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A Qualitative Study to Understand Women's Perceptions on Menstrual Concealment and
Delayed Endometriosis Diagnosis

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Chapter 1

Menstrual Concealment and its Effect on Delayed Endometriosis Diagnosis

What is Endometriosis?

Endometriosis is a hidden and mysterious disease appearing in 10% of women of fertile age (Bertero & Grundstrom, 2017; Steven Simoens, 2012; Cox, Henderson, Andersen, Cagliarini & Ski, 2003). Endometriosis is defined as the presence of endometrial tissue outside of the uterus which induces an inflammatory reaction leading to cyclical bleeding, scarring, and adhesion formation throughout the abdomen (Johnston, Reid & Hunter, 2015; Giudice, 2010; Ballard, Lowton & Wright, 2006; Seear, 2009; Simoens, 2012). Endometriosis may manifest in many different ways which results in a diversity of symptoms that may also fit into other benign pathologies (Ballard, 2006; Johnston, 2015; Cox, 2003). However, since symptoms do not manifest visibly or externally, it is imperative that women account their pain for an expedited diagnosis (Seear, 2009). Symptoms include dysmenorrhea, or menstrual cramps; dyspareunia, or difficult or painful sexual intercourse; subfertility, or infertility; and pelvic pain (Bertero, 2017).

The Impact of Endometriosis

Women who are symptomatic more frequently visit their primary care physician and emergency rooms in comparison to women without the disease (Johnston, 2015). In addition to physical symptoms, endometriosis is associated with mental health and lower quality of life (Bertero & Grundstrom, 2017; Hudelist, 2012; Facchin, 2014; Ballard, 2006). Endometriosis causes women to become bedridden for about 18 days out of a year, leading to missing work, school, increased health care costs and lower quality of life (Ballard, 2006; Seear, 2009; Weir, 2001). Endometriosis affects levels of productivity and quality of life so much that the US Army has disqualified women recruits with a history of endometriosis due to a total lost duty time of

21,746 days in a 6-year time span (Weir, 2001). Endometriosis represents a major burden on women causing significant debilitation (Weir, 2001; Cox, 2003).

Diagnosing Endometriosis

The diversity of endometriosis symptoms and similarity with other benign pathologies seems to lead to a low index of concern among primary and secondary physicians (Pugsley, 2007; Seear, 2009; Mcleon, 2010; Ballard, 2006; Weir, 2001). This low index of concern or suspicion represents the initial impression that physicians may have on the likelihood of a disease or condition. Low index of concern among primary and secondary physicians following office visits with women reporting menstrual abnormalities ultimately causes women with endometriosis to fall between the cracks (Johnston-Robledo, 2013). This phenomenon of women falling between the cracks has led to a 7-10-year delay in diagnosis, on average (Pugsley, 2007; Seear, 2009; Mcleon, 2010; Ballard, 2006). Diagnostic delay seems to vary depending if the woman presents for a complaint of infertility or pelvic pain (Hudelist, 2012). Women who present with infertility issues face up to an average of 4 years of endometriosis diagnostic delay whereas women presenting with pelvic pain face up to an average of 7 or more years of diagnostic delay (Hudelist, 2012). Reasons for diagnostic delay are multifactorial and include cultural attitudes normalizing painful menstruation, lack of awareness or updated guidelines on distinguishing normal from pathologic symptoms, and concern over the invasive standard of diagnosing endometriosis (Johnston-Robledo, 2013). Endometriosis is only diagnosed through direct observation during a laparoscopy (Ballard, 2006; Seear, 2009). This invasive diagnostic method may turn physicians away from pursuing the disease. Thus, endometriosis has been poorly recognized in practice which has resulted in patients dealing with misdiagnosis and suboptimal care (Johnston, 2015).

Why Endometriosis may be Difficult to Diagnose

The difficulties of endometriosis are numerous and problematic due to how little is actually known about the disease (Cox, 2008). Multiple theories have resulted from an attempt to accurately explain the process of endometriosis development and why or how it develops pathologically (Cox, 2008). The most popular theory is the ‘retrograde menstruation theory,’ which refers to the reverse flow of menstruation into the fallopian tubes and pelvis instead of the vagina (Cox, 2008). Regardless of the process, endometriosis is a chronic disease that doctors and nurses do not know enough about and do not manage well (Cox, 2003). Whether women delay medical attention for their symptoms or physicians do not entirely sympathize with women’s reported symptoms, there is a common consensus that knowledge and awareness surrounding endometriosis is lacking (Cox, 2008). However, with varying endometriosis symptom presentations, women are experiencing various medical interactions when seeing a physician about their menstrual abnormalities.

How Healthcare Encounters Affect Women’s Perspectives of Themselves and their Bodies

Bertero and Grundstrom (2017) address the “double-edged” nature of the healthcare encounter and interaction for women who seek medical attention for their endometriosis symptoms. This study utilized qualitative research methods and identified how healthcare encounters may affect the perceptions of women in regard to their self-esteem and hope for their future as they live with pain, distress and endometriosis. The healthcare experiences were termed ‘double-edged’ because they presented ‘contradictory feelings;’ women felt both acknowledged and ignored during visits with different healthcare providers. Destructive encounters were characterized by ignorance, leading to feelings of invisibility, disbelief and risk of mental and physical exposure (Bertero & Grundstrom, 2017). Constructive encounters were characterized by feelings of acknowledgement and confirmation, ultimately helping women feel visible (Bertero & Grundstrom, 2017). The

constructive encounters were associated with women obtaining a deeper understanding of symptoms and symptoms' influence on their lives. Another study utilizing mixed methods and focus groups identified that healthcare providers were reluctant to provide women with referrals to specialists to expedite the diagnosis process; one woman experienced a 12 year delay until she found a healthcare provider who listened to her and diagnosed her with endometriosis (Cox, 2003). Overall, with the Bertero & Grundstrom study suggests that it is likely that the delay in diagnosis can be associated with various different reasonings, but a common one is inadequate health care encounters occurring where patients are left feeling like their voices were not heard (Bertero & Grundstrom, 2017). Women felt acknowledged when their symptoms were heard and confirmed (Bertero & Grundstrom, 2017). Although confirmation of their symptoms did not make the disease disappear, it did make it easier for them to handle and accept their new reality and work towards better quality of life.

How Societal Norms and Expectations Affect how Women Disclose Abnormal Menstrual Symptoms

It is thought that menstrual etiquette is a societal taboo with a long history of setting expectations of how women should disclose and openly discuss their menstruation and menstrual symptoms (Law, 1990; Seear, 2009). Seear emphasizes the phenomenon of menstrual etiquette as it involves the concealment of menstruation and menstrual problems in the healthcare environment as well as with family and friends (Seear, 2009). Seear believes that the persistent nature of delay in endometriosis diagnosis is in part due to the stigmatization women feel when attempting to disclose their symptoms rather than whether or not women know how to identify between normal and abnormal menstrual symptoms. Women experienced or anticipated sanctions from others on menstruation and would decide to practice menstrual etiquette as a way to protect themselves from

the feared stigma (Seear, 2009). Seear's study utilized qualitative research methods and women who were interviewed initially began by disclosing their queries about their menstrual symptoms to a close friend or their mothers. The disclosure was inherently strategic, since the women were careful of who they disclosed their menstrual symptoms with (Seear, 2009). When women reported pain to their close friend or mother, their pain was ironically minimized or diminished by the person, which led them to redefine or reconsider their initial degree of concern for their menstrual pain (Seear, 2009). This dismissal points to the notion that women may normalize menstrual abnormalities to one another simply because of their own discomfort with the issue and the apparent discomfort from close friends and loved ones (Seear, 2009). Without a doubt, Seear points to the ultimate goal of improving open social communication surrounding menstruation and how this would encourage loved ones to acknowledge menstrual abnormalities, which would ultimately improve women's confidence in voicing their menstrual abnormalities with their healthcare providers (Seear, 2009).

Menstrual Education and Communication has the Potential to Expedite Endometriosis Diagnoses

Even though, biologically, menstruation is an index of health for women, it has been characterized as dirty and polluting the beauty of a woman for centuries (Bertero & Grundstrom, 2017; Wilson, 2018). This polluting societal view has led to a social stigma where women are less likely to communicate about their menstrual cycle or irregularities (Wilson, 2018). Women expect pain from menstruation, yet, even if they expect pain, they have difficulty distinguishing "normal" from "abnormal" menstrual pain or symptoms (Manderson, Warren & Markovic, 2008). Abnormal menstrual symptoms include prolonged intervals, severe cramps, excessive menstrual flow and menstrual flow greater than or equal to 6 days per month (Pediatrics, 2006; Vercellini, 1997).

Women who experience menstrual flow equal to or greater than 6 days per month or heavy flow or severe cramps have an increased risk of endometriosis (Vercellini, 1997). However, patients, caregivers and physicians share the same misconception and misunderstanding of what constitutes a normal menstrual cycle, which may ultimately lead to a longer diagnostic delay in the future (Manderson, 2008; Vercellini, 1997).

The lack of communication and understanding surrounding abnormal menstrual symptoms stems from menstrual taboos rooted in history. Menstrual taboos have different characteristics in different societies, however what is common around the world is how there seems to be a distinct set of rules for conduct regarding menstruation (Kissling, 1996). There is a great deal of variability on how women and men in the United States (US) view menstruation and its rules of concealment in society. Kissling identifies the polarizing beliefs of menstruation among girls in the US and adds that how a society deals with menstruation reveals how a woman is viewed by society. These rules on menstrual concealment may lead to feelings of shame and social discomfort surrounding menstruation (Kissling, 1996).

Social discomfort surrounding menstruation leads to three areas of menstrual taboo: concealment, activity and communication (Kissling, 1996). Advertisements advance the concealment aspect of menstrual taboos by promoting products that hide one's period (Kissling, 1996). Activity highlights the perceived notion that women should not participate in certain activities, such as swimming or physical activity when a woman or girl has her period (Kissling, 1996). Communication highlights the belief that menstruation and its symptoms should not be talked about (Kissling, 1996). Subsequently, a majority of US adults and adolescents believe that menstruation should not be discussed, even within the family context (Kissling, 1996). This poses a major threat to prepubescent females who may not be properly educated or prepared for their

future experience with menarche (Kissling, 1996). Furthermore, it is evident that there are various levels where communication, interaction and activity surrounding menstruation are being concealed in our society. This lack of communication and openness poses difficulties on girls and women who may not know how to differentiate between normal and abnormal menstrual symptoms (Kissling, 1996). This disconnect not only paves the way for symptom dismissal amongst friends and family, but it also may allow for the symptomatic woman to become more hesitant about disclosing her symptoms (Kissling, 1996; Seear, 2009). Ultimately, physicians are more likely not to be aware or as knowledgeable on how to approach or treat abnormal menstrual symptoms because of the socialized menstrual etiquette, or concealment occurring (Kissling, 1996; American Academy of Pediatrics, 2006; Seear, 2009).

Theoretical Framework

To understand this phenomenon, Goffman's Stigma Theory and the Socioecological Model will be used. Goffman's Stigma Theory emphasizes the importance of bridging the concepts of stigma and stigmatized identity (Towler, 2005). Explanations defining stigma are scant, and most of them exist in a social context or situational threat (Yang, 2007). Goffman (1963) describes that individuals take on the specific attributes relating to the socially accepted stigma transitioning and leading to a self-stigmatized identity. Negative social norms and taboos surrounding menstruation allow for the social stigmatization of menstruation, which can lead to concealing abnormal symptoms (Wilson, 2018). There exists a paradox in the menstrual taboo which highlights that despite its indicator of health and female characteristic nature, the management of monthly bleeding and its perceived polluting nature counters the feminine stereotype of beauty (Wilson, 2018). This perception leads to a social stigma which ultimately devalues women with messages to conceal the management of their menstrual cycles or avoid disclosing information on their

menstrual irregularities (Wilson, 2018). It is this taboo and history of social stigma foundation in our culture that creates barriers for women to seek out health-care advice and care when menstrual problems arise (Wilson, 2018). By understanding the perception of women diagnosed with endometriosis and how they cope with their social contexts Goffman's theory of stigma will frame how we identify and understand their experiences and address stigma as it relates to menstrual concealment.

The Socioecological Model aids in analyzing stigma as it unfolds at different levels in the context of menstrual concealment and on delayed endometriosis diagnosis from the perspective of the women diagnosed with endometriosis. Women who experience menstrual abnormalities have a choice to make which about whether to address her menstrual abnormalities with a health care provider or loved ones or refraining from doing so. This behavior of voicing concern for menstrual abnormalities is one that may be influenced or affected by external factors or societal norms. Reasons behind women refraining from voicing their concern for their menstrual abnormalities may range from personal fear of judgement, lack of knowledge surrounding issues, societal norms or lack of accessibility to health providers due to health policies.

Within ecological models used for health promotion, the outcome of interest seems to be the behavior (McLeroy, Bibeau, Steckler & Glanz, 1988). However, in this study the behavior identified, menstrual concealment, is ultimately not the outcome hoped for, rather being studied to identify how women with a delayed endometriosis diagnosis understand potential external factors contributing to their diagnostic delay. Stigma surrounding menstruation at different levels will be identified with the Goffman theory in mind.

The socioecological model elaborates on constructs at three different levels: the individual, interpersonal and macrosocietal levels. The individual level provides a deeper understanding of

the transition to self-identification with the normalized stigma. Addressing women's knowledge on menstruation and menstrual abnormalities helps identify if her environment affected her understanding of when or why she should discuss menstrual abnormalities. Also, at the individual level the identification of fear and societal norms may help understand why women may have concealed menstrual abnormalities. Menstrual concealment on the individual level ultimately allows for a deeper understanding of women's decision making surrounding menstrual concealment.

The interpersonal level reveals the trust, openness and respect (or lack of) involved in the patient-physician relationship. The interpersonal level helps gain insight on patient and health care provider interactions during the journey to endometriosis diagnosis. Specific insight on how health care provider interactions went among women who ultimately experienced delayed endometriosis diagnoses is helpful in determining menstrual communication, stigmatization and possible normalization. Depending on how the interaction is described, whether it was constructive or destructive, allows for a greater understanding on why menstrual concealment may have occurred (Seear, 2009). Destructive interactions may occur when providers quickly dismiss or minimize the menstrual abnormality described (Seear, 2009). Whereas constructive interactions may occur when providers seek medical tests to rule out for a possible pathology causing menstrual abnormalities. Although menstrual concealment does put healthcare providers at a disadvantage if they do not know about what the woman is going through, it is typical for women to start concealing more after each office visit if they initially felt dismissed (Ballard, 2006; Seear, 2009). Thus, by identifying selective bias, pain discrimination, menstruation normalization or ignorance within patient and provider interactions, the PI will have a better understanding of why women may have felt the need to conceal their menstrual abnormalities.

Lastly, the macrosocietal level will address how society's view on menstruation may hinder and interrupt the dissemination of information pertaining to endometriosis and ultimately a timely diagnosis. For women to have access to health care providers and afford their doctor visits, insurance policies must allow for affordable costs. Unfortunately, insurance may be a roadblock as some women do not possess insurance and are forced to seek care at emergency rooms for their menstrual abnormalities, which oftentimes may fail to properly address non-emergent issues (Ballard, 2006; Cox, 2003). Additionally, cultural medical and gender norms within a society may be present at institutional levels which educate health care providers during medical schools. If there are certain gaps within gynecologic studies in the United States health care providers may be ill-suited to address menstrual abnormalities when their patients come with to them with these concerns.

Purpose and Aims

This study serves to understand women's perceptions on menstrual concealment as well as their experiences with delayed endometriosis diagnosis. An array of studies have explored reasons for diagnostic delay, however there is a paucity of research pertaining to women's perceptions and understanding of menstrual concealment and how it may play a role in their delayed endometriosis diagnosis. This qualitative study involved semi-structured interviews via Zoom with women 18 years or older, with a clinical endometriosis diagnosis, and who speak English fluently in order to understand their experiences with endometriosis and opinions about their diagnosis, potential diagnostic delay and menstrual concealment. Awareness of menstrual concealment is imperative as it is a significant barrier to initially seeking medical care for menstrual irregularities. With the profound menstrual taboo history and the nature of normalizing menstruation, this study aims to

highlight the effects of menstrual concealment on delayed endometriosis diagnosis. This study explored the following aims:

- To describe the perceptions of menstrual concealment among women experiencing delayed endometriosis diagnosis.
- To identify the factors that shape how women with delayed endometriosis diagnosis view menstrual concealment.

Chapter 2

What is Endometriosis?

Endometriosis is a major contributor to pelvic pain and subfertility (Giudice, 2010; Kelechi, 2011). An endometriosis diagnosis, although poorly recognized in practice, is characterized by endometrial tissue growth outside of the uterus which may cause cyclical bleeding, scarring, and adhesion formation throughout the abdomen (Johnston, 2015; Giudice, 2010). The endometrial tissue growth may respond to hormonal changes during menstruation, causing bleeding, swelling and ultimately leading to lesions and cysts (Seear, 2009). Many women with endometriosis are asymptomatic, while other women experience symptoms such as pelvic pain, infertility, dysmenorrhea, dyspareunia, abdominal pain, painful bowel movements, and/or premenstrual spotting (Barbieri, 2009; Johnston-Robledo, 2013). Morbidity of symptoms among women does not necessarily equate to the severity of disease (Johnston-Robledo, 2013). Pelvic pain in endometriosis is usually chronic and present for six months or more. Pain prior to bleeding may be an indicator for a clinical endometriosis diagnosis (Giudice, 2010; Johnston-Robledo, 2013). Consequently, symptoms may vary from continuous pain to intermittent pain episodes and women with severe symptoms may seek a general practitioner sooner than those who do not have as severe of symptoms (Giudice, 2010; Johnston-Robledo, 2013). Women may also delay seeking help due to the disputing nature of menstrual irregularities and risk of stigmatization (Kelechi, 2011).

Diagnosing Endometriosis

There are several contentions about the current ‘gold standard’ endometriosis diagnostic method. Diagnosis is tricky and typically involves invasive laparoscopic surgery which is expensive and dependent on the expertise of the surgeon and the confirmation of the diagnosis

may be variable (Barbieri, 2009, Kelechi, 2011). Reliability in diagnosis confirmation via pathologic/histologic biopsies vary because there are only a few surgeons who specialize specifically on endometriosis. Women presenting specifically with dyspareunia and subfertility are more frequently referred to secondary care in comparison to women who experience other symptoms (Pugsley, 2007). However, there is a longer delay in diagnosis among women with more “pelvic” symptoms and a higher body mass index (Kelechi, 2011). Thus, it seems that not only are diagnostic methods not reliable or feasible, but there are also specific endometriosis symptoms, that may lead to better access to care and better health outcomes among those women (Pugsley, 2007).

Who is affected by endometriosis?

Endometriosis affects six to 10% of reproductive age women in the United States (Giudice, 2010; Johnston-Robledo, 2013; Pugsley, 2007; Kelechi, 2011). In previously fertile women who underwent laparotomies or laparoscopies, one to 43% of them have an incidence of endometriosis, whereas there is as high as a 52% incidence rate among infertile women (Mahmood, 1991). It is more common for women to become diagnosed with endometriosis after several invasive procedures investigating their infertility than solely presenting to the general practitioner’s office for menstrual pain (Mahmood, 1991). Despite the physical and emotional turmoil that women living with undiagnosed endometriosis face, it is common for them to experience a diagnostic delay of seven to 10 years (Johnston-Robledo, 2013; Pugsley, 2007; Seear, 2009; Mcleon, 2010). Along with the toll that the physical symptoms cause on their lives, women may also face depression, fear, unnecessary suffering, reduced quality of life and anger when their symptoms are dismissed and they later find out that they have been suffering due to a diagnosis of endometriosis (Seear, 2009; Kelechi, 2011).

Diagnostic Delay and Endometriosis

Women affected by endometriosis describe diagnostic delay as a great issue (Husby, 2003). The pathogenesis of endometriosis occurred during the turn of the 19th century and involved an array of scientific discoveries (Benagiano, Brosens & Lippi, 2014). Very little is known about endometriosis, including how it develops and how it may mimic other disorders (Cox, 2008). Even when doctors may suspect endometriosis it is only diagnosed through direct observation (Cox, 2008). Since the method of diagnosis is invasive, many doctors focus on referring their patients to other specialists or avoiding the invasive surgery until they have tried an array of medical remedies to manage the symptoms (As-Sanie, 2018). This process of events and decisions by the medical care team delays endometriosis diagnosis significantly which causes women to undergo lengthy years of menstrual pain and subsequent mental health complications (As-Sanie, 2018). Women describe feeling dismissed, unheard, doubted and vulnerable about their own symptoms during this period of time. (Seear, 2007).

Since endometriosis presents with menstruation-like symptoms, it is sometimes known as a “hidden” chronic disease (Bertero, 2017). As a “hidden” disease, endometriosis is normalized by both health care professionals and women as being part of menstruation (Bertero & Grundstrom, 2017; Johnston-Robledo, 2013; Seear, 2009). Menstruation normalization occurs when symptoms are minimized or diminished and is represented by the lack of concern relating to ‘abnormal’ menstrual symptoms. Consequently, women experiencing symptoms may hesitate to see a general practitioner because of the difficulty they have of distinguishing between ‘normal’ and ‘abnormal’ menstruation and menstrual irregularities (Seear, 2009).

Women who do see a general practitioner mainly experience delays in diagnosis due to delay in referral from their general practitioner to gynecologist (Kelechi, 2011). On average

women visit their general practitioner seven times before a specialist referral. (Kelechi, 2011) This delay in diagnosis may lead to incapacitation, where women are bedridden due to pain and their quality of life substantially decreases (Seear, 2009). Although it is well understood that achieving a diagnosis does not cure endometriosis, it does provide clarity, assistance and treatment options (Seear, 2009). A confirmed endometriosis diagnosis also provides women with self-confirmation and social confirmation that their symptoms are and have been genuine (Ballard, 2006).

Menstrual concealment stigmatization

Menstrual concealment is common in many societies and pertains to the stigma, or the socially undesirable attribute, involving menstruation (Seear, 2009). Within this study two levels of stigma will be discussed, self-stigma and stigma of the physicians. Self-stigma represents the stigma women experience internally when their menstrual symptoms and possible endometriosis symptoms are dismissed and minimized or normalized by providers. Stigma of the physicians represents the external and societal stigma that physicians participate in while dismissing their patient's symptoms due to the societal normalization of menstruation; assessed via recollection of experiences by woman with menstrual symptoms and endometriosis. According to Seear, women "experience menstruation as a secretive and embarrassing period of contamination and they perceive their menstrual cycle as shameful and negative, a cause of social stigma" (page 1222). Stigmas may serve as a barrier to healthcare due to women not wanting to seek medical attention due to embarrassment (Stangl, 2019). Women living with endometrial symptoms face delay in diagnosis because they conceal their abnormal menstrual symptoms and/or because medical professionals choose to normalize these symptoms, ultimately creating a barrier for women. The medical barrier pertains to the concealment of symptoms and diagnostic delay because women feel that their symptoms are not worthy of being sought out or reported to a physician; or if physicians

are dismissive and normalizing abnormal menstrual symptoms and leading women to suffer for longer periods of time.

Self-stigma is when women conceal their menstrual irregularities or abnormalities because they believe society has a distorted view on menstruation. Women who experience self-stigma have either experienced dismissal or have had their reported symptoms minimized by close friends, relatives or health care providers. Self-stigma is further explained using the Goffman Stigma Theory where the stigma, known as a deeply discredited attribute, is known by the stigmatized individual, however, whether she assumes her differentness is evident to society or not creates a double perspective (Goffman, 1963). This double perspective is represented in the individual knowing what her stigmatizing attribute is while members from society that she interacts with may not view this attribute directly. Since menstruation can be physically concealed and hidden from others by the use of pads, tampons or darker clothes, so can its debilitating symptoms. This 'hidden' nature of menstrual irregularities or abnormalities may lead women to feel a greater effect of self-stigma since their debilitating symptoms can go on for a prolonged amount of time without mentioning concern to others that may be in the position to help them.

Stigma of providers is when the physician has preconceptions pertaining to menstruation and dismisses or minimizes a woman's menstrual irregularities or abnormalities. Pain complaints are typically normalized by physicians who suggest that menstrual pain is normal and "non-pathologic" (Seear, 2009). Since the 1980s it has been common for endometriosis to be medically dismissed (Ballweg, 1997). Gynecologists and family practitioners who medically dismiss women with endometriosis symptoms may conclude that they have a psychological pathology instead and refer them to see a psychologist without thoroughly examining them (Ballweg, 1997). Three quarters of endometriosis patients have been told that their symptoms are "in their heads"

(Ballweg, 1997). When physicians attempt to convince a woman that her symptoms are not physical, when indeed they are, this stigma ultimately influences health outcomes by undermining patients' self-confidence and trust in the medical profession (Ballweg, 1997, Stangl, 2019). In a study of women who told their primary physicians they suspected endometriosis, 18% were not referred because their physicians disagreed with their self-diagnosis (Cox, 2008). This apparent disregard that a physician may have towards his or her patient's menstrual concern may also represent a degree of gender pain discrimination, selective bias or ignorance within the health care field. Thus, the stigma surrounding menstrual concealment highlights the nuances in the health care field as it pertains to diagnosing menstrual pain or endometriosis. This stigma has significantly hindered the ability for some women to receive the adequate health care they need to begin coping with their physical symptoms.

Theoretical framework

The Goffman Stigma Theory and the Socioecological Model provide a holistic and ecological approach to understanding stigma as it relates to menstrual concealment and women who may conceal their menstrual abnormalities due to societal norms and taboos. According to Goffman's Stigma Theory, individuals have both a 'virtual' and 'actual' social identity which gives rise to a multiplicity of identities (Neale, 2010). The 'virtual' social identity includes the assumptions that others hold about the individual and the 'actual' social identity involves the assumptions the individual holds about him or herself (Neale, 2010). If there is a discrepancy between the social identities, stigma arises (Neale, 2010). This stigma then causes the individual to feel discredited if the condition is disclosed (Nack, 2011; Parker, 2003). This feeling of discredit may force individuals to transition from a 'normal' to a 'discredited' social status (Kleinman, 2009). Women who experience menstrual symptoms that cause 'abnormal' symptoms may

encounter primary care physicians who make assumptions or judgments about how they manage pain and attribute symptoms to the ‘normal’ menstrual cycle. If women are persistent and return to their primary care physicians with the same complaint or worse, their primary care physicians may dismiss them and may conclude that they have a psychological pathology instead and refer them to see a psychologist without thoroughly examining them (Ballweg, 1997). Overall, as Goffman describes stigma, it has led to the focus on stigma as if it were a physical entity constructed at a cultural level (Parker, 2003). Stigma would not be able to survive outside of the context of a social society. The reason there are stigmatized individuals is because there are preconceptions, biases and misconceptions about specific topics such as menstruation, that have survived throughout history and continue to alter the way we openly communicate with each other. Thus, Goffman’s Stigma Theory only allows for individual level analyses because we are exploring the perception of a known stigmatized population without taking into consideration why they initially became stigmatized. Ultimately, this minimizes the effect of the cultural weight of the ‘undesirable characteristic’ stigmatizing this group of people.

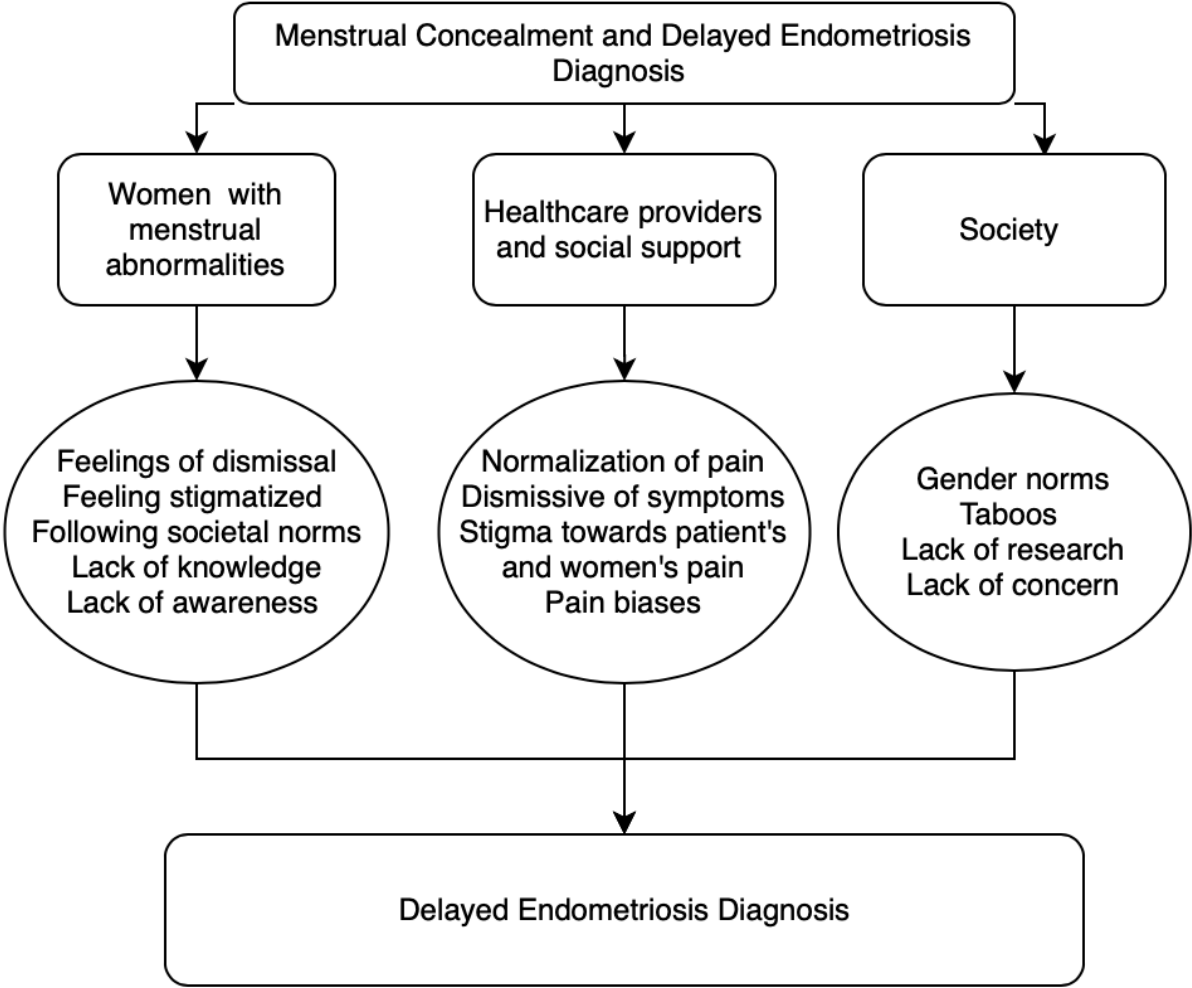
The socioecological model provides a deeper understanding of the inequities in access to adequate health care among women and how the interpersonal and macrosocietal levels affect the persistent stigma surrounding menstrual concealment (Ma, Chan & Loke, 2017). The socioecological model is a popular theory-based framework used for understanding the interactive effects of the individual, interpersonal, community, organizational and environmental factors that determine behaviors within different contexts (Centers for Disease Control and Prevention, 2014; McLeroy, 2018). A recent review has been performed highlighting a stigmatized population’s avoidance or delay in treatment attributable to multi-level factors (Ma, 2017). Similar factors are displayed in the theoretical framework below to address this study (Figure 1). At the individual

level, menstrual concealment may play a role on the timeliness of a diagnosis of endometriosis due to the lack of women's knowledge of menstrual irregularities. Subsequently, when women are unfamiliar with menstrual irregularities, they may dread disclosing information due to fear of social judgement. At the interpersonal level, diagnostic delay may be common because of physician's normalization of menstrual pain, gender pain discrimination, selective bias towards specific pathologies, and ignorance. Lastly, at the macrosocietal level, there may be underlying cultural, medical and gender norms which may affect the level of concern for women experiencing menstrual irregularities consistent with endometriosis diagnoses. These different levels are important in understanding and identifying stigma as it pertains to menstrual concealment.

Overall, the purpose of this study was to understand the perception of women who have had experiences with delayed endometriosis diagnosis. There is a paucity of research on menstrual concealment and diagnostic delays surrounding endometriosis (Seear, 2009). Many studies have investigated the infertility aspect of endometriosis and its effects on conceiving and subsequent mental health turmoil, however very little has been done to listen to the women who lose 7-10 years of their lives to severe menstrual pain without a definitive diagnosis. Thus, this qualitative research study aimed to fill the research gap by performing qualitative interviews with 8 women who have been previously diagnosed with endometriosis to examine their experiences with delay in diagnosis and their awareness and perceptions on menstrual concealment.

Understanding The Relationship Between Menstrual Concealment May contribute to A Delay In Endometriosis Diagnosis

The PI developed this conceptual model in order to better visualize the different factors that may contribute and allow for menstrual concealment within healthcare visits.



Chapter 3 - Methods

Project Conceptualization

The project was originally conceptualized while the PI reflected on her own passions surrounding obstetrics and gynecology (OBGYN). As an aspiring physician assistant OBGYN specialist, the PI has an interest in women's health and well-being dealing with their reproductive health. The PI noticed a gap in the literature surrounding the concern for women reporting menstrual irregularities which then led to a lengthy pursuit in diagnosing endometriosis. The PI was particularly interested in the topic due to the current political and social landscape concerning women's sexual and reproductive rights since endometriosis affects women's fertility, mental health and menstrual cycle and women seem to be dismissed when voicing their concerns.

Research design

This study employed qualitative in-depth phone interviews with eight women with an endometriosis diagnosis who live in the United States. Qualitative research was chosen because it allowed for the opportunity to explore endometriosis diagnosis delays beyond the diagnostic outcome measures (Rich & Ginsberg, 1999). Diagnostic measures and outcomes are typically readily available through medical record data, however, the PI aimed to understand the context surrounding the diagnostic measures and examine why and how women continued to experience endometriosis diagnostic delays despite technological advancements in medicine. The PI also believed that it was best suitable for her future career as a physician assistant to recognize the importance of actively interviewing, receptively listening and evaluating narratives to best understand and meet the differing needs of patients (Rich & Ginsberg, 1999).

Population and sample

Participants were eligible for the research study if they were 18 or older, biologically female, had a definitive endometriosis diagnosis date, spoke English fluently, resided in the United States and if their endometriosis diagnosis was established in the United States.

The recruitment methods consisted of the using of gatekeepers and purposive sampling. The PI researched and sought out online endometriosis social media support groups on Facebook. Participants were recruited from six different endometriosis Facebook support groups. The PI identified potential gatekeepers, consisting of support groups administrators who were asked to share the study ad on the Facebook page in order to inform potential participants about the study and pass on the PI's contact information. The ad provided details about the study's time commitment and eligibility criteria and included the PI's Emory University email as contact information if the participants were interested. Interested participants contacted the PI by email.

Procedures

The PI sent the screening questionnaire to the interested participants via email, which determined their eligibility to participate in the study. The screening questionnaire consisted of a Word Document with six questions addressing potential participants' gender, age, diagnosis date, location of diagnosis, country of residence, and English proficiency in order to determine eligibility. Once the PI received the completed screening questionnaire back from the interested individuals, she provided the eligible participants with a copy of informed consent but allowed the participant to provide verbal consent by phone. The informed consent form described the purpose of the study, procedures, potential risks and benefits to participating, and how confidentiality would be maintained. The participants were asked to read and verbally agree or disagree to participation when they were ready. The PI scheduled a phone call to review the informed consent

form and answer any questions the participant had and followed with the phone or video interview to initiate data collection. The PI then led the interview with the semi-structured guide in order to conduct the interviews (see Appendix), the interviews lasted approximately 1 hour. Eleven participants contacted the PI and were eligible, however only eight participants followed-up for the interviews.

Interviews took place via phone or video meeting using Zoom. The interviews were recorded using the voice memo function on the iPhone or the record function within Zoom. An interview guide was used by the PI to initiate and continue the interviews. The guide consisted of three domains, experiences with menstruation and possible menstrual concealment, endometriosis symptoms, diagnosis and treatment, and personal views and knowledge of endometriosis as well as perception of societal views pertaining to menstruation and endometriosis. The topics present in the interview guide were all surrounding menstruation, endometriosis, and perspectives on personal experiences and how societal menstrual taboos may have affected participants' probability in concealing menstrual symptoms which may have been early symptoms of endometriosis.

The audio recordings were labeled with pseudonyms and all identifying information was redacted in order to preserve confidentiality. The audio recordings were then stored securely through Emory box and were destroyed immediately following data analysis. TEMI transcription software was used to transcribe the audio files; the PI reviewed the transcripts for accuracy.

Data analysis methodology

The PI conducted data analysis at Emory University via MaxQDA software. The PI used a secured password for her MaxQDA account and her Emory box where all the data was stored. The PI used TEMI transcription services to convert audio recorded files into text in order to code the

data. Initially the PI analyzed the resulting data by reading through transcripts to discover emerging salient topics related to the study aims. Then the PI began coming up with codes for reoccurring topics using thematic analysis. Thematic analysis was used in the study as a method to concurrently collect data and perform analyses (Tuckett, 2005). This method of analysis alongside purposeful sampling, memo writing, and member verification led the PI to create a detailed codebook consisting of inductive and deductive codes based off of literature and reoccurring responses throughout the interviews (Tuckett, 2005). Inductive codes consisted of codes specific to salient topics that originated from the raw data (Tuckett, 2005). For example, ‘call to action’ was a popular topic surrounding when women felt was the initial point in time that led her to seek care for her menstrual symptoms. Deductive codes consisted of codes specific at testing the theoretical framework of the study. For example, ‘exclusion due to menstrual cycle’ was a code to identify if women felt stigmatized as Goffman refers to as when there is an undesirable characteristic stigmatizing a group of people. Member verification was utilized by having a colleague code half of the interviews to determine if the codes correctly aligned with the purpose of the study. The PI compared the colleague’s codes to her own to see if the codes aligned with the interview guides and preserved the purpose of the study.

Once the codebook was complete, the PI uploaded an Excel version onto MaxQDA and began coding each transcript line-by-line according to the codebook. The codebook was refined during the coding process. After coding the first two interviews, some codes were merged due to redundancy. For example, initially there were two different codes, ‘symptom conceptualization’ and ‘pain conceptualization.’ The PI felt that both inductive codes were necessary early on after listening to the first 3 interviews, however, the more participants the PI interviewed the codes usage began to overlap. Thus, both codes were merged to create a ‘conceptualization’ code.

As the PI coded the transcripts, she used the memo function on MaxQDA to document notes on similarities, differences and possible emerging themes across the transcripts. The PI also added memos within transcripts to check her reflexivity when assumptions emerged during the coding process. These assumptions varied from biases, ideas or preconceptions about what the participants said. By writing a memo on this thought the PI was able to practice being reflexive by addressing thoughts or assumptions she had. For example, since the PI has a strong medical background, she had expectations and assumptions of the knowledge women should have on menstrual abnormalities and when to see a healthcare provider. Also, since the PI also resides in the same nation as the women interviewed, she had low expectations to how medical providers and loved ones would react to reporting's menstrual abnormalities. This was helpful because her main purpose for creating a qualitative study surrounding the topic of menstrual concealment and endometriosis was for women who have had personal experiences with a medical care team and on-going symptoms of endometriosis to be the main voices expressed through the data and results of this study.

Revisions to the codebook were made early on during the transcription process so that the PI could focus on extracting text from the interviews, or transcriptions, that answered her overall research question and addressed her aims. As the PI was coding, she would create memos. She would also refer back to the study aims and how she could move towards understanding menstrual concealment through the experiences of women with a delayed endometriosis diagnosis. Thus, although the codebook revision was not a process on itself, it occurred naturally during the process of thoughtfully coding all the transcripts.

Once all transcripts were completely coded line-by-line the PI reviewed the memos and started identifying similarities and differences across the dataset. This led to the process of

activating specific codes within the 'code system' on MaxQDA in order to start detecting possible saturation within and across participant transcripts. This method of analyzing data was helpful as it visually detected which participant had coded segments for specific codes and allowed for those segments to populate within one pop-up window. This process was repeated for each code as the PI started to gain a better understanding of the dataset. Free memos were written during this process to help the PI construct an overarching theme for the dataset.

By using thematic analysis as a foundation to draw meaningful information from the data the PI was able to make use of this flexible and accessible technique to compose results from the study (Braun,2019). Thematic analysis allowed the PI to identify, organize and offer insight to patterns and commonalities in the coded data (Braun, 2019). Thematic analysis ultimately allowed the PI to focus on making meaning across the entire data set instead on solely one strong item of the data in order to reciprocate results that were truly meaningful (Braun, 2019).

Chapter 4 – Results

Eight women were interviewed via Zoom for the study. All women received a laparoscopic endometriosis diagnosis in the United States within the last two to 10 years. Participants age ranged from 19 to 49 years of age. The diagnoses were typically determined at regional hospitals; however, one individual had her diagnosis determined at a university hospital. All women identified as female and spoke English fluently.

Participants' experiences varied on the symptomatology spectrum, yet in regard to reactions towards dismissal and how they felt post-diagnosis, many responses were reflective of the overall theme of the study, menstrual concealment awareness. Participants experienced extremely severe cramping, bleeding, passing heavy clots, irregular periods, leg pain, headaches, vomiting, and nausea during their menstrual cycles. Symptom variability seemed to depend on upbringing, age of onset and secondary symptoms. Menstrual concealment awareness was evident as participants discussed being told their symptoms were “normal” from healthcare providers and family/friends. Feelings of doubt when told their symptoms were “normal” was common among participants as well as receiving repeated diagnoses of less severe pathologies, such as ovarian cysts or common syndromes.

Once symptoms became debilitating and interfered with life and work, participants pursued their symptoms again with their healthcare providers, or new healthcare providers, and requested that something different be done to figure out what was wrong. Participants began to accept that their symptoms were true, valid and legitimate after experiencing debilitating symptoms which went against what “normal” menstruation should be like. After a diagnosis, it was common for participants to feel relieved; this led many to feel a new confidence in their

control over their disease that had caused years of suffering and at times feeling like they had lost time.

Overall Description of Themes

The overall goal of the study was to examine the role of menstrual concealment in participants' interactions with healthcare providers and/or friends and family members when reporting their menstrual pain and symptoms. The overarching theme was 'menstrual concealment awareness' which was evident through participants' awareness to dismissal during or after their lengthy process to receiving a diagnosis. Participants described their experiences with menstruation during adolescence in school,

And so that was something that was, that was really, um, that was embarrassing, you know, because, you know, some teachers were, they just didn't let you go to the restroom and that's what it was. And you just had to deal with it until, you know, you kind of, if it was a female, maybe I felt a little bit more comfortable. But even at that growing up I was, I was, I was very shy, so I never wanted to say I'm on my period, let me go to the restroom (Francis).

and at home,

I came home and I was like, mom, like I was like, my stomach hurts so bad today. Like I was really hungry, and she didn't really say anything. And then I went to the bathroom and I was like, oh my gosh, here it is (Gale).

Menstrual communication was typically described when participants recalled experiences with their first menses or receiving some sort of education at school and how students responded to this new change among the females. It was common throughout participants to describe negative responses from students and/or parents when describing early conversations

surrounding menstruation. It was also common for participants to recall feelings of embarrassment of accidentally showing they were on their cycle as a teen. While some participants had good menstrual communication with their parents, others did not, and described not having great menstrual communication and/or education as a teen. Participants also described when they began experiencing symptoms and how healthcare providers and/or friends and family reacted to reported symptoms. One participant recalls what her healthcare provider said to her as she was requesting to rule out for endometriosis, “and the surgeon told me, you know, sometimes, you know, women have this and I’ll go in and do a diagnostic, uh, laparoscopic surgery and find nothing” (Alexa).

Dismissal was described by all eight participants through medical care team interaction experiences or menstrual communication experiences during adolescence. Six out of eight participants realized they had been dismissed during a ‘call to action’ moment, which resembled the moment where participants had had enough and decided not to give up on reporting their symptoms because they had accepted their pain was more than just ‘normal’ or ‘expected’ menstrual symptoms. In the remaining two participants, dismissal was realized at a different time point because of their experiences with secondary symptoms, such as infertility.

The overarching theme includes three major themes, ‘patient autonomy transformation,’ ‘perceived control,’ and ‘call to action,’ which reveal the constructions, awareness’s and transformations throughout participants’ lengthy diagnosis period. Patient Autonomy and Perceived Control have similar dimensions that help define the progression of experiences among the participants. Self-doubt and lack of confidence occur first, then acceptance and confidence improvement follow. In between this transformation, the call to action theme helps identify the moment participants became aware of possible menstrual concealment and dismissal

occurring within their healthcare visits. Altogether, the overarching theme and the themes help depict how the experience with dismissal ultimately allowed women to accept their symptoms and disease which led to improved confidence levels later on.

In the appendix, a table provides information on each participant, their general symptoms and experiences and how their experiences relate to the themes of the study surrounding their menstrual cycle and endometriosis diagnosis.

Menstrual Concealment Awareness: Patient Autonomy Transformation

The discursive theme “patient autonomy transformation” explores women’s constructions and transformations throughout their endometriosis diagnosis journey and the implications this developmental milestone had within the wider scope of their lives. Two subthemes were identified under this theme: “self-doubt” and “acceptance.”

Self-doubt: Participants felt as if their symptoms were not true or valid after reporting their symptoms to their healthcare providers and/or family and friends and being dismissed.

Participants felt bad or guilty for reporting their symptoms or solely experiencing them. They felt like they should be able to handle what they were experiencing. One participant describes how she felt when she attempted to report her symptoms to her healthcare providers, *“It made me feel like, honestly, if I was somewhat fabricating these feelings in my head”* (Alexa).

Four out of eight participants described a similar perception of their symptoms after being dismissed by their healthcare provider or family and friends. For example, one participant said, *“I should be the one to blame because I wasn't handling my pain the way I could have been”* (Gale), and another participant stated, *“there was a lot of like self-doubt. Like maybe they're right. Maybe I am just kind of being a baby. Maybe I just need to suck it up”* (Gale). These instances where participants doubted the legitimacy of their symptoms reflected their

receptiveness to healthcare provider's and family/friend's dismissal when they reported pain. As another participant commented, "*I'm just like, I'm just sensitive so I need to just get over it*" (Debby). Repeatedly, participants encountered healthcare providers who would tell them, "*there was nothing to be done*" (Alexa), or, "*you need to relax, you need to stop stressing out*" (Francis). This ultimately led participants to internalize their symptoms and take their healthcare provider's advice. However, as their symptoms intensified in severity and/or frequency they identify their 'call to action moment,' which resembled the moment where participants had had enough and decided not to give up on reporting their symptoms because they began accepting their pain was more than just their 'normal' or 'expected' menstrual symptoms. After participants had experienced years of medical dismissal surrounding their menstrual cycle abnormalities, they experienced persistent or even worse pain and/or symptoms. In this instance, feelings of self-doubt began changing and transforming into acceptance that there truly was something wrong.

Two out of the eight participants who did not report similar perceptions of self-doubt were still dismissed by their healthcare providers; however their symptomatology was related to infertility rather than heavy menstrual bleeding and cramping. One participant expressed how she was convinced her pain and menstrual symptoms were indicative of other less severe pathologies, "*I was convinced I was just having lots of cysts and I wasn't ovulating I really didn't think that it had anything to do with endometrioses, even if I did have it, you know, I was really hung up on it being from my ovaries and, um, and that, so I didn't really even, you know*" (Beth). Although the healthcare provider still dismissed the possibility of endometriosis, perceptions of self-doubt seemed less pronounced here as compared to the participants above especially because symptoms were not necessarily painful or debilitating. Participants who did feel severe pain or

debilitating symptoms were more commonly guilty, embarrassed or shameful in sharing their symptoms with their healthcare providers, whereas the two participants who experienced infertility and no pain did not feel the same way, thus did not feel self-doubt to the same extent.

One participant did not report similar perceptions of self-doubt even though she was dismissed by her family. Her experience and degree of self-doubt for her symptoms were viewed through the eyes of her family members who also had endometriosis but did not have a diagnosis yet. She expressed her experience with pain and menstrual symptoms through the eyes of her mother and sister as: *“It was normal in the sense that she had the same experience that I had, which is what I guess what made it normal”* (Helen). Thus, her perception of self-doubt was even less severe than the other participants because her symptoms were being shaped by someone else. Her mother and sister having had similar experiences with menstruation and medical dismissal, accepted their healthcare providers’ diagnosis of “normal” menstrual symptoms and relayed this message to her. Since the participant has strong trust with her mother and sister, she accepted their word on her own symptoms. Even though she did experience self-doubt, which ultimately led her to pursue a second medical opinion, she lived in pain and suffering because her symptoms were downplayed due to the trust she placed in the medical advice given to her family.

Acceptance: After participants began becoming aware of menstrual concealment, they began to accept that they were not fabricating their symptoms and became much more assertive in conversations surrounding their symptoms. For example, one participant stated, *“I definitely felt like I was completely truthful because I finally knew, okay, I'm not making this up. This is real”* (Debby).

Six out of eight participants displayed a similar feeling of acceptance temporally following their ‘call to action’ moment. Acceptance was expressed when participants experienced symptoms that were debilitating and interfered with work or school, for example, one participant stated, “...we got to figure this out because like it's affecting my work. Like I'm not able to like even focus because the pain was so bad” (Debby). ‘Call to action’ moments led participants to begin conceptualizing their pain by understanding that there may be an underlying issue that is not being addressed. These moments ultimately allowed for participants to become more assertive with how they voiced their symptoms and what they wanted done to identify an underlying cause. One participant expressed how she had a feeling there may be something causing her pain and menstrual symptoms and urged her healthcare provider to try testing or imaging to rule out for pathologies, “listen, I know something's wrong. I know my body, and I got to figure out what's going on” (Alexa), and, “I knew that there was something wrong that they didn't have no clue and I was trying anything I could” (Eloise). Achieving acceptance over one’s symptoms was a developmental milestone that resulted from years of being dismissed by healthcare providers and family and friends. Acceptance lay the groundwork for participants becoming aware of the menstrual concealment that was embedded in their conversations surrounding their symptoms. One participant expressed her understanding of being dismissed by healthcare providers and acceptance of her symptoms, “...like it's not normal for me to not be able to move because I'm in so much pain and I just didn't feel like I was listened to” (Gale). Thus, through patient autonomy transformation participants were able to break the cyclical diagnostic delay and overcome dismissal in their conversations with healthcare providers and family/friends by overcoming self-doubt, understanding their symptoms are real and deserve more attention than they were receiving.

Menstrual Concealment Awareness: Perceived Control

The discursive theme “perceived control” explores the impact and effect that menstrual concealment and endometriosis diagnostic delay had on participants. The impact of the latter allowed for identification of two subthemes under this theme: “lack of confidence” and “confidence improvement.”

Lack of confidence: When participants were reporting their menstrual symptoms, along with being receptive to healthcare providers’ and/or family and friends’ dismissal, they displayed lack of confidence. This lack of confidence was portrayed as not feeling as if they had much control over their symptoms, treatment, care or prognosis. They were told it was ‘nothing’ or ‘normal’ and they became receptive to the level of care they were receiving and would receive in the future.

All participants experienced at least two or more years of attempting to obtain a diagnosis for their menstrual symptoms. Participants reported that after being dismissed a couple of times, they would trust their healthcare provider and used their healthcare provider’s perspective on their symptoms to be the reason for subsequent symptoms. One participant stated *“I was like, I have a cyst. Why should I go? They did nothing for me, nothing”* (Alexa). This receptive behavior led participants to feel like they did not have control over their symptoms and ultimately displayed lack of confidence in voicing their concerns or opinions on their symptoms. Another participant stated, *“and I was, um, I was put off as being too young to have any of those discussions. I was told that, um, I was too young to even think about pregnancy and that, you know, it's fine. I just needed to try other things to manage the pain”* (Gale). After hearing that their symptoms were ‘normal’ or ‘expected’ for so long, participants continued this cyclical method of temporarily treating their symptoms with their healthcare providers’ advice without

fully addressing the underlying issue due to menstrual concealment present within their healthcare visits.

Power dynamics between the patient and provider also affected participants' confidence, *"I tried to talk to a bunch of doctors about how, um, you know, I had looked stuff up and I was pretty sure that I had endometriosis, but you can't diagnose it until a laparoscopy and nobody wanted to listen to me"* (Gale). It was common among participant and healthcare provider interactions to witness dismissal for menstrual pain and symptoms. This dismissal came from healthcare providers who seemed to believe they knew what was best by continuing the same protocol of treating symptoms with pain relievers or non-severe diagnoses of ovarian cysts or syndromes. Even when participants returned for follow-up appointments and voiced that their symptoms had persisted and/or worsened, healthcare providers continued to utilize their professional titles to dictate the care and treatment their patients received.

Similarly, as before, participants began to break their silence when they experienced persistent and/worse pain and menstrual symptoms. One participant described her 'call to action' moment by stating, *"I don't know what's going on? I don't know if this is the cyst because this is what they've always said. It's a cyst. I said, but we got to figure this out because like it's affecting my work"* (Alexa). Symptoms became debilitating, yet the degree of confidence or ability to change circumstances surrounding their care seemed impossible. With time and a greater awareness of the dismissal present within their healthcare interactions a shift in level of confidence and perseverance seemed to occur among participants. This shift changed how participants began approaching conversations about their pain, symptoms and diagnostics.

Confidence improvement: As women became aware of menstrual concealment within healthcare visits and were diagnosed, they began to take control of their health and how their disease would

affect them. Their confidence ultimately improved as they now portrayed themselves with more authority and even advocated for their health or others around them experiencing similar symptoms.

The shift in level of confidence that participants underwent substantially improved their confidence in pursuing an underlying cause for their symptoms. They realized that their symptoms were legitimate, and they were not being listened to or taken seriously, which prompted them to try harder to figure out what was wrong; This also led participants to serve as self-advocates and advocates for other women experiencing similar symptoms and dismissal through healthcare providers. Four out of the eight participants describe having conversations with other women in their families or friend groups, creating information posters on university campuses, or expanding conversation with coworkers if menstruation pain or symptoms are mentioned. One participant describes how since her endometriosis diagnosis she has been more aware and open to having conversations with other women about menstruation and helping them see healthcare providers as soon as possible,

I think like I've been more of an advocate for it, you know. So, when I have felt comfortable and you know like even if it's HR or coworkers or friends, like I'll be like I have this, this is what it is and this is what I've experienced. And you know like if you ever experience it and make sure you get checked because this happens and it could happen to you, it just doesn't happen to me (Helen).

After their laparoscopic diagnoses, participants' level of confidence and perception of control for their disease and their health improved which ultimately validated their symptoms, *"I think that there is something about all those years waiting and knowing there's something wrong and when you finally get proof and said, yes, ha ha, this is what it is"* (Eloise). Six out of the eight women

experienced relief and validation which led to improved confidence in their journey to improve health outcomes with their disease, *“I was relieved, honestly. I was just relieved to have an answer, to be told that I wasn't crazy. It wasn't just a bad period that I needed to suck up and get over with”* (Gale).

Two participants responded to their endometriosis diagnosis differently because of secondary symptoms, such as infertility. Their reactions to their diagnosis was, *“once they told me the diagnosis and, and that, uh, endometriosis is one of the number one causes for infertility then bingo, I knew”* (Cindy). Secondary symptoms may have led to the lesser degree of confidence improvement compared to those who felt severe pain leading to their diagnosis since they experience as severe of an experience with menstrual pain and symptoms as the other participants. Without experiencing as severe of symptoms, the participants that presented with infertility, may not have gone through similar suffering as those who did experience severe symptoms.

Menstrual concealment awareness may develop at different timepoints for different women. Through the overarching theme and subthemes present it is evident that experiences with participants' healthcare providers, family members and friends helped bring to light the dismissal they encountered during their journey to obtaining an endometriosis diagnosis. The experiences accounted for above, although they caused suffering and a sensation of lost time, helped women become assertive and persistent with their healthcare needs.

Call to Action

The discursive theme “call to action” explores the identification of how participants came to realize they were being dismissed by their healthcare providers, family and/or friends. The impact of this moment for participants allowed them to fight back against the dismissal,

repetitive non-severe diagnoses, and pain relief therapies they had received for years from healthcare providers and/or loved ones.

Four out of the eight participants described their call to action moment as the “worst pain” they had experienced yet. One participant described her pain as, *“I don't know if it was more pain or pressure. It's very uncomfortable and very just like almost like a ripping feeling. Okay. And that's when I knew something was different”* (Alexa). Another participant described being woken up with pain, *“I was sleeping and all of a sudden I woke up with the worst pain. I mean, like somebody just came in and I don't know what a stabbing feels like, but that's what it felt like”* (Francis). These moments of pain prompted participants to schedule a visit with their healthcare providers or rush to the emergency department, which finally led to medical studies that diagnosed them with endometriosis. Physical pain was a commonality among participants’ call to action moment. The physicality of feeling at their worst prompted them to try to be heard by their healthcare providers one more time.

Additionally, two participants had experiences where someone else helped them realize they were being dismissed and prompted them to try again to report their symptoms in hopes of determining the cause or pathology. One participant described her call to action moment when a nurse at a Title X clinic insisted she get a second opinion for her symptoms because the nurse knew there was something wrong but not much could be done at the small clinic,

The midwife who was there told me, you know, you have some skin issues and you have a lot of pain. She was very like aggressive about asking me questions and I was like, Oh no, no, I'm fine. And she was like, honey, you can tell me like you have pain. Like how bad is it? Really? And, um, she was like, you know, I can't do much since this is just like

a little clinic, but I'm telling you like you should really go and get these other things checked.

Following this encounter, the participant had two emergency department visits for severe pain that affected standing and walking. She was diagnosed after the second emergency department visit.

An important consideration about the call to action moments described by participants is the descriptive nature of words used. As pain and symptoms increased in frequency and severity participants were able to differentiate that this moment was different from others they had had. One participant explains her last experience with severe pain as, *“the pain was intensifying, and it was becoming more frequent. Um, I think the final time that I had gone to the emergency room before I had gone down to the city was, um, I had been bleeding for 21 days, my period. Had lasted for 21 days and it was a lot”* (Gale). There was something clearly alarmingly different from these call to action moments than other episodes of pain and/or symptoms they had experienced before. These moments propelled these women to pursue medical care one more time despite being dismissed all these years. These call to action moments led all four participants to their endometriosis diagnoses and allowed them to embark on accepting that their symptoms were true and legitimate and gaining confidence on their perceived control, despite experiencing medical dismissal all these years.

Consequently, three out of eight participants who had secondary symptoms or had family members go through the process of diagnosis did not explicitly experience call to action moments like the four participants described. One participant described the moment where she realized there may be something wrong affecting her ability to conceive, *“as soon as we had health insurance, um, we went to see him and that was our 14th cycle of trying. So just over a*

year, this is what's going on. Help us out, you know, what do you think is the issue? I said, you know, I don't think I'm ovulating” (Beth). As mentioned, this call to action moment seems slightly different than the moments described by the participants who were experiencing menstrual pain and symptoms, however, it still became a turning point in this participant’s journey to diagnosis. Another participant expressed how even though her mother and sister had gone through a similar process to receive their endometriosis diagnoses she was hesitant to receive a laparoscopy surgery despite her severe symptoms, her call to action moment occurred after having a second opinion with another healthcare provider, *“I said, okay, I need a second opinion. So, I did go to another doctor and I think this is part of what helped me learn and realize certain things”* (Helen). Although these participants had different experiences such as secondary symptoms and familial endometriosis diagnoses, they still reported on these specific moments where they knew they needed better medical care and attention for their concerns.

Chapter 5: Discussion

Menstrual concealment awareness

The main finding of this study was that women are aware that menstrual concealment was present during their healthcare visits and/or interactions with family and friends when reporting concerns for menstrual abnormalities. Menstrual concealment through the eyes of women who experienced extensive endometriosis diagnostic delay addresses and highlights the extent of societal norms on menstruation and women's health. Menstrual concealment may occur within healthcare interactions and its uniqueness is important in understanding endometriosis diagnostic delay and how women suffer physical pain and emotional turmoil while being dismissed by family, friends and healthcare providers. The themes identified through this study highlight the overarching theme of menstrual concealment awareness and how when participants described circumstances experienced during their process to gaining an endometriosis diagnosis they may have elicited this awareness which ultimately led to transformative behaviors personally and interpersonally.

The identification of menstrual concealment and the pursuit of understanding it through the eyes of women who experienced endometriosis delay was prompted on the limited literature available. Previous studies have emphasized the significance of menstrual stigmatization as women seem to fear disclosing their menstrual symptoms due to the fear of judgement, or stigma (Seear, 2007). This analysis is concurrent with another study that identified the various different healthcare experiences women were having with their healthcare providers. Some women reported having constructive interactions while others reported they had destructive interactions (Grundstrom, 2017). These healthcare experiences were found to have affected women's perceptions of themselves, their symptoms and their bodies (Grundstrom, 2017). Ultimately,

menstrual stigmatization and perception of oneself seems to be contingent on menstrual concealment within interpersonal interactions with healthcare providers, family and friends. In this study I have argued that women's menstrual perceptions with herself, others and her community are driven by how prominent menstrual communication was and is in her life. Whether menstrual communication was dismissed early on as a teen or within the last year during a doctor's visit, women initially may not feel dismissed; however dismissal may affect confidence in oneself to continue pursuing menstrual abnormalities. It is not until a woman's pain and/or symptoms persist and/or worsen in frequency and/or severity that she becomes aware of possible menstrual concealment within interactions surrounding menstruation and menstrual symptoms. This awareness induces women to begin to accept that their symptoms are legitimate and slowly confidence improves and they are able to overcome stigma and advocate for themselves and their health.

Menstrual concealment awareness trickles into patient autonomy and how women advocate for themselves and others, as well as how women reacted to their sense of control following their diagnosis and how their disease prognosis would proceed. As Goffman describes, individuals take on the specific attributes relating to the socially accepted stigma transitioning and leading to a self-stigmatized identity (Goffman, 1963). Women were prone to feeling self-stigmatized when healthcare providers perpetually minimized concern for their symptoms. Self-stigma led to feeling doubtful that symptoms were legitimate. Addressing menstrual concealment awareness and dismissal through Goffman's Stigma framework allowed for perspective on why women were avoiding conversations about menstruation and their symptoms. By minimizing menstrual pain and symptoms as something 'normal' or 'regular' women began concealing their symptoms due to the stigma they felt. It was not until symptoms and pain became debilitating and interfered with

life that women felt they may have been dismissed during previous healthcare interactions or conversations surrounding menstruation.

Additionally, perceived control manifests similarly to the patient autonomy idea, except it takes into consideration that feelings of self-stigma may decrease overall locus of control and confidence. Being dismissed by family members or friends affects how women communicate within their inner circles and may hinder relationships. However, dismissal in the healthcare environment affects the perception women have over their health and life itself. Previous studies have identified how years of dismissal surrounding menstrual symptoms and eventual endometriosis diagnosis is closely correlated with mental illness (Seear, 2009; Kelechi, 2011).

Furthermore, this study identified that menstrual concealment awareness allows for improved acceptance over one's menstrual symptoms and confidence in regard to locus of control once the symptoms and/or diagnosis settles in and women are living with their new realities. Endometriosis disease perceptions, conceptualizations and prognoses are also improved when an awareness of menstrual concealment is established. When women are dismissed, they begin to identify their symptoms as normal, something not worth mentioning or simply an excuse for something every woman goes through. This allows for menstrual concealment to begin and shape how women describe their health concerns surrounding their menstrual cycle. Yet, once women experience debilitating symptoms, cannot attend work or school, they start to accept that their symptoms are much more than a typical ovarian cyst or PCOS diagnosis. This acceptance is related to improved confidence and both are transformative in a woman's life and validate their long years of suffering and dismissal. It is important to understand that menstrual concealment awareness is not the only method of regaining self-confidence or advocating for one's own health and others, however, it was present largely in this sample.

Strengths

This study is unlike most that have been previously done addressing delayed endometriosis diagnoses. Most studies address this issue solely with quantitative data on delayed years with endometriosis symptoms. However, two studies did make use of qualitative interviewing with women who reported delayed endometriosis diagnoses yet did not address the possibility of menstrual concealment playing a role in the average 7-10 years of delayed diagnosis (Johnston-Robledo, 2013; Pugsley, 2007; Seear, 2009; Mcleon, 2010). With the overall goal of improving the understanding of delayed endometriosis diagnosis, menstrual concealment was addressed due to recommendations in other research studies performed where stigma among menstruation and symptom normalization by healthcare providers was indicated to be contributing to the delayed diagnosis. Thus, this study took these recommendations and addressed stigma and normalization of symptoms through understanding menstrual concealment awareness and its potential association with delayed endometriosis diagnosis. Qualitative interviewing aided in providing genuine experiences with endometriosis delay and perceptions of menstrual concealment awareness.

Limitations

It is important to acknowledge three limitations associated with the study above. Although qualitative methods allow for a more in-depth understanding of a topic that had little input from actual individuals experiencing endometriosis diagnosis delay, it does, however, limit the ability to generalize that menstrual concealment may be contributing to endometriosis diagnosis delay. Additionally, this study had a small sample size which may have limited the scope of data analysis, despite its data saturation. Since the sample was small, exploring other options such as reaching out to healthcare providers could have added to the data input on menstrual concealment by adding

a different socioecological level dynamic. Lastly, eligibility requirements limited the participants who could participate. For example, an eligibility requirement limited women who received an endometriosis diagnosis outside of the United States as well as those who do not have social media and are not a part of communities like the ones I reached out to for recruitment.

Implications

One may ask why the difficulty in receiving a timely endometriosis diagnosis remains despite medical advancements. However, it is not that medical equipment or technology is lacking, it seems to be that most women are dismissed for being too young or not at risk for having endometriosis despite their array of symptoms. The socioecological model allowed for identification of how imperative it is to focus on interpersonal interactions as women are typically dismissed within these interactions. Also, cultural and societal norms and stigmas exist and may be the underlying issue for dismissal surrounding menstruation pain and symptoms. However, in order to make changes at higher levels within the socioecological model it is imperative to improve knowledge and awareness individually across all individuals at stake, young girls, teens, adolescents, adult women, healthcare providers and family and friends. By improving overall knowledge and awareness of the issues surrounding menstruation and menstrual symptoms, individuals will be more likely to start having conversations surrounding the subject and be more likely to dive deeper into why women are experiencing pain and symptoms. Without a doubt, in order to improve timely endometriosis diagnoses, heightened awareness for endometriosis is required at the individual level among reproductive aged women, among caregivers, and healthcare providers. Once this heightened awareness and knowledge is achieved, language will change surrounding menstruation, medical schools will extend curriculum on women's health to expand teaching points and young girls will be taught about menstruation in a positive light while

shedding light on abnormal symptoms to discuss and report in order to avoid delay in medical diagnosis in the future.

Future research

This study among others would benefit from continued research with individuals involved in diagnosing women with endometriosis. It would be interesting to perform a qualitative study among healthcare providers, family physicians, primary care physicians, OBGYNs and even advanced practice providers who work closely with reproductive aged women. Conducting a study where healthcare providers are interviewed in order to understand their views on menstrual concealment would unveil the other side of the equation and ultimately provide us with the tools to address this issue from a broader standpoint. Some tools that may improve timely endometriosis diagnoses may be awareness as a healthcare provider of expanding upon menstrual communication and education. Depending on the state, some women as teens do not receive adequate reproductive health teaching from health courses at school. Thus, by improving healthcare provider communicative methods with their patients they will start to break down the present stigma with reporting menstrual pain and symptoms within the doctor visit.

Conclusions

To conclude, delayed endometriosis is common among many women diagnosed with the disease. There are embedded societal norms and taboos that have survived throughout history which may be stigmatizing against women who describe painful menstruation or abnormal symptoms to their healthcare providers, family members and friends. Addressing menstrual concealment may provide women with the courage, confidence and ability to overcome succumbing to societal norms and taboos surrounding menstruation. Addressing menstrual concealment to the community will bring heightened awareness to those in positions that could

help expedite the process of an endometriosis diagnosis. Without a doubt, by improving menstruation communication the hope is that institutions will be prompted to expand research and education on the topic. This expansion among institutions will ultimately equip healthcare providers and educators with more information on the topic for themselves and their patients and students.

Appendix

1. Participant data.

Participants	General experience with menstruation symptoms and endometriosis diagnosis	Menstrual concealment awareness	Patient autonomy	Perceived control
Alexa	<ul style="list-style-type: none"> Extremely severe bleeding and cramping Described feeling that her pain was “just another cyst” There was a point where she felt the pain was so unbearable and debilitating that she requested they do something different to “figure this out.” Once diagnosed, realized that she “pushed through the pain” and wants society to be more aware of the severity of this disease 	Communication is not open about menstruation. As an adult it was easier to hide her menstrual cycle. Hopes there was more information on menstrual pain and how it can mean an underlying issue.	Persistent pain was present, but she doubted her symptoms when HCP kept diagnosing her with cysts. When pain began to interfere with work, she requested HCP(s) figure this out.	Low confidence in her prognosis when diagnosed with multiple cysts. After diagnosis gained confidence that she knew what was best for her all along and advocates to her nieces.
Beth	<ul style="list-style-type: none"> Passing heavy clots and tissue Didn’t describe cramping as an issue Infertility was turning point for her She was “convinced” she was just having 	Finds menstruation a private thing, but once began pursuing secondary menstrual symptoms noticed her symptoms and later her disease are masked or	Secondary symptoms caused self-doubt to a lesser degree. Didn’t have severe symptoms to doubt but did doubt her infertility was due to	Endometriosis was never mentioned so her she began to lose confidence in finding true reasons why she was struggling with infertility.

	<p>cysts and not ovulating</p> <ul style="list-style-type: none"> Healthcare providers suggested a hysterectomy before considering a laparoscopic surgery 	<p>minimized by HCP(s).</p>	<p>endometriosis since it was never mentioned. Once diagnosed, accepted her infertility caused symptoms and realized she had underlying symptoms all along.</p>	<p>Once diagnosed her confidence improved and she became patient in advocating through her community.</p>
Cindy	<ul style="list-style-type: none"> Cramping Didn't consider pain to be debilitating or "out of the ordinary." Infertility was one of her main reasons to pursue medical help Felt that for 10 years healthcare providers didn't find her infertility an issue. Until she decided to pursue a healthcare provider that would listen to her 	<p>After 10 years of infertility and never being educated about endometriosis she realized her HCPs didn't ask her questions that would lead to a diagnosis and she wasn't aware to mention them.</p>	<p>Experienced self-doubt about symptoms to lesser degree because of secondary symptoms.</p>	<p>During her lengthy diagnosis period she had low confidence and felt that this was her reality. Once diagnosed and pregnant she felt she had better control over her disease and prognosis.</p>
Debby	<ul style="list-style-type: none"> At first, her pain "wasn't a big deal" because family and friends always told her that it was "normal." Began feeling pain at 11 years old but only saw a 	<p>Went 8 years without seeing a HCP because family convinced her symptoms were "normal" so she dealt with the symptoms herself until she had health insurance</p>	<p>Due to dismissal through family and friends she doubted her symptoms were legitimate and convinced</p>	<p>During her teen years when she was forced to deal with her symptoms due to family beliefs that they were "normal" she</p>

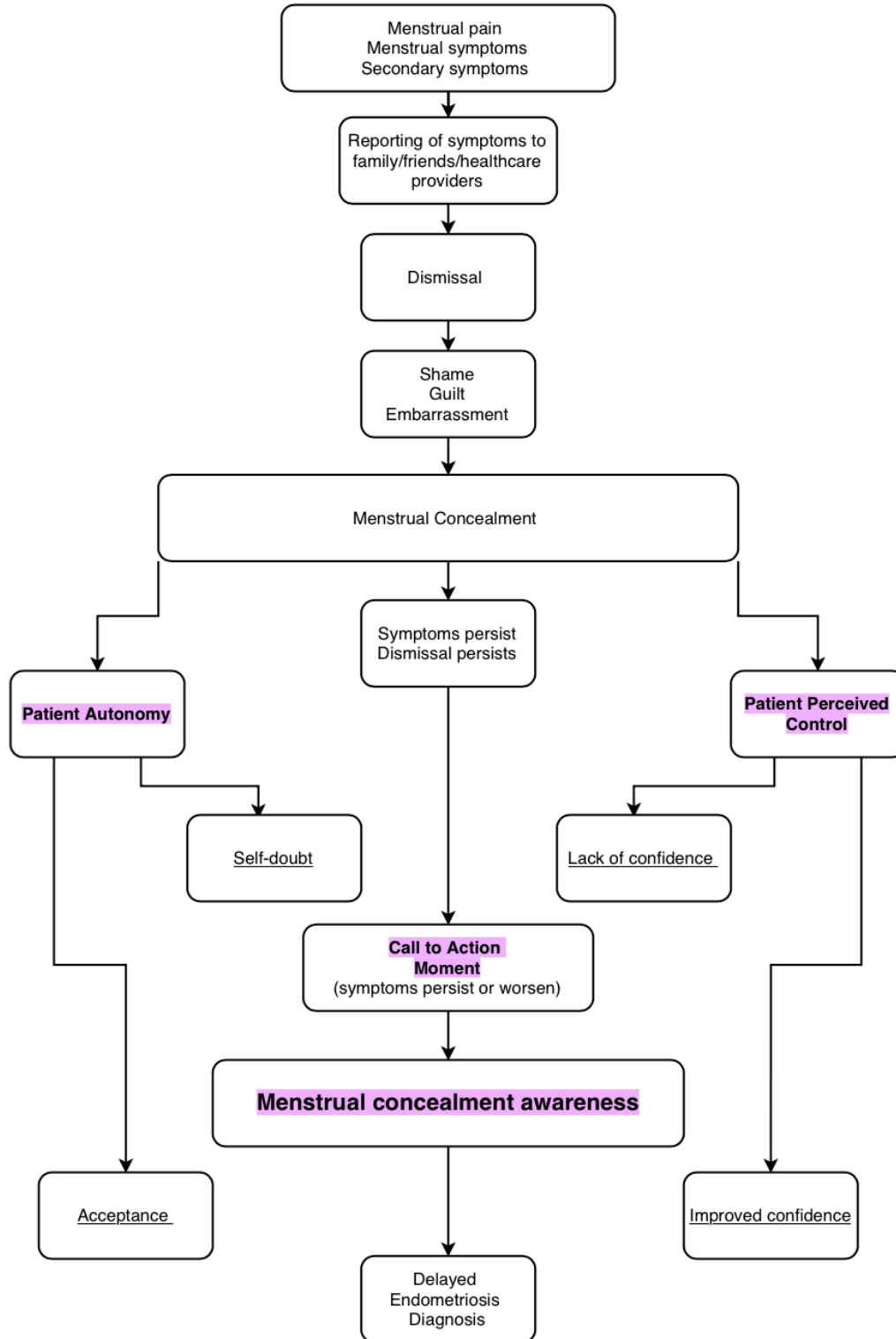
	<p>healthcare provider at age 19</p> <ul style="list-style-type: none"> • Family would say it was just how her menstrual cycle was • Pain started to affect her daily life • She had never heard of endometriosis before her diagnosis 	<p>through her university.</p>	<p>herself she could continue on with her life. Once she was old enough to see HCP on her own and her symptoms began interfering with work, she accepted they were not “normal”</p>	<p>lost confidence in the control she had over her body. She was ashamed for always being in pain. However, when she got her diagnosis, she felt empowered and confident. She began sharing with others at her university about her experience in hopes of creating conversations and breaking the stigma surrounding menstruation.</p>
Eloise	<ul style="list-style-type: none"> • “Bad cramps” • Became accustomed to having pain and would just have to remember to take two pain relievers. • She was told there was nothing “wrong” with her several times by different healthcare providers • But she began to feel that “painful periods are not 	<p>Felt that menstrual concealment was part of life, and socially didn’t care too much about concealing that she was menstruating however somehow all her endometriosis symptoms went undetected by healthcare providers as they would tell her “there’s nothing wrong with you.”</p>	<p>During the three-year period where she was dismissed for her symptoms, she doubted her symptoms were legitimate since her healthcare provider reassured her there was nothing wrong with her. It wasn’t</p>	<p>Due to symptoms and pain she stayed home from work and addresses fear of being poor and low confidence in the future. After diagnosis, she felt validated and almost identified with the disease because she had suffered with</p>

	<p>normal” and that the healthcare providers just didn’t know what was wrong with her</p> <ul style="list-style-type: none"> • After her diagnosis she was initially angry, but then started to feel that all the symptoms she had within the last 10 years were “real” and this validated what she had felt 		<p>until her friend urged her to go to the ER with her and advocated, they run more tests that Eloise began accepting her symptoms were real.</p>	<p>symptoms for 10 years and was dismissed by healthcare providers for 3 years. She was relieved that she had an answer for the years she lost due to pain.</p>
Francis	<ul style="list-style-type: none"> • “Pretty traumatic” menstrual experience • Extremely heavy and painful periods • Told that her symptoms were “part of being a woman” • Was recommended to take pain relievers. • Had done research and felt her symptoms could be due to endometriosis • After her diagnosis, she told her healthcare provider: “I told you, obviously I’m not a doctor, but every 	<p>Felt that menstrual concealment was present as a teen, in school, yet it was never really talked about. When she began experiencing symptoms, she felt that she reported all her symptoms to her healthcare providers yet was told her symptoms were “normal” and part of being a woman.</p>	<p>Even though she did research on her symptoms and came across endometriosis she doubted her symptoms since her healthcare providers insisted they were normal. The more time that passed by, the more pain she was in and the more frequent she experienced symptoms, thus leading to symptom acceptance and pursuing healthcare</p>	<p>Even though she had done her research and suspected endometriosis, she still didn’t have a diagnosis and felt power dynamics affected her confidence in suggesting endometriosis. After her diagnosis she became confident in addressing her concerns and opinions despite the power dynamic relationship with healthcare providers.</p>

	symptom looked this way.”		providers that would listen to her.	
Gale	<ul style="list-style-type: none"> • Irregular periods • Extreme pain • Had period for 21 days at one point which led her to the ER • Became accustomed to starting pain relievers sooner when she knew her period was coming • She would tell her healthcare providers that she didn't feel like her symptoms were “normal” • After diagnosis, felt validated and relieved to have an answer to her symptoms and to be told she was not “crazy” 	Reports that menstruation, reproductive and sexual health is not an openly discussed topic. Growing up and attempting to discuss menstruation with her mother was difficult because her mother would not discuss symptoms with her.	Healthcare provider interactions consisted of being prescribed birth control, since she required a referral at the time to see a specialist. For a couple of years, she doubted her symptoms were a cause for concern since healthcare providers did not seem impressed with her heavy bleeding and anemia. Severe symptoms that lasted for 21 days straight prompted her to accept her symptoms were legitimate and pursued second opinions.	Once diagnosed she was relieved to have an answer. Years of pain and suffering interfering with daily life left her feeling hopeless for potential jobs she could pursue.
Helen	<ul style="list-style-type: none"> • Heavy bleeding, cramps, bedridden, leg 	Feelings of embarrassment due to	Doubting of symptoms stemmed	After years of believing her symptoms

	<p>pain, lightheaded, vomiting and nausea.</p> <ul style="list-style-type: none"> • Always felt her period was “normal” because of what family would tell her when she reported her symptoms • When she was diagnosed, she realized her symptoms “weren’t normal” and that’s not what they were supposed to feel like • Had no idea what endometriosis was but was relieved that she was given an answer to her symptoms 	<p>menstruation and possibly showing through clothes occurred as a teen. Expectation to still show up at work despite feeling ill and unable to work. Felt that reporting symptoms and being open about menstruation was an excuse to some people at work and some healthcare providers she interacted with.</p>	<p>from mother and sister going through similar symptoms and reassuring that hers were “normal” or “regular.” As her symptoms broadened and became more severe, she asked herself “what is regular?” This prompted her to accept her symptoms were legitimate and pursue a second opinion, a healthcare provider who hadn’t also seen her mother and sister.</p>	<p>were “normal” and experiencing debilitating symptoms as a college student, her diagnosis brought her relief and hope for more control over her symptoms.</p>
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2. Participant Menstrual Concealment and Delayed Endometriosis Process of Events.



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