**A feminist analysis of endometriosis discourse: Experiences of disempowerment and dismissal, and moving towards an ethics of care for endometriosis patients**

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**Abstract**

Endometriosis is a devastating condition with significant physical and social implications. Analyzing the experiences of women and gender diverse peoples with endometriosis through semi-structured interviews and the application of a multifaceted feminist framework, the present research analyzes discourses surrounding feminized illness and pain, and how both physical and social factors contribute to the disadvantage that endometriosis patients face. The present analysis illuminates themes of the detrimental feminine, compulsory motherhood, intersections, and language of care and care for the future. Through thematic analysis, I present the urgency of moving towards an ethics of care for endometriosis patients.

**Keywords**

Endometriosis, gender, healthcare, disparities, feminist theory, Canada

**Introduction**

The egregious dismissal, disempowerment, and disbelief of women and their pain has long existed throughout patriarchal history. This act of violence is imparted upon women suffering from a variety of illnesses but is particularly detrimental for those suffering from feminized illnesses; one such disease is endometriosis. Approximately one million Canadian women and gender diverse peoples have endometriosis (Wahl et al., 2020), a devastating oestrogen-dependant inflammatory condition (Singh et al., 2020) that has long been misunderstood and underrepresented within the medical literature (Seear, 2014; Singh et al., 2020; Wahl et al., 2020). The present paper will analyze the experiences of women and gender diverse individuals diagnosed with endometriosis in Canada. In particular, this analysis focuses on the medical encounter for endometriosis care by applying a multifaceted feminist framework to analyze discourses surrounding feminized illness and pain, and how both physical and social factors contribute to the disadvantage that endometriosis patients face.

Endometriosis affects between 5-10% of the female population across the globe in their reproductive years (Lukas et al., 2018), although diagnostic delay is thought to lead to an underestimate of prevalence (Agarwal et al., 2018). Endometriosis is characterized by the existence of tissue similar to that of the endometrium found within parts of the body other than the uterus (Verchellini et al., 2013). The symptomatic burden of endometriosis is significant (Singh et al., 2020) and is often detrimental to the wellbeing of sufferers (Denny & Mann, 2007; Jones, 2016). Symptoms associated with endometriosis include intense pain and cramping both within (dysmenorrhea) and outside of the menstrual cycle; pelvic pain and pressure; dyspareunia (painful sexual intercourse); and infertility (Singh et al., 2020). Further, endometriosis carries a significant economic burden for Canadians; an annual $1.8 billion dollars is spent on care for endometriosis patients in Canada (Levy et al., 2011). It is because of disparities such as the following that I sought to conduct patient-centred endometriosis research, rooted within a focus on patient experiences of care. Thus, I seek to unveil what it means to be disadvantaged within the healthcare system, what such disadvantages produce and reproduce, and how we can move towards an ethics of care (Tronto, 1993) for endometriosis patients.

Embarking on the present research, I sought to foster conversations with endometriosis patients to discuss their experiences within the medical encounter. Through speaking to each participant, I was able to engage in in-depth conversations in a way that unveiled the nuanced experiences that characterize their navigations of the Canadian healthcare institute. In the analysis that follows, I have engaged in an analysis of participant experience through the presentation of four primary themes unveiled by the voices of the research participants.

Further, as I approach this research grounded within a feminist framework of analysis, I find it pertinent to note my personal experience with endometriosis. As a researcher, my positionality is shaped through my own experience of being diagnosed with endometriosis. Engaging in a reflexive analysis, I was able to recognize my internal influence on my analysis, while also valuing my own lived experience as a means of imparting understanding and empathy towards the research participants.

**Literature review**

Endometriosis has been recognized by scholars and medical practitioners as an enigmatic disease (Seear, 2014). This enigma, which I will return to throughout the present research, is multifaceted and can be theorized in various ways; endometriosis is enigmatic to the naked eye as we cannot see endometrial adhesions on the outside of the body. We cannot see the physical toll that endometriosis reproduces within the body on the outside. We also do not see a wealth of qualitative endometriosis scholarship (Pettersson & Berterö, 2020). Endometriosis discourse is shaped by the aforementioned spheres of invisibility, and there is so much that we cannot and do not see, both physically and epistemologically. Further still, the existing discourse surrounding endometriosis has been identified by sociologists and feminist scholars as being harmful to those who live with the condition (Cole et al., 2021, Jones, 2015; Lukas et al., 2018, Markovic et al., 2008; Young et al., 2020).

Qualitative endometriosis discourse supports the theory that feminine emotionality stereotypes have perpetuated a reality in which women struggle to receive adequate healthcare for chronic pain conditions (Hamberg, 2008; Lloyd et al., 2020; Manne, 2020). Here, it is important to understand the implications of hysteria discourse for women seeking healthcare. Jones (2015) identifies that endometriosis is not merely a physical condition, and that it encompasses both social and physical consequences. Jones positions the social consequences of endometriosis diagnosis as being entrenched within hysteria discourse and the construction of the female body as a means of reproduction. This hysteria discourse remains a prominent attribute of endometriosis care (Jones, 2015; Jones, 2016; Young et al., 2020).

Further, the medical community has long recognized that the delay between the onset of symptoms and diagnosis of endometriosis is widespread, with an average diagnostic delay of 11.7 years in the United States (Lukas et al., 2018). This diagnostic delay is often characterized by practitioners’ dismissal of patients’ symptoms (Markovic et al., 2008). Further, literature supporting the dismissal of female pain has identified that emotionality stereotypes pose detriment to the provision of equitable care (Jones, 2015; Lloyd et al., 2020). Examining chronic pain and gender stereotypes on emotionality, Lloyd et al. (2020) have pointed to emotionality stereotypes as being 2 to 4 times more detrimental to the provision of healthcare than any other gendered stereotypical beliefs. Feminine emotionality stereotypes suggest that women “dramatize, overemphasize, or even fabricate their experiences of pain” (Lloyd et al., 2020, p. 198). The consequence of such emotionality stereotypes is two-fold: women are thought to lie, and women are thought to be incapable of telling the truth. While to lie and to be incapable of truth telling both result in the disbelief of women, they have separate consequences. When women are framed as liars, they are thought to be inherently manipulative and attention seeking. Moreover, when women are stereotyped as incapable of understanding the reality of their experience, they are thought to be hysterical. Denying the truth of women’s experiences poses dire physical and social consequences for endometriosis patients; how is one to be believed and how is a disease to be understood when its sufferers are thought to be inherently deceptive, or chronically incompetent?

Research on the psychosocial implications of endometriosis theorizes that it is gender stereotypes that influence the lack of information surrounding endometriosis (Pettersson & Berterö 2020; Seear, 2014). Seear (2014) calls attention to the *enigma* of endometriosis throughout her book, *The Makings of a Modern Epidemic: Endometriosis, Gender and Politics*. Describing the uncertainty surrounding endometriosis in the medical discourse, Seear suggests that the enigmatic nature of endometriosis is productive of the notion of women and the feminine as being inherently perplexing. Seear posits that the notion of the feminine as elusive produces and reproduces men and masculinity as inherent holders of truth and knowledge. The interaction between the feminine as enigma and the masculine as truth work mutually to produce uncertainty surrounding endometriosis not as an inherent fault of the medical discourse alone, but rather as Seear suggests, “an artefact of the feminine” (p. 65). Seear’s discourse of endometriosis as an *artefact of the feminine* is supportive of the notion of endometriosis as a condition silenced (Hudson, 2021).

To investigate how misunderstanding and lack of information as it has been evidenced in the literature shapes the medical encounter for endometriosis, Lukas et al. (2018) surveyed 500 participants in a retrospective cohort study investigating their satisfaction with medical support for endometriosis. Through their questionnaire responses, Lukas et al. (2018) demonstrate a fundamental lack in patient satisfaction with medical support for endometriosis patients. The study findings unveil that most participants lacked information about the disease and available treatment options (Lukas et al., 2018). Applying a proactive approach, Lukas et al. asked the study participants how their experience within the medical encounter might be improved. Of note, participants provided suggestions for the improvement of endometriosis education and information dissemination, the implementation of multifaceted treatment approaches, and for their pain to be taken seriously.

Further, the consequences of the lack of information surrounding endometriosis within the medical discourse extend outside of the interpersonal interactions of patient and provider; the psychological consequences of dismissal have been well documented throughout the literature. Young et al. (2020) utilized qualitative interviews to investigate how women with endometriosis navigate knowledge and power within the medical encounter. Themes raised by participants in the study included doctors’ displaying a lack of expertise, the need for self-advocacy to avoid gender stereotypes such as hysteria discourse, and pain and symptom dismissal. Thus, Young et al. (2020) concluded that medical education needs to consider patient knowledge to assist in the elimination of gender bias within endometriosis care provision.

The aforementioned challenges of emotionality stereotypes, hysteria discourse, and lack of patient satisfaction pose dire consequences for the endometriotic subject. Bullo (2018) examined the consequences of disempowerment and endometriosis in a comprehensive multi-faceted research study. Bullo used a corpus of online data analysis and in-depth interviews to address: 1) What discourses of disempowerment are identified by women with endometriosis, 2) how do women present themselves as either empowered or disempowered in light of such discourses, and 3) how can understanding the discourses utilized by women with endometriosis advance medical practices and diagnostic delay of endometriosis? This research began with an analysis of online endometriosis self-help forums which were cross-referenced with medical and sociological scholarly articles on endometriosis. Bullo (2018) identified three themes of disempowerment experienced by participants: disempowerment caused by endometriosis, such as failing to perform gender roles; disempowerment caused by pain normalization and misdiagnosis; and the need to demonstrate self-advocacy to receive care. The shortcomings in medical care experienced by endometriosis patients illustrated by previous research underlines the urgency of the proposed research as patients routinely experience neglect and unnecessary pain.

**Methodology**

The present research was guided by a broad feminist theoretical framework. Rather than a particular feminist framework, conducting analysis through a broad feminist framework speaks to the multiplicities of living with endometriosis. Informed by both critical and social constructionist epistemology as theorized within a feminist framework, more broadly, the present methodology is informed by the nuances and multiplicities of the participant experience. Guidance for the theoretical framework was implemented in accordance with Franks (2002) theorization of the feminist social research framework. Franks (2002) posits that it is not conducive to form a stringently defined feminist social research methodology, rather, she suggests the implementation of a cross-ideological feminist research standpoint in which researcher reflexivity can be best practiced. As noted by Seear (2008), researcher positionality is a critical attribute of feminist social research. Thus, reflexivity was an integral part of the research process spanning from interview conduction to data analysis. Importantly, my positionality as a woman diagnosed with endometriosis was made known to the research participants. The purpose of this disclosure is to uphold the importance of establishing positionality and practicing reflexivity (Seear, 2008).

*Ethics*

The present research was approved with no required revisions by the Thompson Rivers University Human Ethics Review Board and was further endorsed by the Ethical Advisory Committee of The Endometriosis Network Canada (TENC). I submitted a request to revise the recruitment methodology to the Research Ethics Board to include dissemination of invitations to online support groups to facilitate timelier recruitment, this request was approved and required no further revision to be implemented.

*Participants and recruitment*

The invitation to participate in research was disseminated by The Endometriosis Network Canada, a not-for-profit organization engaged in facilitating support for endometriosis patients and spreading awareness of endometriosis drawn from top medical experts internationally (The Endometriosis Network Canada, 2022). The invitation was also disseminated by The World Endometriosis Research Foundation (WERF), a global not-for-profit supporting the conduction of international endometriosis research (World Endometriosis Society, 2022). Lastly, I disseminated the call to participate through various online endometriosis support groups. A trilateral stream of recruitment allowed for the completion of the research within the time constraints of undergraduate research and the supportive funding. The recruitment materials disseminated included an infographic containing details about the research, as well as the document containing the invitation to participate in research. The infographic explained the criteria to participate in research, inviting Canadian citizens nineteen years of age or older surgically diagnosed with endometriosis to participate in an online semi-structured interview to discuss their endometriosis experience. Participants were provided with a $20 gift card in appreciation for their time and participation.

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| **Pseudonym** | **Ethnicity/ Ethnicities** | **Sexuality** | **Age** | **Province/ Territory** | **Diagnostic Delay [[1]](#footnote-1)** |
| Jaime (she/they) | White | Bisexual | 23 | British Columbia | 2 years |
| Nita (she/her) | Indigenous, White | Heterosexual | 28 | British Columbia | 8 years |
| Meg (she/her) | White | Heterosexual | 37 | British Columbia | 5 years |
| Eliza (she/her) | White | Heterosexual | 44 | Alberta | 1 year |
| Amy (she/her) | White | Heterosexual | 33 | Quebec | 18 years |
| Beth (she/her) | White | Heterosexual | 22 | Ontario | 8 years |
| Amia (she/her) | White | Heterosexual | 38 | Saskatchewan | 2 years |
| Quinn (he/him) | White | Bisexual | 35 | British Columbia | 4 years |
| Jude (she/her) | White | Heterosexual | 47 | Alberta | 6 years |

Through the three recruitment streams, nine women and gender-diverse individuals self-reporting to have received a surgical endometriosis diagnosis volunteered to participate in the semi-structured interview. Of the nine participants, eight (89%) identified their ethnicity as being

*Participant characteristics: Figure 1*

white, and one (11%) as Indigenous and white. Further, seven (78%) identified their sexuality as heterosexual, and two (22%) as bisexual. As there are significant disparities of inclusion between Black, Indigenous, people of colour (BIPOC) and gender diverse endometriosis sufferers, the recruitment methodology involved the specific invitation of BIPOC and gender diverse individuals for participation. Respectively, the present research garnered the participation of three (33%) individuals living with endometriosis as well as a minority status (2SLGBTQIA+ and or BIPOC). The ages of the participants were between 22 and 47 years old, with a mean of 34 years of age.

­­­­­*Data collection*

Data for the present study was collected through online semi-structured qualitative interviews. Participants were sent the interview questions with the informed consent form. The length of the interviews was between 26 and 48 minutes, with average interview length being 39 minutes. Data was manually transcribed through online transcriptional services in a streamlined manner. Utterances were not included in the transcriptional analysis. However, significant pauses and silences are noted as they occur throughout the interviews. Following transcription of the interviews, data was imported to AtlasTI Qualitative Data Analysis Software and was coded and thematically analyzed in accordance with a broad feminist framework, guided by the perspectives of social constructionist and critical theory frameworks. Four prominent themes were identified through thematic analysis: *The detrimental feminine,* with subthemes *disempowerment and dismissal;* *compulsory motherhood; intersections,* with subthemes *intersecting autism,* and *intersecting gender;* and *the language of care and care for the future,* with subthemes *language of emotion* and *care for the future.*

**Analysis**

*Theme 1: The detrimental feminine*

The first overarching theme presented throughout the research was a phenomenon that I have identified as the detrimental feminine. The detrimental feminine refers to a catalyst of the disparities that women and gender diverse endometriosis patients experience within the Canadian healthcare system pertaining to endometriosis diagnosis and treatment. Characterized by both implicit and explicit sexism, the identity of the feminine is experienced as detrimental to the credibility and reliability of women’s knowing (Manne, 2020). Thus, the following theme presents disparities associated with disempowerment and discredit, which coalesce to reproduce hysteria discourse. As it has been regarded within feminist research and literature, hysteria is deeply entrenched within medical sexism. The word hysteria, meaning uterus in ancient Greek, has been regarded as one of the most misogynist words used in the English language (Hossain, 2021). Stemming from the word uterus, hysteria implies that the feminine is inherently flawed.

Inspired in part by Gilman’s seminal (1891) essay, *The Yellow Wallpaper,* the proceeding theme presents the hysteria discourse that flows within endometriosis discourse, which I propose to be due to its feminized pathology. Gilman’s critical piece, *The Yellow Wallpaper,* presents feminized hysteria discourse as it is experienced by a woman, wife to a physician. Gilman tells the story of an unwell patient and a practitioner who does not believe her to be unwell at all. Although Gilman’s focus is on women’s experiences of mental illnesses and the delegitimization of women’s knowing, I propose that *The Yellow Wallpaper* is a poignant piece which can be applied to analysis of physical illnesses and their social consequences. Trapped both mentally and physically, Gilman’s account of mental illness is a timely piece which can be applied to the hysteria discourse experienced by endometriosis patients: “If a physician of high standing […] assures friends and relatives that there is really nothing the matter with one but a temporary nervous depression—a slight hysterical tendency—what is one to do?” (Gilman, 1891, p. 1). In the medical arena, the physician’s word is most authoritative, whether it is to diagnose an illness or deny one. For Gilman, the denial of illness, or likening its existence to “hysterical tendencies”, is akin to denial as she is left alone to her pain and her bodily reality.

To examine the concept of the detrimental feminine, the theme has been divided into sub-themes each with a facet interacting with the healthcare encounter and hegemonic femininity discourse. Disempowerment and dismissal interact under the purview of the detrimental feminine to contribute to the disparities and barriers that those with endometriosis face within the healthcare encounter. For analytic purposes, I find it important to distinguish how disempowerment and dismissal interact separately to reproduce hysteria discourse. As I will refer to the concepts thought the present analysis, disempowerment can be thought of as product of dismissal. When endometriosis patients are dismissed, as the forthcoming analysis will present, this results in feelings of disempowerment and loss of trust in the practitioners who are meant to care for them.

*Dismissal*

Each participant of the present research has experienced dismissal within the medical encounter, and this phenomenon has been well documented within the literature (Jones, 2015; Jones, 2016; Markovic et al., 2008; Young et al., 2020). Dismissal varies between patient experiences and is contended with by patients in a variety of differing forms. The present sub-theme focuses particularly on the participant’s experiences of pain normalization, pain dismissal, and the consequences that they yield. Beginning with a sentiment shared by all the research participants, Meg made the succinct remark: “I think women are not taken as seriously by doctors.” Decades of analysis and feminist discourse posit the same sentiment; women are not taken seriously for their pain (Cole et al., 2021; Jones, 2015; Jones, 2016; Seear, 2009b; Young et al., 2020). It is pertinent to note that each one of the research participants spoke of plentiful examples of pain normalization and dismissal, experiences that could span the length of this report in its entirety. Through the experiences of the research participants, I have sought to identify the consequences of dismissal, and how dismissal mutually reproduces the enigmatic nature of endometriosis (Seear, 2014).

Contending with pain dismissal, Eliza described a conversation that took place between her and her surgeon following one of her excision surgeries. She informed the surgeon that she was still in pain, to which he told her:

*"Well, you know, you could have cancer, it could be worse, I did the best I could, you're just gonna have to live with it for the rest of your life."*

To this, Eliza remarked: *which was awful, but I accepted that because what else can you do?*

Eliza sheds light upon the dismissal and comparison that endometriosis patients face. The comparison of endometriosis and cancer as noted by Eliza’s surgeon suggests that the lack of terminal illness associated with endometriosis negates the need for further care. Here, the focus becomes survival, rather than an improved quality of life.

Moreover, many of the present research participants noted that they were dismissed based upon a normalization of menstrual pain. As endometriosis is associated with but not limited to dysmenorrhea, there is a significant amount of dismissal based upon what it means to have “normal” menstrual pain, something that is misunderstood within medical literature. The research participants of the present study described the concerns that they expressed to their healthcare providers regarding menstrual pain which were met with pain normalization and dismissal.

Amy: *I will receive comments like, “Oh, maybe you're a bit too sensitive.”*

Beth: *“All women have bad periods.” Or “you’re just really anxious or stressed.”*

Jude: *“All girls have bad periods.”*

Further, a notable account of pain normalization occurred for Beth when she warned her care provider that she experienced extreme pain during internal pelvic exams due to her endometriosis and was not comfortable, to which her physician proclaimed that she would be fine, and immediately inserted the speculum despite Beth’s protest. Here, the visceral reality of pain dismissal is presented yet again. Dismissal can and does result in the violation of one’s bodily autonomy, injury, and contributes to the excusal of medical malpractice. Similar to Beth’s experience, Amia noted that the pain that she experienced during pelvic examination was dismissed and psychologized. Amia recalled that her care provider suggested that she experienced pain during the examination simply because she saw the speculum device and thus thought that it would be painful. The psychologizing of pain, as experienced by Beth and Amia, is representative of the invisibility of endometriosis and the denouncement of the pain that we cannot see as being psychological rather than physiological.

As presented within the introduction of the present theme, Gilman (1891) posed a question that continues to perplex endometriosis patients and feminist scholars still, 131 years later, when one is routinely dismissed and discredited, “… what is one to do?” (p. 1).

*Disempowerment*

Conducting research on chronic pelvic pain (CPP) including endometriosis, Hawkey et al. (2022) identified that the normalization of female pain contributes not only to women’s dismissal within the medical encounter, but also to patients self-silencing about the existence of their pain. It is this disempowerment, a consequence of dismissal, that renders endometriosis patients and their pain invisible. Disempowerment featured prominently throughout the participant interviews; what does it mean to feel disempowered? For many endometriosis patients, and for those of the present research, disempowerment is a loss of advocacy, a loss of agency, a loss of bodily autonomy, a loss of personhood.

Each of the participants experienced disempowerment through a denial of knowing and loss of bodily autonomy. For Nita, disempowerment occurred when she was denied the provision of a hysterectomy for the management of her endometriosis pain. Nita told me that she had always known that she did not want to carry her own children, and that she was adamant about this with her surgeon and the surgical fellow. However, Nita was required to attend a counselling program and to write a letter as to why she felt that she wanted, or needed, to have a hysterectomy preformed. Nita recalls how she felt when she couldn’t simply be believed and have her surgery performed:

*I'm coming to you in tears with pages and pages of medical history and saying like, "I need this for my health. I will not be around long enough to have children— if that's what you think I should be doing— if you don't remove this organ."*

In this moment, Nita recognizes the loss of bodily autonomy that she is experiencing through the denial of her knowing. Further still, Nita stated that she had been seeing her own counsellor, an Indigenous counsellor with whom she felt most comfortable but was still not able to receive the kind of counselling that would satisfy her doctor’s requirements before a hysterectomy preformed. However, seeing her own counsellor could have been a part of culturally appropriate care provision should Nita have wanted counselling. Nita spoke of the loneliness associated with navigating the healthcare encounter while feeling disempowered. In some of her concluding words of our interview, Nita said to me:

*[T]here's only one instance in the world that makes me think I want a partner, and that's when I'm lying flat on my back in some medical office, because it's just really scary to do that alone.*

The disempowerment that presents itself when women’s knowing is dismissed is a visceral, emotional experience, one that can be lonely and isolating. In closing, Eliza remarked:

*I just wanted things to be better and not to be in pain. And it takes a lot to go in and speak to a provider and be really honest about your symptoms, and just... Yeah, it's just awful, yeah. It's been a traumatic difficult journey*.

*Theme 2: Compulsory motherhood*

The second theme, compulsory motherhood, featured prominently throughout each of the participant experiences. Although it was presented in various ways, almost all the participants spoke with candor when they proclaimed that they do not exist solely to become a mother, which is in opposition to the discourse many experienced pertaining to their endometriosis care. The present research identifies motherhood as a complex and multifaceted identity. For the endometriosis patients in this study, motherhood is a compulsory constant; motherhood is assumed, expected, and medically prescribed.

During the period of second-wave feminism, Firestone (1970) proclaimed that, “women, biologically distinguished from men, are culturally distinguished from ‘human’” (p. 1). For Firestone, reproduction is the primary mechanism through which women are oppressed. While Firestone presents a compelling argument for the consequences of reproduction and its oppression of women, I challenge that it is not only motherhood or the bearing of children that oppress women, but specifically the concept of compulsory motherhood that is deeply intrenched within patriarchal society. Within a patriarchy that sees some bodies as only a means of reproduction, is often deemed unfathomable for a woman to not desire to become a mother. Moreover, the pressure of compulsory motherhood is also felt by women who desire children, although it is presented differently, the compulsion remains. Those who desire children are demanded that they have them immediately, before it is too late. Here, motherhood becomes a prescription.

The effect of motherhood as described by participants varied in two distinct ways, yet an overlapping constant remained the same: motherhood was expected. Both for participants who anticipated having children, for those expressing ambivalence, and to those steadfast in abstaining from motherhood, the discourse that those who bear a uterus shall bear children remained prominent. In many instances, motherhood was championed over the personhood of participants.

*Experiences of those who want children*

For many of the participants desiring children, motherhood was compulsory by being medically prescribed. Suggesting pregnancy as a treatment for the symptoms of endometriosis has been questioned by scholars (Jones, 2015). This “prescription” was troubling for my participants who desired children, as it instills hope that they would easily be able to become pregnant, and that pregnancy was urgent. Amy describes her physician’s suggestions for pain management after it felt as though she has exhausted all treatment options:

*"Laparoscopy is the way for us to go, you need surgery, we need to remove the tissues. You'll be fine after that. Or you need to get pregnant."*

*So, it was like one or the other and you shouldn't be in pain anymore or very lower pain. So, she never really addressed, or she dismissed very quickly what happened after the surgery.*

*It was like, "this is a solution, that's it."*

For Amy, the two options presented before her are difficult to contend with. She described feeling hopeful at the idea of becoming pregnant and having her pain subside following laparoscopy. However, this was not the case. Amy continues to experience debilitating pain and a miscarriage.

Motherhood as a prescribed endometriosis treatment was experienced for many of the participants, even for some at a very young age. Despite desiring children, the urgency of becoming pregnant was polarizing for Jude and Beth, who recounted the advice of their practitioners given to them at the ages of 19 and 21 years old.

Jude: *So, when I had my first laparoscopy, when they give it, they gave me a definitive diagnosis, the male gynecologist’s solution was to for me to go get pregnant at 19 years old.*

Beth: *She’s* [physician] *like, “Well, so what are you thinking for kids?” And I said, “Well, I would really like to have kids someday.” And she said, “Well, as a woman with endometriosis it’s gonna be harder for you.” And that was the first time anyone had ever addressed me honestly about that, and it was kinda hard to hear* […] *I told her, “I’m going back to school, I just finished my undergrad”, and she said, “If I were to give you advice, have kids instead of going back to school.” And I was kind of shocked to hear that because we’re taught a completely different thing growing up, right? And yeah, so she told me, “Babies aren’t that expensive anyway, maybe go ahead and have kids and then go back to school. I’m not gonna follow that advice, I don’t think.*

Prescribing pregnancy for endometriosis pain relief in young patients speaks to compulsory motherhood, as this “treatment” suggests temporary pain relief, but the birth of a child immediately follows, a permanent consequence. Despite Jude and Beth desiring motherhood in the future, the immediate prescription of motherhood denies the bodily autonomy and personhood of the patient.

*Experiences of those who do not want children*

Eliza spoke to me about her experience of self-advocacy in having a hysterectomy performed when her healthcare provider was very apprehensive about conducting the surgery. When asked about the experience of being a woman who did not what children and seeking a hysterectomy, Eliza reflected:

*I tried all the other treatments, and they were like, “Well, maybe your husband will want to have children, so we should just wait and see until you’re married.” And then once I was married, they said, “Oh well, you don’t really know yet.” And I said, “No, I know. I never wanted children; I want my uterus out.” And they were like, “No, no, you don’t really know, let’s give it time.” … [T]hey think, you’re gonna change your mind.*

*I think it was that they were more worried that I would regret the decision… that everybody should want to be a mother, that it was somehow incomprehensible to them that I would know my own mind and that I would want to choose that.*

Eliza presents a startling analysis that women know all too well; to deny the bearing of children is to deny one’s life itself. While it is the perspective of Eliza’s surgeon that it is incomprehensible that she did not desire motherhood, the disbelief of her surgeon is grounded in a broader discourse of a refusal of women’s knowing, or, as Eliza reflects, *that she would know her own mind.* This refusal of knowing followed Eliza throughout her experience of endometriosis care as well as the refusal of such care. Eliza recalled that she had repeatedly asked to have a hysterectomy preformed before she was reluctantly given the procedure, something that she requested for six consecutive years.

Further, this is an experience that was not unique to Eliza alone. The conflict of women who know that they do not desire to have children is omnipresent within the healthcare encounter. As Nita describes:

*I believe as someone who had, or previously had a uterus, I didn’t exist purely to give birth to children. … I had known I didn’t want to carry my own children since I was a teenager, but I had to explain this to multiple GPs, multiple OBGYNs. I had to explain it to my surgeon and her fellow.*

Rather than simply establishing an understanding of their desire to be child-free with their practitioner, the patient feels inclined to, and in many instances that it is necessary to, defend their desire to remain without children.

Moreover, motherhood is also prescribed for those that do not desire children. Eliza recounts her physician’s advice to her before she was able to obtain a hysterectomy and her contention:

*She suggested that instead of doing surgery that I should get pregnant because all my symptoms would go away for nine months. “Yes, but then I’ll be left with the baby, and I’ll be worse off than I was before.” And she said, “Well, that’s my only suggestion to you.” So, it was really awful, I had some really negative experiences definitely.*

As exemplified by Eliza, Amy, Jude, Meg, and Nita, compulsory motherhood operates in various ways to influence healthcare for endometriosis. As the participants all experienced different facets of compulsory motherhood, some also faced experiences of miscarriage. While miscarriage is not associated with all accounts of endometriosis, I believe that it is an important facet of compulsory motherhood to consider. As exemplified by the accounts of participants, physicians are adamant that their patients engage in motherhood, yet this urgency is not always replicated when the possibility of motherhood is lost. Contending with the subject of endometriosis and miscarriage, as experienced by both Amy and Jude, Jude tells the story of one of the eight miscarriages she experienced:

*I had one miscarriage at Christmas. And on Christmas day, I was hemorrhaging … And they didn't wanna call the gynecologist in on Christmas day, even though he was on call. I was sat on an ER stretcher for a full 24 hours; they would not put me into a bed. … They told me that the bed was for someone else…* *I asked if the doctor could speak to my husband to tell him what actually happened and what they found. And the nurse said, "No, you have to get up and walk to the phone." I'm on an ER stretcher, they could have just wheeled me over. So my dad and my husband carried me over to the phone, and I asked the doctor, "Can you talk to my husband?" He goes, "Of course I can. What are you doing out of bed?" And I said, "Well, they never gave me a bed." I was still on a stretcher. My hemoglobin had dropped so low that I should have had a blood transfusion, but they never gave me one. And they were going to send me home, and when I stood up to go to the bathroom, I left a blood trail.* … *Until my husband put his foot down and said, "No, she's not going anywhere." And then they listened.*

Endometriosis patients contend with motherhood through so many facets of their healthcare experiences and their lives. Compulsory motherhood is a significant force that shapes the experiences of many endometriosis patients; through both a desire for, and abstinence from childbearing, the prospect of motherhood is inextricably linked to personhood and for some, a loss of bodily autonomy entirely.

*Theme 3: Intersections*

Drawing from Kimberle W. Crenshaw’s poignant (1989) essay in which she identifies the concept of intersectionality, the following section identifies the avenues at which the identity of the endometriosis patient interweaves with the oppressions of being a gender, or neurocognitive minority. Further expanding upon the concept of intersectionality, Crenshaw’s (1991) concept of structural intersectionality is particularly applicable to the forthcoming analysis. Crenshaw posits structural intersectionality as the convergence of race, gender, and class domination at structural and institutional levels. Structural intersectionality is pertinent to my analysis as it is the imposition of visceral structures of inequality that both inhibit the reception of care and additionally impede the quality of care that minority endometriosis patients receive when they can access it.

Crenshaw identified the concept of intersectionality in analysis of racial and gendered oppressions and their intersections, her theorization of this intersection is well regarded as a cornerstone of critical race theory and black feminist theorems. Moreover, Crenshaw’s notion of intersectionality has been widely applied across disciplines and context. For the purposes of the present research, discussing the intersections of the feminine abject and the healthcare encounter allows for a nuanced analysis of participant experiences, which is integral to an in-depth qualitative analysis.

Each participant described instances in which their feminine identity interacted within the healthcare encounter. For some, this was the identity of being a women diagnosed with endometriosis, and much of this discourse has been noted within the preceding thematic analysis. While being a woman with a chronic illness is met with immeasurable inequality, many participants identified the ways in which other intersecting identities contributed to multifaceted challenges within the healthcare encounter. For analytic purposes, the proceeding section will analyze two participant experiences and will be divided into subthemes that include *intersecting autism, and intersecting gender.*

*Intersecting autism: Amia*

Amia, a participant diagnosed with both endometriosis and Autism Spectrum Disorder described that having been diagnosed with Autism [[2]](#footnote-2) presents unique challenges within the healthcare encounter. Amia noted that she often felt that her healthcare providers discuss her gender identity with her, but that her identity as an Autistic woman was often left out of the narrative.

Amia recalled her previous visit with her healthcare provider in which she was questioned as to what her *plans* werefor childbearing. Conscious of the word *plans,* Amia describes her struggle with the language surrounding having a *plan* for having children,

*I was like, "I didn't know I was supposed to come in here with a plan. Was I supposed to have a pregnancy plan right now?”*

Here, Amia contends with the realities of having Autism and navigating language use, now reflecting on the fact that she was completely unsure of what her care provider meant by *plans*. Additionally, she was forced to contend with the disbelief surrounding the pain she was experiencing when she was asked such a question; having been told that childbearing was not possible for her, a woman with endometriosis, she struggled to understand how one could possibly have such a *plan* in place.

*And I was having a panic attack about that the last time around because I just hadn't been able to dream about that for years. So normally when people say, "do you think about getting pregnant?" they're like excited for you, but … I feel like at least lately with the endometriosis thing, I feel like it's a battle plan.*

Amia has presented a barrier of language, associated with Autism, as well as a barrier of the definitive discourse often relayed to endometriosis patients in which they are told that having children is not possible. Rooted within a lack of information surrounding endometriosis, this discourse is problematic when there is no consensus between physicians. When a patient is told by one practitioner that they will never bear children, then is told that they can conceive by another, the ambiguity is significant and overwhelming for the patient. This significance is amplified when there are communication barriers in place, and for Amia, Autism is one such barrier.

*Intersecting gender: Quinn*

Quinn, a transgender participant, contended with endometriosis as a cisgender woman and now as a transgender man. Quinn struggled with chronic endometriosis pain and was prescribed Robaxacet, a muscle relaxant. After taking Robaxacet for several years as the only way to manage his pain, Quinn began to develop a heart murmur as a result of consistent use of the medication. Despite his efforts, Quinn was not able to convince practitioners that he required more permanent pain management. Through transitioning and unveiling his transgender identity to his healthcare providers, Quinn garnered unique insight into the discourse surrounding femininity and health care provision. Describing the first encounter with his medical provider after disclosing his transgender identity, Quinn recalls the conversation with his physician:

*“Oh, you're trans, well, here's a new muscle relaxant so you don't have to take Robaxacet* [anymore] *and we'll get you started on a hysterectomy.” I'm like… “That easy, it was that easy.” And I know that they don't take women seriously, but... I had no idea it was that bad.*

In contrast, unveiling his experience as a cisgender woman, Quinn described contending with dismissal of pain:

*At that time, they thought I was a cis female, and they generally dismissed my pain complaints or suggested I take up journaling or meditation. I was in the ER every year for some form of intense pain, often doctors would be like, “Oh, that sounds like you had a cyst burst, well, the worst is over now”, and they would do nothing for pain management.*

It must be noted that transgender people experience significant stigmatization and disparity within the healthcare system. [[3]](#footnote-3) However, despite the precarious nature of Quinn’s status as a transgender man, he found that his pain was legitimized, and the care that he received was more equitable than when he identified as a cisgender woman. After many years of being described as simply being anxious, Quinn was beginning to have his pain taken seriously, something that he had not experienced prior to his disclosure of being trans. However, Quinn was not able to continue receiving this newfound quality of care, as hormonal therapies and birth control are commonly used for the management of endometriosis pain, and his care providers were unable to provide him with necessary gender-affirming care and pain management.

It is pertinent to note that the purpose of the above analysis is not to problematize the use of hormonal therapies or birth control for the management of endometriosis and chronic pain associated with endometriosis. Such therapies are important and, when prescribed alongside laparoscopic excision, have proven to be necessary and vital to the improvement of quality of life for endometriosis patients.[[4]](#footnote-4) Rather, the purpose of presenting Quinn’s difficulty in obtaining endometriosis pain management is in service of the importance of multifaceted care for endometriosis treatment. Many research participants spoke of the importance of an implementation of a multifaceted treatment approach, including laparoscopic excision, hysterectomy, hormonal therapies, birth control, pelvic floor physiotherapy, central sensitization therapies, and alternative therapies.[[5]](#footnote-5)

*Theme 4: The language of care and care for the future*

Each of the participants in the present research were asked to describe words that they associate with their healthcare encounters. It is important to note that all participants experienced a negative encounter with a healthcare provider at one point in their endometriosis care. Some have navigated the healthcare system and have found caring and compassionate care, while others are still seeking to receive empathy and understanding*.* I want to shed light on the emotional impact of being supported within the healthcare system, as well as the detriment of being unsupported, which will be presented in *the language of emotion*. Further, the shortcomings of the healthcare system for endometriosis patients have sparked calls to action that the participants have addressed in the proceeding responses to the prompt: *What, if any, suggestions would you make to improve your experience within the healthcare system pertaining to your endometriosis care*, which will be presented within the subsection *care for the future.*

*The language of emotion*

Emotion is a significant aspect of endometriosis care and was expressed by all the participants. The proceeding words are a collection of emotion words expressed by participants when asked how they would describe how they felt proceeding and during their interactions with their care providers. Many of such words were mentioned by more than one participant, and there was significant overlap between participants and emotion words associated with this prompt.

The experiences of some of the participants were marked by positive emotions. *Understood, kind, listens,* and *caring* were used to describe the participants emotions when under the care of empathic physicians. The positive emotions associated with the provision of equitable and empathetic care exemplify the value of such care. Above all, most frequently noted by participants was the significance of a practitioner who listens. The participants who noted that their care provider listened to them spoke highly of their experiences with that care provider. As noted by Amia, *the most important thing that a gynecologist can do is listen.*

Alternatively, many of the participants’ experiences were characterized by negative emotions. *Blunt, terse, calculated, frustrating, embarrassing, difficult, cold, apprehensive, uncompassionate, defensive, drained, disappointing, dismissed, gaslit, unhelpful, unsupportive,* and *exhausting* were all emotions associated with participants healthcare encounters. Quinn solemnly describes the impact of the pain that his endometriosis causes him:

*At this point, I cannot mince words when it comes to the impact financially or socially of the pain I have… I have to be very blunt and say, “I have days where I cannot get out of bed. I have days where I'm walking home and I have the urge to just lay down and die somewhere”, people don't understand that sort of pain sometimes, unless you put it really bluntly.*

*One experience that comes to mind is just how it felt when I realized that a lot of people who I was talking to who were much worse off than I with their endometriosis were considering medically assisted suicide… the emotional impact of that. Not only do I suffer, but that so many others are suffering more and having so many barriers to their care, in a way it's a secondary emotional impact.* … *It's something that I don't think is going to be easy to talk about in the medical system, but it's like the casualties… the unexpected casualties of trying to change and get better, is we're going to have to look at those we failed.*

Here, the difficultly to describe the pain caused by endometriosis becomes evident. Poignantly, Quinn articulates that it is not physical pain alone, but emotional pain, and the pain associated with the profound intensity of others’ pain that characterizes the reality of living with endometriosis. I have chosen to present Quinn’s description of such pain in detail because his honesty is powerful, it is powerful because it is sincere, and it conveys the urgency of the improvement of endometriosis care.

*Care for the future*

The following section is a space in which I want to centre the participant narrative and step back from engaging in an analytic discourse regarding the forthcoming suggestions. Here, my intention is that the self-education and advocacy of the research participants, and of other endometriosis sufferers, is made clear. Envisioning an ethics of care (Tronto, 1993), and the improvement of their own care, this section serves to present visions for the future as described by nine people with endometriosis.

Meg, Eliza, Quinn, Amy, Beth, Amia, Jude, Nita, and Jaime offer the following calls to action:

* *For practitioners to listen to their experiences, and to hear their pain*
* *Improved endometriosis education and resources*
* *Improved individualized, multifaceted care*
* *Increased access to specialist programs*
* *Increased political involvement, funding and policy making pertaining to endometriosis*
* *Improved pre-emptive care and screening for endometriosis*
* *Improved education about endometriosis for general practitioners, gynaecologists, and surgeons*

The calls to action were each replicated by a systematic review of qualitative endometriosis literature by Dancet et al. (2014), in which calls for improved care for endometriosis patients were analyzed. In the present research, participants most commonly called for practitioners to listen to them, to hear them, and to believe them, a sentiment shared by a wealth of endometriosis research participants (Lukas et al., 2018; Young et al., 2020). Moreover, many of the present research participants called for and emphasized the importance of access to multifaceted, patient-centred care wherein laparoscopy, other surgical interventions, hormonal therapies, counselling, support groups, and pelvic floor physiotherapy are all a part of an integrated care program.

Through the presentation of their calls to action, it becomes evident that the lived experience of the present research participants has necessitated an engagement in emotional labour to care for oneself. The laborious nature of educating and advocating for oneself is well documented within feminist endometriosis literature (Seear, 2009a; Young et al., 2020). As proposed by Seear (2009a), endometriosis patients are required to engage in care and self-education through a “third-shift,” wherein visions for the future of care come to life.

**Discussion**

The present research has explored the experiences navigating healthcare with endometriosis in Canada. In particular, I have sought to analyze the detriment and disparities associated with the medical encounter for endometriosis care by applying a multifaceted feminist framework to analyze discourses surrounding feminized illness and pain, and how both physical and social factors contribute to the disadvantage that endometriosis patients face. While there is significant lack of qualitative endometriosis discourse within the literature, the present literature review identified commonalities with existing literature, as well as additions to the present body of literature found within the present research.

Interwoven within the present analysis is Seear’s (2014) discourse of endometriosis as *enigmatic* and the feminine as being inherently mysterious. While engaging in analysis of the participant transcripts, I often returned to the idea of endometriosis as an enigma, and how this enigma contributes to healthcare disparities for endometriosis patients. The invisibility of the feminine, and therefore of endometriosis has largely shaped the present analysis. Seear’s discourse of endometriosis as a feminized enigma has informed each of the themes of the present research; but has particularly informed *Theme 1: The detrimental feminine.* Seear’s analysis is relevant to the *detrimental feminine* and subthemes *dismissal* and *disempowerment* as the enigmatic nature of endometriosis is justified in part through the dismissal of real pain and psychological distress. Endometriosis as enigma has allowed for the excusing of female pain as a mystery, a mystery that remains as such due to a lack of research, funding, and policy making, all of which mutually reinforce the dismissal and disempowerment of a patient in dire pain.

Moreover, the present research findings on dismissal and disempowerment were very similar to those of Bullo (2018). Bullo’s study was multifaceted and included an analysis of a corpus of online data, as well as semi-structured participant interviews. Within the semi-structured interviews, Bullo found that disempowerment existed within and thereafter the medical encounter. Bullo suggests that “disempowerment and vulnerability are also consequences of obstacles encountered by women in the social and medical environment” (p. 577). In my analysis of the present research, I found the same to be true; participants spoke of experiences of disempowerment and proclaimed that those feelings where in relation to the medical encounter and consequences of dismissal. Bullo’s findings were based on 21 research participants; thus, her findings bolster and support those of the present research with a larger sample of qualitative research participants. However, Bullo was not able to compile a diverse research sample, with a research study comprised entirely of white, heterosexual participants. Thus, together with the present research, wherein I was able to obtain a more diverse, smaller sample size, the studies complement one another with similar findings with slightly different population demographics.

The present research identified compulsory motherhood as a prominently featured theme throughout the participant accounts of endometriosis experiences. This is a finding that is commonly presented within feminist endometriosis discourse (Jones, 2015). Jones (2015) posits that endometriosis patients are regularly prescribed hormonal suppression and pregnancy for the treatment of endometriosis induced pain. Hormonal suppression is utilized to mimic pregnancy in this context (Jones, 2015). Different from Jones, the present research and analysis emphasizes the compulsion associated with pregnancy and motherhood described by participants. Often, compulsory motherhood presented itself through a practitioner’s refusal to provide the patient with a hysterectomy in the interest of preserving fertility and childbearing capabilities. While two participants reported being urged to obtain a hysterectomy when the provision of endometriosis excision and hormonal therapies were proven ineffective for the patient, this was not the case for most participants. Moreover, the participants who desired children but were urged to proceed with a hysterectomy for the management of symptoms also experienced compulsory motherhood.[[6]](#footnote-6)Although their experience differed from those who wanted a hysterectomy but were denied, those who desired children were urged to do so immediately. This sense of urgency fostered feelings of anxiety and fear for participants experiencing difficulty to become pregnant.

The third theme of the present research, *intersections* is a relatively novel analysis imparted specifically upon endometriosis research. While the literature review for the present research did not find Crenshaw’s (1989) concept of intersectionality applied to endometriosis patients, the discourse is well represented within Hossain (2021), wherein the experiences of Black female patients are highlighted as being more inequitable in comparison to their white counterparts. The failure to cite Crenshaw was a common finding as I embarked on a literature review for the present research. I suggest that Crenshaw’s intersectionality is not directly applied by many scholars conducting similar research and composing literature, in part because of the fame of the concept of intersectionality. Despite the knowledge of the concept of intersectionality that many academics and writers possess, citing Crenshaw (1989) is necessary and important, and failing to do so contributes to the dispossession of the intellectual labour of Black feminist scholars.

Similar to the third theme of the present research, *Theme 4: The language of care and care for the future*, presents a novel analysis of endometriosis experiences. Particularly, the language of care and the use of key words to describe emotions during the health care encounter was not employed within the articles of the present literature review. The addition of emotion words associated with the healthcare encounter was important to the present analysis and allowed for a more in-depth analysis of the emotions that the participants were describing through experiences. The purpose of the use of emotion language is twofold: rather than relying on an entirely deductive analysis, I questioned the participants about specific emotion words to facilitate a more comprehensive analysis of their experiences in all four themes, as well as to compose a collection of emotion words for presentation in the present paper.

Moreover, the thematic analysis of the second part of the theme, *care for the future,* has been well replicated within both qualitative (Dancet et al., 2014) and quantitative (Lukas et al., 2018) literature. Like the participants of the reviewed literature of both Dancet et al. and Lukas et al., the present research participants valued improved endometriosis education, multifaceted care programs, increased political involvement, funding and policy making pertaining to endometriosis, improved pre-emptive care and screening for endometriosis, and most importantly, for practitioners to listen to their experiences and to hear their pain. However, the significance of the aforementioned care practices varied between the present research participants and those of Dancet at al. (2014) and Lukas et al. (2018). For instance, Lukas et al. noted increased education through medical practitioners as the most prominent call to action, rather than listening and empathy, which was the primary call to action of the present research study.

*Limitations*

While the present research has significant strengths, such as in-depth qualitative interviews and rich feminist analysis, it is pertinent to note that there are limitations associated with the present research that call attention to the importance of further inquiry into patient experiences with endometriosis and care provision. As the present research was conducted under the time constraints of the received funding the sample size is relatively small; future research would benefit from a broader sample of a representative population of women and gender diverse peoples. The achievement of diversity is also of note; while the present research was comprised of three individuals (33%) living with endometriosis and a minority status, future research would benefit immeasurably from further purposive recruitment and inclusion of BIPOC and 2SLGBTQIA+ participants. The proportionate measure of 33% of participants with a minority status is unfortunately not often replicated in larger endometriosis research samples. Often this proportion is much fewer when sample size increases; thus, the research continues to largely be comprised of the experiences of white, cisgender women. Namely, an intersectional analysis of the conditions of limited access to endometriosis care and the associated disparities for Northern, rural, and Indigenous Canadian communities is an area of research which requires further inquiry.

It must be recognized that the disparities associated with endometriosis cannot be completely understood without representative, diverse endometriosis research. Further, as endometriosis research has as relatively small prevalence within the literature, it is important to call attention to the continuation of endometriosis research and to support such research with adequate funding and policy implementation, such as that proposed by EndoAct, which seeks to implement policy regarding the funding and support of Canadian endometriosis research and to integrate visions for the future of endometriosis care (Wahl et al., 2020).

**Conclusion**

It is difficult to bring the present research to a conclusion. The notion of a conclusion suggests an ending, when really, it has only just begun. There is an emerging body of literature on qualitative endometriosis research, largely conducted through feminist thought. This research is important; it is a critical facet of how we can move towards an ethics of care (Tronto, 1993), providing more equitable, timely care, and an improved quality of life for endometriosis patients. The present research has presented disparities of femininized illness that have long existed. Furthermore, it has provided hope for the future of care as presented by endometriosis patients themselves. While the present research has presented the stark reality that so many endometriosis patients face, I complete this endeavour with hope. To conclude, I want to leave my readers, my participants, and the endometriosis community with a sentiment that remained with me throughout the duration of my research and remains still: I hope for a world in which endometriosis patients speak, all will listen, and I hope more than anything that when you do, your concerns are met with empathy, compassion, and the provision of equitable care.

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**Conflict of interest**

The author reports that she has no monetary or financial conflicts of interest.

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1. Note that the values for diagnostic delay are approximate as estimated by participants. Additionally, Jaime and Amia noted that they now recognize that they had seen their providers for symptoms related to endometriosis from the time of being a teenager but did not recognize this as seeking care for endometriosis related symptoms. Rather, both women reported the time at which they began to seek care for what they suspected to be endometriosis as approximately two years. [↑](#footnote-ref-1)
2. Note that the term Autism will be used throughout the proceeding analysis, rather than Autism Spectrum Disorder (ASD) as this is how Amia refers to herself throughout her interview. [↑](#footnote-ref-2)
3. Poteat, T., German, D., & Kerrigan, D. (2013). Managing uncertainty: A grounded theory of stigma in transgender health care encounters. *Social Science & Medicine, 84*, 22-29. <http://dx.doi.org/10.1016/j.socscimed.2013.02.019>. [↑](#footnote-ref-3)
4. Jensen, J. T., Schlaff, W., Gordon, K. (2018). Use of combined hormonal contraceptives for the treatment of endometriosis related pain: a systematic review of the evidence. *Fertility and Sterility 110*(1), 137-152. <https://doi.org/10.1016/j.fertnstert.2018.03.012>. [↑](#footnote-ref-4)
5. The Practice Committee of the American Society for Reproductive Medicine. (2014). Treatment of pelvic pain associated with endometriosis: A committee opinion. *Fertility and Sterility 101*(4), 927-935. <http://dx.doi.org/10.1016/j.fertnstert.2014.02.012>. [↑](#footnote-ref-5)
6. Please note that the purpose of the analytic discourse compulsory motherhood and the denial of hysterectomy provision does not serve to analyze the efficacy of hysterectomy or pregnancy for endometriosis management. Rather, the present analysis is grounded within the denial of women’s knowing and refusal to provide the patient with the healthcare procedures which they choose to engage in. For an analytic discourse of the efficacy of hysterectomy for the treatment of endometriosis, please see Jones (2015). [↑](#footnote-ref-6)