do I want to put myself through that? I don't know.

Participant A (00:55:21):

That's one of the main reasons why I don't want kids anymore because I just don't want to be pregnant and I don't think I could be, maintain mental stability, while being, while my body changing that much and how much of a toll it takes on your body with the lack of knowledge so many doctors have.

Participant B (00:55:38):

Yeah.

Participant C (00:55:42):

Yeah I am anti-children personally, but part of it is because of how scary pregnancy is, and I don't like kids.

Participant F (00:55:54):

That's a big one too. <laughter>

Participant E (00:55:56):

You're fine. Well, the worst thing you can do for the environment is reproduce, so <laughter>

Participant F (00:56:04):

Okay.

Participant A (00:56:07):

I'm perfectly happy with being

Participant C (00:56:08):

So you're saying women are the enemy?

Participant A (00:56:08):

an aunt

Participant E (00:56:09):

I never said that. <laughter> I never said that.

Facilitator (00:56:13):

She's saying individuals can make an impact. <laughter>

Participant E (00:56:15):

Yeah. Going back to my jeopardy, <laugh>

Participant C (00:56:18):

Oh right.

Participant D (00:56:22):

I have a friend who is black and she, in October of 2021 had a cyst on her breast and it had ruptured and she went into the local ER here and they said there was nothing to worry about and it wasn't cancerous. And then she was diagnosed with breast cancer in December, and then, oh my God <crying>, they withheld her healthcare treatment for so long that she had surgery and was in a coma for three weeks and it was a miracle that she's still living. And it's like I asked her, I was like, do you think part of this is because you're a person of color? And she was like, I would hate to think that way. But at some point it's like it's a part of the equation. It's a part of the system. You are a woman and a person of color. Why did it take four months for you to have this life saving surgery when you were at stage, whatever in December and now you're having heart attacks and dying in a coma in June. It's like, it's crazy to think about

Participant B (00:57:35):

It's not, it's hard not to think that way when the actions are literally,

Participant D (00:57:40):

Yeah.

Participant B (00:57:41):

that way.

Participant F (00:57:41):

There's proof.

Participant D (00:57:42):

I didn't want to make her uncomfortable with me as a white person being like, Hey, do you think it's because you're black? I feel, but I felt like it was a valid question to ask because her symptoms were being disregarded or her surgeries were being pushed back. And it's like at what point is that part of the equation?

Participant A (00:58:02):

And you know if that was a straight wealthy white man, that wouldn't happen.

Participant D (00:58:08):

Yeah.

Participant E (00:58:08):

Yeah.

Participant F (00:58:08):

Yeah.

Participant A (00:58:09):

That would've been looked at immediately.

Participant B (00:58:10):

Yeah. My sister just got out of a medically induced coma too, where she has really bad lungs because she does, I don't know, she's asthmatic and just does not take care of herself and continues to

smoke and has been for the past, I don't know how long. And it wasn't until she was in a coma and still could hear us and shit that she had a wake up call, which I'm glad she has a wake up call and I'm glad that she's alive, but I'm just, it took forever for her to get seen. It took them a while to even get to her, and by the time they did, she had to be placed into a medically induced coma because she literally could not breathe on her own anymore. She had to be put on a ventilator. So it was scary. And that's the kind of shit that I hate going to the doctor's for, which is why I wait and I prolong going to the doctors until it gets to the point where it's so bad, but then it's like, okay, it's really bad.

(00:59:10):

I need to be seen. But I can't be, whether that's because yeah, whether that's I'm black, whether that's because whatever. Because that thought crossed my mind. I mean, my friend had appendicitis a week or two before me, and she got seen within the hour and heard her, had her scheduled surgery in three hours and she was out by the next day and I had to wait 16 hours just to get seen. I'm glad it wasn't appendicitis and it was just my cyst rupturing, but that pain level in itself, no one did anything. And she, my, I'm not trying to play the race card, but my friend is white, so it really mentally fucked me because I was like, and I was alone and they wouldn't let my dad or anyone come in after a certain time. He got out of work at 11 and they wouldn't let him come in. And I was like, okay, I just have to sit here by myself at this point. I can't do anything. So.

Facilitator (01:00:17):

Ultimately, how did you find out that it was your cyst rupturing?

Participant B (01:00:20):

After this, the CAT scan, they sent me to my primary care after they left me and they were like, make us make an appointment with your primary care doctor. And so I did. And then he sent me to the OBGYN to do a internal ultrasound and that's how she found them. So.

Participant D (01:00:41):

Even that process is weeks.

Participant B (01:00:42):

Yeah.

Participant A (01:00:42):

Yeah.

Participant F (01:00:44):

Yeah and expensive.

Participant D (01:00:45):

Yes. And the statistics of comparatively in the United States, the number of white women who die from childbirth and the number of women of color who die from childbirth.

Participant B (01:00:57):

It's scary.

Participant D (01:00:58):

Yeah, it's awful.

Facilitator (01:01:09):

Alright so this is the last question. Is there anything else you would like to say about healthcare for individuals with uteruses or your own healthcare experiences relating to gynecological healthcare or diseases including endometriosis? So this is opening up for talk specifically about endometriosis or any other diseases. I'm personally not going to participate as I haven't been. But if you do need a definition for endometriosis you are to come up with it on your own and through conversation.

Participant D (01:01:58):

The only reason I know about endometriosis is because my gynecologist suspects that I have it. To be diagnosed with it, you need an exploratory surgery, which is again expensive. So unless you are for

sure that you have endometriosis, a lot of folks don't get it. So that's my understanding of it. Also, because I did a presentation endometriosis costs I think \$106,000 more over a lifetime along with birth control and period products on average. So clearly there's something there.

Participant C (01:02:42):

So what is it?

Participant D (01:02:44):

I think, oh boy. I think it has something to do with the way your uterus actually functions during your period. So are we allowed to use the internet?

Facilitator (01:02:57):

No.

Participant D (01:02:57):

No.

Participant A (01:02:58):

Isn't it excess tissue growth?

Participant D (01:03:00):

Yes.

Participant A (01:03:01):

And it can go outside your uterine lining.

Participant C (01:03:05):

Endo

Participant B (01:03:05):

metriosis

Participant C (01:03:05):

metriosis

Participant E (01:03:05):

metriosis

Participant D (01:03:09):

So this is TMI, but they suspected it because I was literally experiencing contractions and I had passed a very large piece of tissue and they were like, oh, that's not normal. I was like, really? Or you bleed for 30 days at a time.

Participant B (01:03:32):

Yeah.

Participant C (01:03:33):

Okay.

Participant D (01:03:35):

Which I've experienced.

Participant F (01:03:35):

And there's other symptoms.

Participant C (01:03:36):

Yeah.

Participant F (01:03:37):

That you have to, unfortunately, as people with uteruses, we're frequently labeled. Everything has to do with your weight and diet. But unfortunately that is a symptom. Is like a lot of fluctuation. Especially if they're going to prescribe you 30 different birth controls. <laughter> It's going to impact that. And also everything influences everything. But there's a lot of stigma related to gain gaining weight

Participant D (01:04:00):

And migraines.

Participant C (01:04:01):

Oh yeah.

Participant D (01:04:02):

I have migraines all the time.

Participant F (01:04:05):

Me too.

(01:04:06):

There's also like PCOS too.

Participant B (01:04:08):

Yeah.

Participant D (01:04:08):

Yeah.

Participant F (01:04:12):

It's another disease that is related to having a uterus. My friend has PCOS and she like

Participant B (01:04:18):

My friend has PCOS and diabetes. I'm like

Participant F (01:04:20):

It's a terrible combo. Yeah.

Participant B (01:04:22):

It's the worst combo. I'm like, thank you for being alive. One day she got pulled over by cop. We laugh about this, but she got pulled over by COP for driving on the far left lane, which is technically a passing lane, which we didn't know until we learned that day. So if it's late at night and you don't have to be on that lane, you're not passing a car, don't drive on that lane cause they will pull you over and they will give you a ticket. But she was speeding and the cop pulled her over. So she was like, I'm so sorry, I'm

just, my blood sugar's running really low. I just have to get home and get my insulin. And he was like, oh my God, go. I was like <laughter>

Participant E (01:04:57):

Damn.

Participant B (01:04:58):

She just got a ticket for driving on that lane and it was like \$150 compared to the speeding and that which would've been like \$500.

Participant A (01:05:07):

Right.

Participant B (01:05:07):

I was like, we laugh about it, but I'm like, girl,

Participant A (01:05:10):

I think that's wild.

Participant B (01:05:11):

your blood sugar is something you need to be concerned about, whatever. And I was like, yeah. But it's a terrible combination.

Participant F (01:05:18):

Yeah like comorbidities with a lot of these different diseases,

Participant B (01:05:20):

Yeah.

Participant F (01:05:22):

Especially getting a diagnosis, that makes it 30 times more difficult. Do you want us to reach a definition for things?

Facilitator (01:05:31):

No, I do not. I'll give you a definition to further have conversation in a little bit. But if there's anything else you wanted to say about healthcare or experiences, you can go ahead or I can launch into my little thing.

Participant B (01:05:47):

I just want them to do better. <agreement> That's a consensus with everyone, but I just want them to do better because it's known that the type of care and treatment that men get is different than the type of treatment that women get. And then on top of that, it boils down to, I don't know, gay, straight, white, black, Muslim, I don't even know what else. Everything. Your sexuality, your religion, your ethnicity, your racial status, even sometimes your social status, which yeah, is,

(01:06:21):

I don't know. So fucked up. This country's built on just making money. And I literally hate it sometimes. I hate it so much. I'm like my aunt went because she fucking had a thing stuck on her throat and had to pay \$500 to see a doctor just for him to be come back tomorrow and it was stuck in her throat. So one of the nurses was like pulled her aside as she was leaving, she was like, eat a spoonful of peanut butter. It'll get it out. And it did. But he just wanted money. And that's the stigma that, and unfortunately when people want to be doctors, majority of them are looking at the fucking salary that they're getting.

Participant D (01:07:00):

Of course

Participant B (01:07:01):

You know, like they're looking at the money that they're going to get after they do all this medical shit. Which is probably why they don't know shit.

Participant A (01:07:08):

They don't care.

Participant B (01:07:09):

And they don't care enough to know shit. You might have one or two here and there that actually care about what they're doing and the service that they provide and they care for their patients and stuff like that. But when it comes down to it, it's about making money and being able to support yourself.

Participant E (01:07:26):

My mom had to go to the hospital right before Christmas for something and now she has to pay the medical bills for that. And they were going to buy my dad a new car and now they have to pay the bills instead. And my dad's car doesn't work. But they only have enough money to pay these medical bills.

Participant B (01:07:40):

And you have a certain amount of time to pay them by. Oh my God, my sister has to pay thousands of dollars worth of medical expenses because of the medication, being on the ventilator, being on all this shit and going in and out and you can't afford it. But then they're like, they'll hit you up the day. Actually somebody came in the hospital while she was recovering and was like, I need you to give me at least something. It was the day she got out of a coma.

Participant D (01:08:11):

Oh my God.

Participant B (01:08:12):

And I literally sat there and I was like, she's not ready to right now. Please come back.

(01:08:18):

They have no shame. They literally have no, I was like flabbergasted. I almost punched this lady in the face. <laughter>, I was like walk the fuck out tomorrow. And then if she did end up dying, it would've been on us. Someone's going to have to pay those medical bills because they're not going to

accept no for an answer. They need their money. And then the funeral costs just sell my body to science.

If I ever die, just give it to them because

Participant A (01:08:49):

mm-hmm

Participant B (01:08:49):

I'm not putting my family through that shit.

Participant E (01:08:51):

I'm going to be compost. Yep.

Participant C (01:08:53):

Yeah, I'm going to be a tree.

Participant D (01:08:58):

I just found out that when, this is related to women's health, but when psychiatrists or counselors, what is it called? Prescribe medication, they tell women that they're supposed to take it on a regular schedule and that men can just take it whenever they want. I didn't know that.

Participant F (01:09:23):

Yes. I've had that experience <unintelligible words> cause you're paying money. And I think they do that for any pill, which is,

Participant B (01:09:34):

I work at a pharmacy tech. I didn't even know that.

Participant F (01:09:38):

I think it depends on your psychiatrist. And again, they don't talk to your gynecologist, they don't talk. You're just a guinea pig in some capacity that just pays money for them to, I I'm, I have been paying my own copays to go to the doctor and we have really shitty insurance in my family. And I'm just like, I've been doing that since I was 15. Yeah.

(01:10:05):

When I had to get an emergency ultrasound and I had to pay 300 bucks for it, just in addition to my visiting them fee. And it's just for them to tell me I'm fine and then this is probably

Participant B (01:10:17):

It's normal.

Participant F (01:10:17):

Disappeared. Yeah, I'm fine.

Participant B (01:10:18):

It just dissolves back into your body. Yeah. You'll probably get another one. <laughter> And when it ruptures, it's going to go dissolve back into your body

Participant F (01:10:24):

<laughter> That's what they said to me.

Participant B (01:10:24):

and you're fine. You're normal.

Participant F (01:10:26):

And I learned that via email. <laughter>

(01:10:30):

No one called me. I just got an email. They were a little notification saying, Dartmouth updated your response. That's so upsetting. And also my friend just got married to get good health insurance because they're

Participant B (01:10:45):

You gotta do what you gotta do sis. <laughter>

Participant F (01:10:48):

They're immunocompromised and have PCOS. And they are like, they've got a lot of things going on and literally can't afford it. So married someone with good health insurance.

Participant B (01:10:57):

But they need it

Participant F (01:10:58):

because they turned 26.

Participant B (01:10:59):

Yeah. Yeah.

Participant D (01:11:03):

And yet there's research that say cramps are equal to the pain of like

Participant B (01:11:08):

Getting kicked in the nuts.

Participant D (01:11:10):

A heartattack <laughter>.

Participant B (01:11:10):

Getting kicked in the nuts. I saw that. I was like,

Participant F (01:11:12):

Okay.

Participant C (01:11:12):

Have you guys seen the videos of people who made a machine to like

Participant B (01:11:17):

Oh the stimuli?

Participant C (01:11:18):

Yeah.

Participant B (01:11:18):

And they put the guys on that

Participant A (01:11:20):

They can't handle it.

Participant D (01:11:21):

Yeah.

Participant F (01:12:12):

Okay. Also, the fact that we were told potentially as 15 year olds, hey, you might not ever have kids. And then they just moved by it.

Participant D (01:12:21):

So scary.

Participant F (01:12:21):

Yeah.

Participant C (01:12:23):

I was happy about that.

Participant F (01:12:24):

Yeah. God so scary. Just saying

Participant D (01:12:28):

This could affect your fertility at 14.

Participant F (01:12:34):

And they like, don't provide any further, if you ask questions they're like we'll address it at a later point.

Participant D (01:12:39):

Yeah. When we cross the road.

Participant B (01:12:41):

I kind of want to go into a sex education class now because they do change slightly. And I want to know what kind of information they're giving them now, especially now if they've even updated with actually people coming out, the LGBTQ+ community and all of that. There are other protective what's the word I'm looking for? Not just fucking condoms, but you know what I mean? Yeah. Protective measures for lesbians, for other relationships and stuff like that. And I do kind of want to see what that

Participant A (01:13:15):

Like at a school?

Participant B (01:13:16):

Yeah

Participant E (01:13:16):

I think definitely dependent on where you go.

Participant A (01:13:19):

Yeah like location dependent. Like New Hampshire

Participant F (01:13:20):

In New Hampshire, there's a divisive concepts law. So someone asked about Stonewall in my sister's health class and they weren't allowed to talk about it.

Participant B (01:13:28):

Oh wow.

Participant F (01:13:28):

Because they would've gotten charges from the school. They're not allowed to talk about anything that's divisive. So parts of sex ed and talking especially about queer theory is just not an option.

Participant F (01:13:43):

(01:13:51):

No. It's scary what you can and can't learn. God. And when I was in church, they said, don't use condoms. I went to

Participant C (01:13:59):

What?

Participant D (01:13:59):

It's all God's will.

Participant F (01:14:02):

In New Hampshire they said to a room of eighth graders, hey, if you're going to have sex, don't wear condoms because you're choosing to possibly have children with that with that person. So just so you know, I'm 20 that I was 14 when that happened. 13 when that happened. So time hasn't, seven years isn't going to do much there.

Participant B (01:14:21):

You're choosing to have a baby with that person.

Participant D (01:14:25):

That's so crazy.

Participant B (01:14:25):

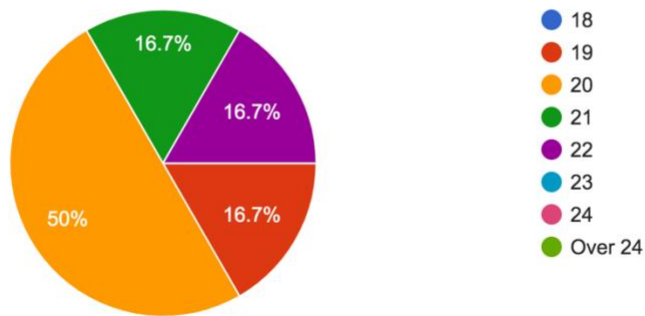
Oh my god.

Appendix G

Google Forms Answers: Graphs and Charts

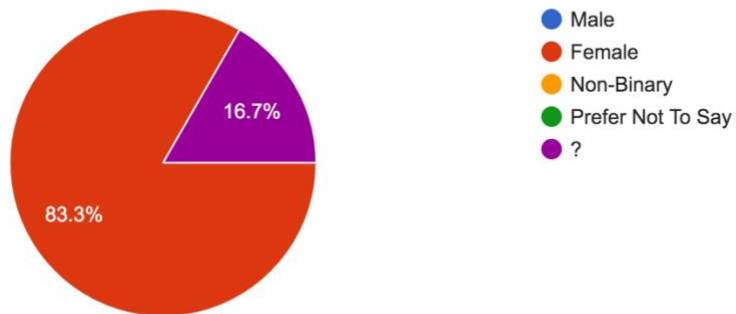
Age

6 responses



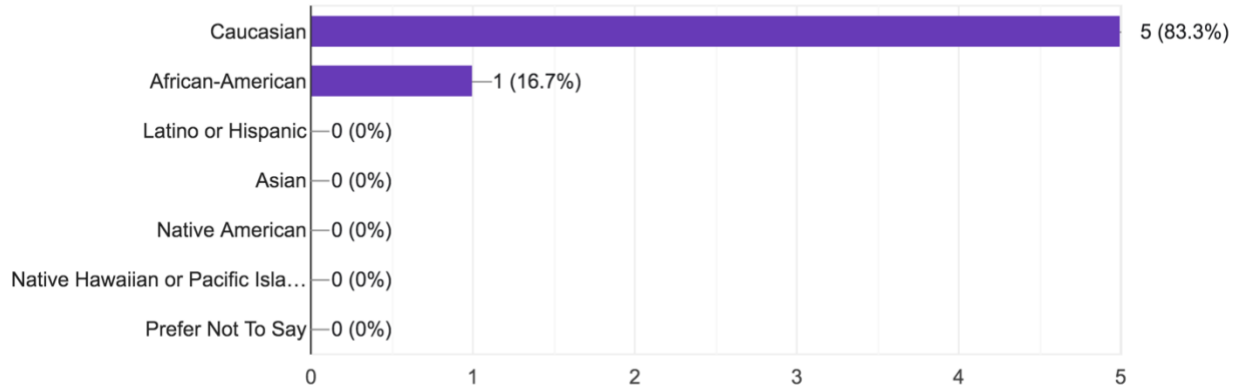
What gender do you identify as?

6 responses



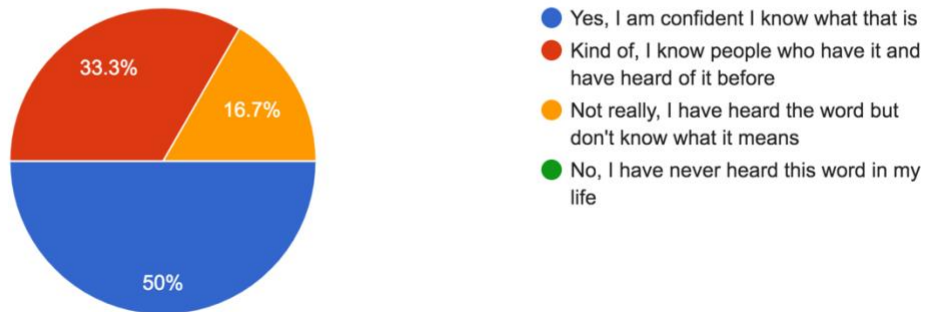
Please specify your ethnicity (you may click more than one)

6 responses



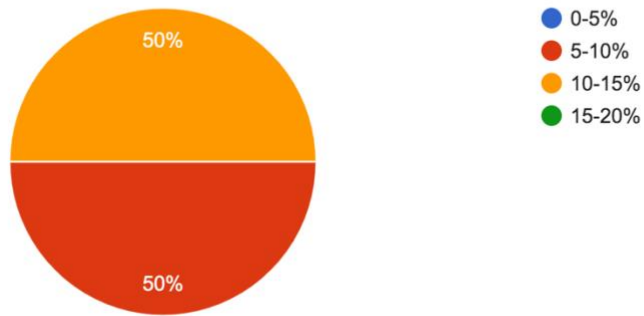
Are you familiar with the term endometriosis?

6 responses



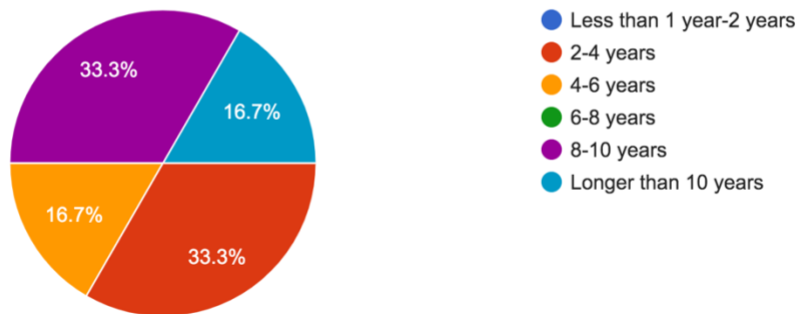
On average, how many people with a uterus do you think are affected by endometriosis?

6 responses



On average, how long do you think it takes for an individual to be diagnosed with endometriosis after exhibiting symptoms (average diagnostic delay) ?

6 responses



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