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Communicating Pain Unseen: Addressing Health Outcomes in Sexual Activity for Women with Endometriosis

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COMMUNICATING PAIN UNSEEN: ADDRESSING HEALTH OUTCOMES IN SEXUAL ACTIVITY FOR WOMEN WITH ENDOMETRIOSIS

By

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Abstract

Roughly 160 million women live with endometriosis, a chronic disease involving the uterine lining shedding on the outside of the uterus causing immense physical and emotional pain (Becker et al., 2020). One common symptom of endometriosis is dyspareunia, or painful sex (Ballard et al., 2008). This study aims to uncover how gender expectations from society impact women with endometriosis specifically in sexual encounters. Informed by the traditional sexual script theory and sexual script theory, the study examines how traditional gender norms might influence women's prioritization of their own health needs as well as the physical, emotional, and relational health outcomes of such prioritization (Byers, 1996). To more closely explore these experiences, 90 posts from Reddit were coded and examined to identify the relationship between the script types (self, partner, or relationship) and the valence of physical, emotional, and relational health outcomes. Results indicate a significant prioritization of the self script. Additionally, the relationship among the prioritized script (self, partner, or relationship) and the positive and negative outcomes as related to physical, emotional, and relational health is nonsignificant. Nevertheless, the results highlight the physical, emotional, and relational barriers women face in their sexual health. Furthermore, additional analyses demonstrate a significant relationship among physical, emotional, and relational health variables as valence of health outcome shifts. Specifically, women's physical and emotional health experiences are primarily negative in nature which ultimately highlights the important role communication plays in supporting women with endometriosis' sexual health. Discussion, implications, and directions for future research follow.

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Dedication

To the endo community, to the women whose stories guided this research, to the strength that you hold in the midst of constant doubt, disbelief, and invalidation of your pain and bodies. To anyone who has never been believed, in their pain or their experiences.

May we continue to move beyond what the eye sees. To trust the pain within.

To move towards the other side of struggle with newfound light of life

and the courage to speak until

we are finally seen.

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Chapter 1: Introduction

For most women struggling with a pelvic chronic disease such as endometriosis, the physical pain isn't necessarily the worst part. In the span of a fifteen-minute doctor's appointment, countless women are told that their pelvic floor is "wrecked," that their uterus is "bad," and they are asked if they want children (that is if they are even able to conceive). In the span of fifteen minutes, some women with pelvic conditions are even expected to choose between relieving physical symptoms or the future of having a family, a partnership, and children - all while simultaneously being given a working diagnosis of a chronic illness that will forever change every aspect of their life. While receiving a diagnosis can serve as a great relief for women, the diagnosis nevertheless reflects the culmination of years' worth of IBS, bad periods, cramps, or even hysteria misdiagnoses (to name a few) to finally be taken seriously. After years of unanswered questions, misdiagnoses and false hope, women's mental and emotional health experience compromise. Messages with lifetime implications are delivered within fifteen minutes.

What is crucial to realize is that the oft-sterile communication accompanying these diagnoses - the disbelief, lack of emotional and relational attention, and matter-of-fact statements about fertility - lingers in the minds of women well beyond appointments, surgeries, and long-term treatment plans. The mind now houses ideas that say *your body is defective; your fertility and reproductive desires are at stake; your pain is something you just have to live with. Physical, emotional, and relational pain are your new reality.* Such messages with a diagnosis highly impact the way one interacts with people, especially in one's most deep and intimate relationships. When illness is conjoined with taboo topics such as sexual health and female sexuality, women are set forth on the seemingly impossible path of navigating not only body

shame, but navigating intimacy, sexual health, and relationships with a new-found illness and the presence of pain. Further, the sexual stigma from society and narratives from medical professionals can become embodied. The disbelief and stigma created in doctor's offices and the shame that follows for being a "defective" woman can be internalized and physically contribute to lower levels of sexual self-comfort, which is correlated with a decrease in sexual satisfaction and orgasm (Armstrong et al., 2012). Similarly, women experience such stigma from a variety of socio-cultural interactions. For example, women who have experienced non-consensual sexual acts have reported feeling defective or damaged (Koon-Magnin & Schulze, 2019). According to the traditional sexual script, Byers (1996) and Byers and O'Sullivan (2013) also argue this stigma can be applied to women with sexual experience. While men are celebrated for sexual acts and experience, women might fear that they be viewed as "damaged goods." In sum, messages about female sexuality communicated from society and/or medical professionals can become engrained in minds, which can impact the physical health and well-being of women. The physical, emotional, and relational pain are accompanied, and made worse, by internalized negative messages about their pain, bodies, and health.

In this study, I work to understand how traditional and sexual scripts might be at play as women navigate physical, emotional, and relational decisions about sexual behavior. Specifically, the study aims to uncover whose health and well-being women privilege in the face of the pelvic chronic illness endometriosis and sexual encounters. Second, through conducting a content analysis of those with lived experience, this study aims to uncover if script privileging is related to the valence of emotional outcomes. By looking at the interpersonal and health communication associated with pain with sex and sexual health, communication dually becomes a way to understand barriers present as well as to recognize communication as a powerful tool in

rewriting narratives that empower, rather than adversely affect, the physical, emotional, and relational health of women in the face of chronic illness.

Chapter 2: Literature Review

Endometriosis and Physical Health

Endometriosis is a chronic illness where endometrial tissue, or blood from menstruation, occurs outside of the uterus wall. Over 10% of reproductive age people are affected by endometriosis, or roughly 190 million women (Becker et al., 2020). There are four stages of endometriosis (minimum, mild, moderate, and severe) measured by the spread, depth, and locations of the endometrial tissue (Szendei et al., 2005). Medical professionals have not found a correlation between stage of endometriosis and severity of pelvic pain, meaning that no matter the stage, the presence of endometriosis can cause serious symptoms (Szendi et al., 2005). Individuals with endometriosis have reported an array of physical symptoms, including pelvic pain, fatigue, and higher infertility rates (Rush et al., 2019). Despite the severity of symptoms, it takes an average of nine years for women with endometriosis to receive a diagnosis due to a lack of medical awareness about the disease and reducing serious symptoms to "normal" menstruation pain (Namazi et al., 2020). Typically, when women do receive a diagnosis, doctors often prescribe hormone therapies, birth control, and pain medication; but ultimately endometriosis is a chronic condition that impacts women until menopause, and in rare cases throughout the one's entire lifespan. Medical professionals have created a laparoscopic surgery to remove the tissue that has become the best solution for symptom management (Becker et al., 2020). That said, however, many women must undergo a subsequent laparoscopic surgery within three years of their initial surgery (Cea Soriana et al., 2017) and 12% of women later undergo a hysterectomy which further highlights the complexity and toll endometriosis takes on one's body. In a word, endometriosis continues to bring pain to areas of life that transcend the uterine lining (Vercellini et al., 2009). In many cases, women are put in a position of having to decide if

they want to have a hysterectomy or wait and live with the variant types of attendant pain if they desire to bear children. The women who choose the latter decision know full well that fertility and pregnancy will be challenges, if not longshots. Given that endometriosis impacts the reproductive organs, there are many physical, emotional, and relational implications for going through with a hysterectomy; that said, there exist like implications for not succumbing to a hysterectomy.

Along with the daily symptoms women with endometriosis experience is dyspareunia or pain with sex, which is 9x higher in women with endometriosis than in the general population (Ballard et al., 2008). Namazi et al. (2020) interviewed women with dyspareunia and found that intercourse elicited a great deal of pain and was extremely unbearable. To cope with painful sex, women have used strategies such as adjusting positions based on pain, engaging in non vaginal types of intercourse such as oral/anal sex, engaging in partner-only centered sexual behavior (e.g., perform oral sex on partner), having less sex, or avoiding sex all together (Barbara et al., 2017). More specifically, 88% of women living with endometriosis report pain interrupting their sexual experience while 59% of women avoid sex all together (Wahl et al., 2021). Although removing endometriosis through laparoscopic surgery is the major pathway toward pain relief, some women still report decreased libido and trouble orgasming due to additional diagnoses caused by endometriosis such as pelvic floor dysfunction which impacts the body's ability to climax (Barbara et al., 2017; Wahl et al., 2021). While little is known about the impact of endometriosis on women's sexual health and pleasure, a handful of studies have found that the chronic illness plays a major role in the emotional, relational, and sexual health of women (Kralik et al., 2001).

Endometriosis and Emotional Health

In addition to an array of physical symptoms, women who struggle with endometriosis suffer from emotional and relational disruptions. Pain is not simply physical. Research has found that endometriosis patients have higher mental health diagnoses such as depression or anxiety that contribute to lower levels of subjective well-being (Rush et al., 2019). Psychologists have found that health anxiety, or the stress that comes with a health diagnosis, impacts the physical body, and can even exacerbate pain (Meana & Lykins, 2009). Additionally, women with pain during sex report greater negative affect with interpersonal connections and social discomfort (Meana & Lykins). In other words, health anxiety is perpetuated by failure to engage in "normal" activities, such as going out with friends or having sex with a partner; anxiety increases when sex is accompanied by pain. Even further, emotional components like anxiety and depression were also found to impact sexual functioning for women with endometriosis (Youseflu et al., 2020).

Another emotional impact on women with endometriosis is the invalidation that occurs with years of going undiagnosed or misdiagnosed by doctors (Namazi et al., 2020). Many women report feeling insignificant and invalidated, resulting in belief that their pain is psychosomatic because medical professionals often dismiss their symptoms, diminish their experience as "lady problems" or misdiagnose endometriosis as PMS, IBS, or chronic fatigue (Wahl et al., 2021). In a similar way, research has found that when women do experience validation from medical professionals about their pain, they feel immense hope and acknowledgement for finally being believed (Fernley, 2021). In this way, a diagnosis not only becomes the first step in treating endometriosis, but it also provides extreme emotional release, validation, and legitimization of the woman's voice and experience.

Endometriosis and Relational Health

Lastly, the physical and emotional implications of endometriosis are highlighted in relational health. Chronic illness brings an array of challenges to one's life; however, some challenges are discussed less frequently due to their taboo nature. Adjusting or eliminating social and/or relational behaviors such as sex can further heighten women's concerns regarding social isolation, relational turbulence, and mental health state (Barbara et al., 2017). While sex and pleasure tend to be left out of medical conversations about pain, women with chronic illness have reported feelings of shame, guilt, and relational turbulence when unable to engage in sex in a normal way (Kralik et al., 2001). Research has found that women might even go to extreme lengths to feel a sense of normalcy in sex, even in the presence of pain. Schultz et al. (2005) and Herbenick et al. (2015) found that one of the ways women try to feel "normal" is continuing to have sex with their partner and "tough out" the pain. Cole et al. (2021) also found that women with endometriosis reported they would "suffer in silence just to have a normal relationship" (p. 185). Not only does continuing to have sex while in pain physically hurt, but it takes an immense negative toll on women's psychosocial well-being (Wahl et al., 2021). Additionally, Loofbourow (2018) suggests that faking orgasms might be a way for women to end sex quickly to have pain relief. Even further, research suggests that couples have completely different definitions of what "normal" and "good" sex are. For example, women categorize bad sex as including components such as coercion, feeling uncomfortable, and having physical pain. On the other hand, good sex for women means the lack of pain or discomfort, while for men it usually means achieving orgasm (Herbenick et al., 2015). McClelland (2010) discovered similar findings in her study of sexual satisfaction rates in young adults. While women's low end of sexual satisfaction includes intense pain and negative emotions, men rarely if ever consider damaging results for themselves (Loofbourow, 2018; McClelland, 2010, 2010).

Another coping strategy women use when experiencing pain with sex is to avoid sexual activity all together (Herbenick et al., 2015; Schultz et al., 2005; Wahl et al., 2021). Having to avoid relational norms, such as having sex, has a greater impact on one's physical, mental, and emotional health than one might expect. Social determinants such as "social exclusion, stigmatization, pain catastrophizing, depressed mood, behaviors, motivation, anxiety, and fear" all play an important role in increasing or diminishing pain (Darnall et al., 2017, p. 1414). Barbara et al. (2017) noted that the physical pain and difficulty orgasming creates an emotional distress that can bring stress into a relational dynamic. Women might be faced with anxiety about the decision to have sex as well. For example, women face fear of the physical pain that comes with sexual engagement while simultaneously experiencing the fear of not having sex and the potential relational implications (Wahl et al., 2021, 2021). Ultimately, research demonstrates that coping strategies such as continuing to have sex when in pain or avoiding sexual activity have negative consequences on women's relational and emotional health.

Sex Communication

The presence of anxiety might contribute to the lack of relational communication that takes place about sex and chronic illness. Women who have pain with sex report having had to dissolve their relationship rather than communicate with their partner or work through it (Wahl et al., 2021), which is consistent with other findings that sexual communication is especially difficult in uncertain or challenging circumstances (Delaney, 2021). To understand how communication can improve the emotional and social components of endometriosis and sex, it is important to look at the complexity chronic illness and sex add to a communication dynamic. Communicating about chronic illness or disease with a partner can be deemed as taboo among couples. For example, previous research indicates that one's perceived ability to manage their

health issues leads to greater health outcomes. Lichtman et al. (1987) found that women with breast cancer who openly disclosed their feelings and concerns with their husbands adapted more easily to the transition of losing their breasts. Additionally, communication about the impact of illness positively impacted self-esteem and social and emotional connection when adjusting to the new norms (Zenmore & Shepel, 1989).

Disclosures about a chronic illness bring a whole new complexity to sex communication. Sex communication is often challenging within health diagnoses' arenas such as depression (Delaney, 2021), communication-debilitating illnesses (Bute et al., 2007), and dementia (Baxter et al., 2002). One way to combat taboo topics is educating patients with chronic illnesses, such as endometriosis, to help them understand how to navigate newfound challenges with sex, which works to empower patients toward fulfilling sexual encounters (Delaney, 2019). After understanding the complexity of chronic illness and sex, some patients have worked to rewrite existing narratives to improve their conceptions of illness and sexuality (Bute et al., 2007). Thus, communication becomes a major factor in improving sexual and overall well-being in the presence of uncertainty that comes with illness (Checton et al., 2012). By first understanding the intersectionality of communication, sex, and illness communication can then be used for partners to navigate chronic illness together to better their overall well-being (Badr & Acitelli, 2005).

It is important to note that chronic illness not only impacts the patient's relational health, but it brings challenges to their partner or potential future partner. When an individual in a committed partnership is diagnosed with a health issue, a couple goes through a similar process of grieving. In other words, the presence of chronic illness and pain in a relational dynamic significantly impacts the relational health of a partnership(s). However, through communal coping, couples might find a new strength and closeness in navigating illness together

(Fernandez et al., 2006). At the same time, the stage of the relationship plays an important role in sex communication and disclosures of illness. While research is lacking regarding endometriosis disclosures in dating, Shpigelman et al. (2019) found that women might experience fear of disclosing their illness in early stages of dating due to fear of rejection or stigma and that disclosing about illness late in the relationship dynamic has more negative outcomes whereas disclosures early on are perceived as being managed effectively. Additionally, in hook-up encounters research has found that little to no communication happens and discussions of female pleasure are often non-existent (Lehmiller et al., 2012; Paul & Hayes, 2002). Thus, communication becomes a highly impactful avenue for improving the mental distress that comes with discussing one's needs and areas for improvement sexually for both the one with endometriosis and their partner to work towards greater relational health in any stage of the relationship.

That said, there exist situations in which an individual does not feel support from their committed partner regarding a chronic illness diagnosis. For example, the partner might be unsupportive and/or demonstrate more focus and concern on the self (e.g., I feel deprived sexually due to my partner's chronic illness) than for the partner affected with endometriosis. In such cases, individuals with endometriosis might focus more on the partner and the health of the relationship vs their own personal physical and emotional well-being. In one study of long-term relationships where women were diagnosed with endometriosis, their male partners reported feeling shocked, angry, and being in a worse mood (Fernandez et al., 2006). Some of the men reported distress was caused by doctors who failed to provide answers while others reflected feeling emotionally distressed about the pain their partner was going through. Feelings of anger and being misled were also present when partners disclosed a chronic illness late in the

relationship (Shpigelman et al., 2019). However, the grieving does not necessarily mean that the grieving is done together. More than half of women with endometriosis report feeling misunderstood and unsupported by their partners (Schlesinger, 1996). On the contrary, women who perceive their partners as interested and supportive in their health condition experience an increase in relational satisfaction, thereby highlighting the importance of relational health in navigating endometriosis and sexual health (Facchin et al., 2021).

Additionally, women can feel guilty for being unable to engage in sex with their partners and disclosed feeling neglected, rejected, or desiring to end the relationship (Denny & Mann, 2007). Byers (1996) notes that with traditional gender expectations, women are conditioned to be more sexually reserved to protect their reputation yet might fear that their partner will seek sex elsewhere if they don't engage in enough sexual activity. Over 75% of women with endometriosis report their sex life being impacted and 56% report endometriosis significantly impacting their relationship (Moradi et al., 2014). Schlesinger (1996) found that due to stigma, women had difficulty talking about their pain with sex and reported using indirect communication such as non-verbal cues as the main form of communication.

Many studies acknowledge the social and psychological impact of chronic illness, especially those conditions impacting sexual functioning and pleasure (Fernandez et al., 2006). A handful of medical experts acknowledge that a multidisciplinary health approach is crucial to improve sexual functioning and overall well-being (Nosek, 1996). Pain experts have also acknowledged communication as a key component to understanding and managing pain in interpersonal and social contexts (Hadjistavropoulos et al., 2011). Yet, despite the growing evidence of the social, psychological, and physical distress caused by having endometriosis on one's overall sexual health and wellbeing, most medical practitioners solely focus on the

physical aspect. In order to find information to help their well-being that might not be mentioned by doctors, many people have increasingly turned to online forms of communication to make-sense of their sexual health (Record et al., 2018).

Health Communication on Reddit

Due to the taboo nature of chronic illness and sexuality, many individuals dealing with a stigmatized health issue like endometriosis and sexual health might not feel comfortable discussing their issues in medical clinics or in everyday life (Baxter & Wilmot, 1985). Yet, research findings demonstrate that individuals with stigmatized health issues frequently turn to social media to find, share, and discuss information as well as solicit and receive social support from people with similar lived experiences (Moreno & Whitehill, 2012). Unlike other social media platforms where one must create an account to be a part of the community, such as Facebook, Reddit is publicly available and accessible to anyone on the internet (Record et al., 2018). Reddit offers thousands of online communities known as "subreddits" hosting a variety of interests and topics (Van der Nagel & Frith, 2015). A moderator oversees each subreddit and actively checks posts/comments to ensure they fall within the community agreements (rules and regulations for each forum) as well as promote engagement with users. Reddit also allows users to interact anonymously (Sowles et al., 2018). Research findings demonstrate that individuals will specifically create "throwaway accounts" or anonymous accounts to post about stigmatized issues (Leavitt, 2015). In one study, scholars found that parents dealing with a stigmatized issue such as abuse, divorce, or pregnancy loss, often turn to Reddit to discuss their concerns rather than using Facebook to eliminate fear of judgment from their friends and family (Andalibi & Forte, 2018). Parents report social media sites that require one's identity disclosure exacerbate expectations of what it means to be a "good parent" which creates a barrier to discuss

stigmatized topics with their community. Nobles et al.'s (2018) research has also found that Reddit's accessibility allows people to look for information on topics like sexual health and STD's. Even the process of disclosing one's issue online has psychological and physical health implications (Ammari et al., 2019). Thus, Reddit becomes a powerful space for people to connect, ask questions, and seek information about stigmatized issues.

Reddit's accessibility, crowdsourced information, and anonymous feature specifically draw individuals to talk about health issues and even influence their lived behaviors (Nobles et al., 2018; Record et al., 2018). Scholars concluded that, "users who are specifically seeking health-related information are more like to enact that information in their own lives" (Record et al., p. 471). Like Nobles et al. (2018), other research has found that the information on Reddit can translate offline into real life health decisions (Record et al., 2018). Additionally, the more people looked for health information about a specific topic, the more they adapted the recommendations found on the board in their lives. For example, users have used Reddit to find health information about alcohol use (Taylor et al., 2015), vaccines (Harmsen et al., 2013), and sexual health (Whitfield et al., 2013). However, it is important to note that individuals looking for answers on Reddit possibly absorb the information regardless of whether it is it credible or not. Even further, individuals may use internet forums in lieu of consulting medical or mental health professionals possibly resulting in their receiving false or misleading information about their bodies or health conditions. Of note is that not only does Reddit provide community and social support for topics that might otherwise have negative social outcomes from stigma, but individuals who seek information might be more likely to change their behavior based on the information they find. The medium of Reddit provides a unique space for people to communicate about otherwise stigmatized and uncomfortable topics with the comfort of opportunity of

remaining unidentified (Sowles et al., 2018). Thus, the health messages on these sites are highly influential and have the power to further impact the health and well-being of its users (Record et al., 2018).

Overall, identifying communication about stigmatized health issues online, like endometriosis and sexual health, is helpful for understanding how women are conceptualizing their illness and making decisions about their behaviors. Further, the communication about one's sexual health during illness might translate to health behaviors offline that could benefit or harm one's health and well-being (Nobles et al., 2018; Record et al., 2018). By understanding how the physical, emotional, and relational dimensions of endometriosis intertwine, communication can begin to serve as a powerful tool to overcome the barriers of stigma and help women express their lived experiences thereby improving their overall sexual health and wellbeing. To further address communication and health, sexual script theory (e.g., Simon & Gagnon, 1984, 1986; Gagnon, 1990) and attendant theories, such as the traditional sexual script (Byers, 1996; Byers & O'Sullivan, 2013) can inform the lens through which one might understand sexual scripts, conditioning and their association with communication and relationships, particularly as related to various health outcomes.

Sexual Script Theory

Similar to the pain that comes with chronic illness, sex is more than biological. Sex is biological, cognitive, and social (Lawler, 2006). One's cognitive patterns, cultural messages and interpersonal experiences are known as sexual scripts that influence one's sexual attitude, beliefs, and behavior (Dworkin & O'Sullivan, 2005). Sexual scripts are comprised of three levels: cultural, intrapsychic, and interpersonal (Simon & Gagnon, 1984). The cultural level of sexual scripts reflects societal norms, expectations, and practices of sexual behavior. Cultural scripts

give social and cultural blueprints for acceptable sexual choices such as who or what one desires, goals and relationship dynamics, when and where to engage in sexual behavior and how to feel about such interactions (Emmers-Sommer & Allen, 2005). Socially acceptable forms of sexual behavior are portrayed through media, education, and societal messages of sexuality which then influence one's ideas of what sexual situations should look like (Simon & Gagnon, 1998). However, what is deemed as normal and acceptable behavior for one identity might differ for another. In other words, cultural attitudes assign different standards and meaning to behavior based on different identities (Berger et al., 1973). For example, within a Western, heterosexual cultural context, men and women are often exposed to varied scripts about what it means to have sex. Men are conditioned through masculine stereotypes and messages to be assertive, in control, and dominant. On the other hand, women are culturally conditioned to have self-control and connect sex to romance and committed heterosexual relationships (Byers, 1996; Byers & O'Sullivan, 2013; Wiederman, 2005). Cultural scripts ultimately influence one's expectations about a sexual interaction based on societal messages about gender. The cultural script within sexual script theory tends to be traditional and heteronormative in nature. That is, what are men and women expected to do relationally and sexually speaking? Culturally, it is more acceptable for men to be sexually pursuant and women to be sexually more passive. It is also often more acceptable and expected for the woman to be the relational gatekeeper and harmonizer—that is, she is conditioned to acquiesce her own feelings to elevate those of others (Emmers-Sommer, 2002). However, though cultural scripts represent beliefs about appropriate sexual behavior, that does not necessarily mean that the cultural script aligns with individual desires or beliefs about sex (Dworkin & O'Sullivan, 2005). Individual sexual attitudes are internalized cultural scripts as well as one's own fantasies, desires, and conceptions surrounding sex called intrapsychic scripts.

Intrapsychic scripts reflect how one might interpret cultural messages about sexuality and craft their own beliefs about sexual desires and wants (Metts & Spitzberg, 1996). Intrapsychic scripts continue to build from messages which then shape one's thoughts, values, and beliefs about sex (Simon & Gagnon, 1986). In addition to reflecting individual desires, intrapsychic scripts reflect expectations for sexual interactions (Emmers-Sommer & Allen, 2005). An individual's intrapsychic script might or might not mesh with cultural script expectations. For example, whereas a cultural script might champion sexual behavior for a man and frown upon it for a woman, there exist men who might not personally wish to be sexually proactive or women who might not wish to be sexually reactive, passive, or dismissive. Due to cultural and social pressures, individuals might suppress intrapsychic scripted personal desires and give in to cultural sexual expectations; conversely, an individual could stand firm on privileging their intrapsychic script, personal wants and desires, even if they go against the cultural expectations' grain (Emmers-Sommer, 2002). While cultural scripts are broad narratives about sexuality and then cognitively processed at the intrapsychic level, sexual scripts are then interpreted and enacted through one's "personal experiences, socialization, and motives to shape action" in an interpersonal sexual encounter (Dworkin & O-Sullivan, 2005, p. 150). In other words, cultural messages about sex and personal sexual attitudes are then linked and enacted through interpersonal interactions. When cultural and intrapsychic scripts are enacted in a sexual encounter they create the final level of sexual scripts: the interpersonal script.

Through interpersonal scripts, one begins to adapt and play out their interpretations of cultural scripts and know what is expected of them. Simon and Gagnon (1984) describe interpersonal scripts as "representations of self and implied mirroring of the other that facilitates the occurrence of a sexual exchange" (p. 31). By following cultural scripts and internalizing

cognitive beliefs about sex via intrapsychic scripts, one becomes familiar with the roles in a sexual encounter and how to behave accordingly. Communication (non-verbal and/or verbal) is the means in which sexual scripts are played out in real life through interpersonal interactions (Metts & Spitzberg, 1996). While sexual scripts provide guidelines for people to know how to act sexually, dissonance is created, as noted, when one's intrapsychic script and cultural script do not align. For example, if a woman is in pain due to endometriosis and does not want to have sex, but her partner is asking for intimacy, she must decide if she follows the cultural script that conveys assumptions about relational expectations (e.g., cultural/social expectations to have sex in a romantic relationship; media portrayals of sex and women easily orgasming, etc.) or to act from her intrapsychic script that aligns with what she actually wants in a situation (e.g., refrain from sex due to anticipated physical pain). That is, she might experience anxiety and pressure due to the perception that sexual activity is assumed as socially and culturally expected in an intimate relationship (cultural script) yet does not want to engage in sexual activity due to the expected attendant physical pain associated with her medical condition (intrapsychic script). Laumann et al. (2000) explain such situations as the scripting model bringing together "the two levels of meaning (the intersubjective or cultural and the intrapsychic) and links them to a system of interpersonal action" (p. 7). Thus, interpersonal scripts help showcase behavior that comes out of the cultural script and intrapsychic script an individual holds. Often, women elevate or privilege the intrapsychic script of others over that of her own (Emmers-Sommer, 2002). For example, the woman who doesn't want to have sex (her intrapsychic script) but has a partner who does want to have sex (his intrapsychic script) might acquiesce and privilege his wishes, his script, and soldier through the pain (Loofbourow, 2018) out of fear that her partner will be upset without sex or seek it elsewhere (e.g., Byers, 1996; Byers & O'Sullivan, 2013). Within the

context of sexual activity, Loofbourow (2018) argues that women often put up with painful sex because they feel it is expected of them.

Sexual script theory clarifies a variety of sexual behaviors such as consent (Fritz & Paul, 2017), sexual coercion (Emmers-Sommer & Allen, 2005; Marshall et al., 2021), and gender expectations (Simon & Gagnon, 1984). Given endometriosis and sexual health are influenced by cultural, cognitive, and interpersonal dimensions, it is critical to look at the common beliefs, patterns and behaviors women with endometriosis might have about sex (Simon & Gagnon, 1986).

Traditional Sexual Script Theory

While sexual scripts can help understand sexual beliefs and behavior, such scripts within Western culture prioritize cisgender experiences and pleasure, otherwise known as the traditional sexual script (TSS), and are typically heteronormative in nature (Byers, 1996). Despite some advancement, modification and neutralization, many traditional, scripted expectations nevertheless seem to hold. For example, results from a recent study conducted by the Pew Research Center (Parker et al., 2017) regarding perceptions of positive and negative gendered traits largely reflect traditional beliefs. Collecting data from 4,573 Americans, respondents offered 1500 unique terms related to what they valued (and didn't) in the men and women. For example, 67% of the respondents perceived the word "powerful" as being positive for men, but 92% of the respondents perceived the term "powerful" as negative for women. "Beautiful" was almost exclusively used to describe women, whereas "provider" was used specific to men. Ninety-five percent of respondents perceived "emotional" as negative for men. "Promiscuous" was perceived by 95% of the respondents as negative for women. Similarly, in a study of dating

scripts and sexual expectations, Emmers-Sommer et al. (2010) found strong support for traditional sexual script prevalence.

Emmers-Sommer and Allen (2005) explain that the traditional sexual script can "affect men's and women's ideologies and scripts about what they are supposed to do in sexual situations verses what they might want to do" (p. 8). In other words, cultural messages may influence an individual to engage in sexual situations because they feel like they must rather than genuinely desire to. Women are more likely to engage in unwanted sexual behavior because there are different gender expectations for sexual roles, attitudes, and behaviors (Byers, 1996). For example, women's pleasure is rarely centered in cultural messages about sex (Simon & Gagnon, 1984). At the same time, cultural messages might have women believe they lack entitlement to receive pleasure during sex (Mahar et al., 2020). Byers (1996) explains how the TSS prescribes different sexual roles based on gender in heterosexual contexts. The TSS portrays men as having strong urges for sex, obsessing over sex, and even exploiting sexual advances on women. On the other hand, women are represented as less sexual, more sexually timid, and using sex to connect in love rather than for their own pleasure. According to the TSS, men gain status by having sex whereas women lose status by engaging in sexual behavior. For example, after a sexual encounter, men are rewarded with a "walk of fame" while women have a "walk of shame." According to the TSS, men are typically championed for their sexual pursuits whereas the woman is perceived negatively (Emmers-Sommer, 2002). Additionally, the traditional sexual script lends more sexual agency to men and can further instill the idea that female pleasure is passive (Blair et al., 2018). According to the TSS, women are also socialized to reject or give some resistance to sexual advances as "forceful resistance is inconsistent with women's gender role scripts which dictate women to be passive, submissive, and unassertive" (Byers, 1996, p.

10). In this way, the traditional sexual script prescribes a passive female sexuality while further normalizing male centric sexual encounters (Byers, 1996).

In addition to the traditional sexual script prescribing gender roles for sexual interactions that center women as sexual objects void of agency, the TSS also depicts specific ideas about interpersonal relationships. For example, women are expected to prioritize the needs of their male partner (Byers, 1996). In this way, the TSS might fail to acknowledge a women's feelings for not wanting to have sex or engage in sex for the purpose of pleasing their partner. On the other hand, men are prescribed scripts that can be interpreted as more self-focused, unemotional, and less sensitive to needs of others. Ultimately, the traditional sexual script perpetuates ideologies that center male needs in sexual encounters and interpersonal relationships which can legitimize coercion through sexual socialization (Byers 1996; Emmers-Sommer & Allen, 2005; Marshall et al., 2021).

While sexual scripts provide a layout for how to think, talk, and behave sexually, previous communication often fails to address the different messages given to men and women about pleasure, chronic illness, and pain. In certain cases, such as discussing sexual history, sexually-transmitted-infections, or discussing fantasies, individuals do not have the blueprint or linguistic tools to communicate what they want. These conversations are what Hample et al. (2018) calls unscripted interactions. What this means is that people most likely do not know how to interact, behave, or communicate due to the lack of education and sexual scripts provided to talk about sex, illness, and pain. Indeed, Loofbourow (2018) comments that women are socialized to grin and bear it when it comes to painful sexual encounters. It is important to identify women's intrapsychic beliefs, ideologies, and conceptions about sex considering pain and endometriosis. Additionally, understanding interpersonal scripts can uncover how the

traditional sexual script might be at play and how communication can work to craft new sexual scripts that center, validate, and legitimize female pleasure, equitable sexual encounters, and the experience of pain.

Sexual Scripts and Endometriosis

While research about endometriosis and sexual scripts is limited, a few studies reflect common themes, cognitive patterns, and identity shifts that happen in a health diagnosis that impact sexual activity. Common sexual scripts for women with endometriosis have shown how the diagnosis changes one's identity and, in turn, the role that a woman plays in her life and to the people in her life (Cole et al., 2021). The coping strategy of self-silencing has been found extremely prevalent at the intersections of gender and chronic illness. Self-silencing is a coping technique reflecting how an individual decides to withhold or suppress topics that might cause conflict to maintain peace in a relationship. Self-silencing has been found to have significant associations with negative mental health outcomes, lower quality of life, and poor self-care (Sormanti, 2010). For many women, the change in identity was negative as they felt like they were failing others, missing out, and the identity shift served as a source of distress for the people in their lives so self-silencing was used to maintain a sense of normalcy. Cole et al. (2021) further explain that, "for many of the women in this study, expectations of women as selfless caretakers constructed in Western society were increasingly difficult to reconcile with symptoms of endometriosis such as infidelity concerns, sexual difficulties, and the limitations of chronic pain" (p. 185). Moreover, deciding to use self-silencing as a coping mechanism further harms the well-being of the woman as she ignores her emotional and physical health needs to avoid conflict. In this way, the tenets of the traditional sexual script remain prominent despite changes in women's health status (Cole et al., 2021).

Other researchers have examined common themes and cognitive patterns that emerge for women with endometriosis. When looking at endometriosis and sex, Nosek (1996) found that several things were important to women with chronic illness and sex including having healthy relationships, sexual functioning, seeing sex in a positive light, and receiving information about pain and sex in order to navigate sex with illness. Additionally, when asking women with endometriosis about their attitudes toward sex, researchers found three major themes: the body changing, meeting the needs of others, and communication about sex (Kralik et al., 2001). Given endometriosis causes bloating, pelvic pain, and inevitable surgery, women discuss that managing their changing bodies with their relational partner is difficult to cope with. Women who received a diagnosis in a relationship also desired more information and skills on how to communicate about sex in the presence of pain to their partners to combat difficult feelings. Additionally, pelvic pain caused by endometriosis lowers self-esteem, decreases feelings of femininity, and increases guilt toward their relational partner (Barbara et al., 2017). Women with endometriosis report feelings of shame and guilt for not having sexual desire or fear of not meeting their partner's needs. Even though 53.1% of women with endometriosis reported a decreased sex drive, they did not report having less sexual intercourse (Kralik et al., 2001; Moradi et al., 2014).

Scholars have found that sex communication can cause partners to experience anxiety, embarrassment, or fear of creating relational turbulence; thus, it is understandable why women with endometriosis might face challenges discussing painful sex with their partners (Rehman et al., 2017). At the same time, examining this phenomenon through a traditional and sexual script lens might magnify the presence of women privileging male pleasure and relational/partner needs above their own pain (Byers, 1996). Then, again, perhaps the investigation will shed new light and perspective on the scripts and outcomes. Despite the knowledge that communication is

a crucial part of navigating sex and illness, little research has addressed understanding the major role communication can play in crafting sexual scripts that account for the physical, emotional, and relational aspects of endometriosis and women's sexual health. Based on previous sexual script theory research, the traditional sexual script, and the biopsychosocial health impacts of endometriosis, the current investigation aims to address the following questions:

RQ1: Whose script (self, partner, relationship) is prioritized in sexual experiences with women who have endometriosis?

RQ2: What, if any, is the relationship between the prioritized script and valence of outcome for physical, relational, and emotional health (positive/negative)?

Chapter 3: Method

Procedures

A content analysis was conducted to identify script privileging and physical, relational, and emotional health outcomes. Sexual script theory (Simon & Gagnon, 1984, 1986; Gagnon, 1990) and the traditional sexual script (Byers, 1996; Byers & O'Sullivan, 2013) informed the lens through which the data were examined. Directed content analysis uses theory as a guide to determine coding schemas and potential relationships between/among codes (Hsieh & Shannon, 2005). The goal of using a directed content analysis for addressing the research questions is to identify and categorize what script is being prioritized and given partiality (self, partner, relationship) and the physical, relational, and emotional outcomes (positive vs negative valence) of using such scripts. The conceptualization and operationalization of coded themes are further unpacked below.

As previously stated, the traditional sexual script primarily privileges male pleasure and assigns women a more passive and reactive role in sexual encounters (Byers, 1996). The TSS aligns similarly with sexual script theory (Simon & Gagnon, 1984; 1986). The initial step of the directed content analysis is to identify whose health and well-being women prioritize when dealing with endometriosis and sexual encounters. For this study, health is defined as "a balance and integration of physical, social, emotional, and spiritual elements of life" (Kasle et al., 2002, p. 180). On a similar note, well-being is conceptualized to consider the feelings of positive emotions such as happiness, life satisfaction and feeling good about life overall (Diener, 2000). The use of the traditional script has become engrained in Western thought of gender roles, even to the extent that when women experience pain, they are still likely to continue taking on the selfless caregiver role (Cole et al., 2021). That is, traditional sexual script assumptions are

prevalent in sexual encounters where women are continuing to have sex despite the pain they experience (Herbenick et al., 2015; Schultz et al., 2005).

With that in mind, the first category of codes used to identify whose script is being prioritized is coded as follows: (1) *self,* (2) *partner*, and (3) *relationship.* The coding category *self* captures when women prioritize their personal health and well-being. An example of a self code is if a woman states that her partner wants to have sex, but she tells him "no" because she needs to rest. The *self* category includes the decision to avoid sex all together, especially when done to minimize one's own pain. Additionally, any comment that illustrates the women doing what is best for her health and well-being and engaging in self-care falls under *self*. On the other hand, the *partner* category identifies when women discuss putting the needs of their partner above their own health and well-being. Examples of privileging the partner script might include, "I was in pain but wanted to make him happy" or, "He was feeling bad about himself because we haven't had sex in a while, so I pushed through the pain." The *partner* coding category highlights the traditional sexual script where men's needs and pleasure are front and center in sexual experiences despite women experiencing pain or not wanting to engage in sexual activity (Byers, 1996).

Lastly, the coding category of *relationship* is coded when women discuss prioritizing the health and well-being of the relationship over themselves or their partner. For example, a post discussing a woman feeling like the relationship is fading away so she decides to engage in sex was coded as prioritizing the relationship. Prioritizing the relationship can be distinguished from prioritizing the partner when the data refer to acting in the interests of "we" or "us" instead of "he" or "him". Recognized in the latter code is that personal and partner considerations might be subsumed within the *relationship* code; yet, how the who (i.e., self, partner) or what

(relationship) is communicated in the data, as aforementioned, assists in illuminating script partiality and mutual exclusivity when referring to the self, partner, and relationship as separate entities in the communication. If the post used language of one or more categories that changed throughout the post, it was coded separately. For example, a post about how a woman didn't want to have sex but "toughed out" the pain to please her boyfriend but then later states in the same post she is doing what she can to preserve the relationship, was coded separately as *partner* and *relationship.*

After the first codes were complete, the valence of physical, relational, and emotional outcomes were coded. The second coding of categories to address RQ2 examined the valence of outcome of the decision. In other words, after identifying whose script is privileged, the physical, emotional, and relational outcomes experienced due to how endometriosis and sex are managed, were coded as (1) *positive* or (2) *negative* for each health code of (1) *physical health*, (2*) relational health*, and (3) *emotional health*. Collectively, six categories were created to reflect the outcomes of including positive outcomes of: (1) *positive/physical health*, (2) *positive/relational health*, (3) *positive/emotional health* and negative outcomes: (4) *negative/physical health*, (5) *negative/relational health* and (6) *negative/emotional health.*

The first health code is *physical health*. Physical health encompasses tangible experiences of the body. For example, when a post states how a women's body is feeling, this was coded as *physical*. Further, keys words such as pain, painful, discomfort, burning, tightness, etc. were coded as *negative/physical*. For example, if a post said, "Every time we try to have sex, everything hurts. The next day, I can barely function because my whole body is tense and uncomfortable." To work toward an intimate justice framework (McClelland, 2010) and following previous criticisms of "good sex" being measured by the *lack* of pain (Herbenick et al.,

2015; Loofbourow, 2018), the lack of physical pain or discomfort was not be coded as *positive/physical health*. With this in mind, *positive/physical health* included ideas of the body feeling good, having an orgasm, and experiencing pleasurable sensations. For example, "We are learning to do things that don't cause me pain. External stimulation from my partner feels incredible so anyone else who has had pain with sex, maybe try this instead!"

The next code is *relational health.* Relational health refers to "interpersonal interactions that are growth-fostering or mutually empathic and empowering" (Liang & West, 2011, p. 246). Various considerations can contribute to relational health, such as social support. Social support is thought of as "an exchange of resources between two individuals perceived by the provider or the recipient to be intended to enhance the well-being of the recipient" (Shumaker & Brownell, 1984, p. 11). Given such definitions, this code addresses the perceived state of relational health that the woman has of her relationship. Examples of discussing issues of coercion, unwanted behavior, manipulation, betrayal, or dynamics that harm or isolate the partner were coded as *negative/relational health.* For example, a post saying, "My partner doesn't care about the pain I feel during sex and he says that having sex is what people in relationships are supposed to do." On the other hand, posts that included a "sense of self-worth, vitality, and validation, a knowledge of self and others and a desire for further connection" represents a *positive/relational health* (Liang et al., 2002, p. 25). For example, if a post stated something along the lines of, "We as a couple decided to stop having sex as I work with doctors toward a solution(s). I feel really supported by my partner and am so grateful that we are in this together" then it is reflecting support indicative of *positive/relational health.*

The last code is *emotional health*. The emotional health codes reflect how a woman feels or the mood that she is experiencing about the events in the posts. For example, anything that

explicitly states “I feel…” is indicative of her emotional state. *Negative/emotional health* encompass feelings of distress, turmoil, anger, frustration, sadness, or resentment. An example of negative/emotional health is, “I feel horrible about the way my partner talked about my illness after we had sex. He doesn’t understand my chronic illness at all.” On the other hand, *positive/emotional health* codes included anything that reflects the women feeling confident, happy, or comfortable with who or what she is prioritizing. Such as, “I’m so happy to feel supported by my partner. I feel he really understands as to why sex is off the table for us right now.” For data that did not explicitly state emotional outcomes, the researcher attempted to derive valence from tone that might allude to either positive or negative emotion.

Sample

Given that the sample was targeted to encompass endometriosis and sexual encounters, this study used purposive sampling drawn from Reddit (Suri, 2011). Reddit as a platform includes subreddit boards that serve as forums for individuals to address various issues, including health conditions such as endometriosis, to pose questions, foster social support, and find community in their illness. The boards have different flairs, or tags that specify different interests within the community and some key words included in this investigation’s sample were “sex” “sexual health” and “sex and intimacy”. After a subreddit board that discussed sexual health and endometriosis was identified using the aforementioned flairs for the purposes of this study, the posts under the keywords were timestamped from September 30th 2020 - September 30th 2021 and included to serve as the data in the analysis. The unit of analysis is the utterances within the selected posts from this timeframe. As a decision rule for a post to be included in the data set, it must have met the four following criteria. First, Reddit posts include personal stories from women about living with endometriosis. Posts from family, friends, or partners who do not have

the illness were not included in the data set. Second, posts must explicitly discuss sexual health in the context of endometriosis. Sexual health is not just physical sex, but "a state of physical, mental and social well-being in relation to sexuality… and the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence" (WHO, 2020). While some posts tagged under key words talked about dating or romance, the data set was primarily looking at mentions of sexual activity or lack thereof. For example, anything related to sexual pleasure, sexual desire, pain with sex, orgasms, and any form of sexual acts met study decision rule criteria for inclusion. Any relational issues mentioned that relate to sexual activity were included. Third, the post must reference sexual health in the context of a relational partnership or a specific sexual instance with their partner. For example, a woman talking about her sex life with her partner since getting diagnosed or attempting to have sex after a date but experiencing physical pain met the inclusion criteria. Given the posts do not usually include a lot of context around the stage or type of relationship, the study considered any stage as long as it refers to sexual health with another person(s). If the post is from a women's relational partner, it was not included as it is outside the scope of the unit of analysis for this investigation. Lastly, the post must explicitly or implicitly state if the women is prioritizing her health, her partner's health, or the health of the relationship as defined in the procedures and include outcomes. For the study, prioritization is defined as putting one thing in front of the other or treating something more valuable than other things (Schmidt & DeShon, 2007). In other words, for all four decision rule criteria to be met for a post, the post must reflect a sexual situation with a woman who has endometriosis whose health (self, partner, or relationship) is being put first and include an outcome to the script privileging. The study's decision rule inclusion criteria ensures that a sexual script could be identified and reveal thought patterns communicated by women when

navigating sex and pain from endometriosis within a sexual partnership. Any comments on the included posts that match the inclusion criteria were also included in the data analysis. For example, if a woman posted her experience about prioritizing her partner's pleasure and feels poorly about it and another woman with endometriosis comments and says that she found that avoiding sexual encounters with her partner for a time has helped her pain and emotional state, it was coded. In other words, if the comment fits the inclusion criteria and could stand alone as its own post, it was included in the dataset.

Publicly posted Reddit usernames indicated in the public forum, while contrived, were nevertheless changed to pseudonyms to protect the identity of posters. Given the posts are created anonymously and identifying traits such as age, race and sexuality are unknown, it is important to note that the study operates under a few basic assumptions. The study assumes that the posts are written by those who identify as women and are either diagnosed or living with symptoms of endometriosis. Additionally, the work assumes that unless stated otherwise, the women posting are in heterosexual partnerships. Given the study aims at understanding the traditional sexual script and gender expectations, the study operates with the assumption that the woman is the one with experiencing the endometriosis and in a partnership with a man. While solely addressing heterosexual relationships allows for a tighter sample with future generalizability considerations, the author will acknowledge the limitations of such assumptions at the conclusion of the study and address various unit of analysis considerations in the Future Directions' section of this project.

Data Analysis

Once the posts from September 30th, 2020-September 30th, 2021 were gathered and met the decision rule inclusion criteria, the data were analyzed. Included in the dataset are posts and

comments in response to posts from the subreddit if they met the inclusion criteria. The coding categories were informed by the traditional and sexual script and served as an insightful, informative lens through with which revelations about whose health is prioritized in a sexual encounter and the emotional outcome of such prioritization. To start, the data set was printed, and the coding progress the entire data set was read through. Next, each post was read individually and repeatedly with great attention. Then, the original dataset, which consisted of over 1,000 posts, was combed through, and revised to only include posts that fit the inclusion criteria. There were 90 posts total. After the dataset was narrowed down, the author read and highlighted each post to determine if self, partner, or relationship was being prioritized. Self was highlighted in yellow; partner was highlighted in green, and relationship was highlighted in orange. The process was repeated, and several passes were made. Then, a similar process took place to code valence of physical, relational, and emotional health outcomes. Physical positive was highlighted in orange and physical negative was highlighted in blue. When coding physical outcomes, a neutral code emerged that captured experiences between positive and negative. A neutral category was created and defined as, "not the body feeling good or the body feeling bad, such as feeling "less pain" or "more comfortable" but isn't necessarily experiencing pleasure." For example, "We try different positions and it's less painful." Neutral physical outcomes were given a star next to them. Relational health was then coded, emotional positive was highlighted in yellow and emotional negative was highlighted in pink. Lastly, relational positive was highlighted in green and relational negative was highlighted in orange. Each code was passed through several times until the data was saturated and exhausted (e.g., the data was reviewed repeatedly and coded appropriately and then coded by an independent reliability check.

After repeated coding passes through the data, the researcher felt saturation had been achieved, with codes appropriately placed with confidence into their respective categories. Following, an independent coder, unaware of the nature of the study, served as an intercoder reliability check and coded a random 20% of the data across coding categories. Prior to the coding of the random 20% of the data, the researcher trained the independent coder using the coding rubric created by the researcher. After the first coding pass, comparisons were made regarding coding agreement and there existed 16 coding agreement discrepancies between the researcher and the independent coder. After discussion, agreement between the researcher and independent coder was achieved at 100%, $\kappa = 1.00$ (Cohen's *Kappa*).

To address RQ1, the self, partner, or relationship codes were frequency counted. Next, to address RQ2, the valence of physical, relational, and emotional health outcomes in the data set associated with the script prioritization(s) were counted and moved to an Excel spreadsheet. RQ1 was then tested with a goodness-of-fit chi-square to ascertain if a significant difference exists between the coded script prioritizations observed and theoretical chance. RQ2 was tested with a 3X6 chi-square test of independence to determine if, as one moves across scripted codes observed, outcome valence of physical, relational and emotional health shifts observed differs beyond theoretical chance.

Chapter 4: Results and Interpretation

Initially, two research questions were proposed in this investigation to better examine the relationships among different script types as well as between scripts and health outcomes. More specifically, the purpose of this investigation was to examine women's experience with endometriosis and their navigation of sexual activity. Furthermore, the study works to understand who women are privileging in their health encounters and the physical, emotional, and relational health outcomes of such privileging. To do so, posts from public subreddit boards were examined between September 30th, 2020-September 30th, 2021. Ninety posts met the inclusion criteria of the study and are included in the analysis.

As the first research question was being coded, it became apparent that the data expressed more than originally asked in the question. More specifically, there appeared to be thematic similarities and consistencies among the utterances in the data speaking to scripts. To account for the thematic threads for which the self script was expressed, a qualitative analysis was added to RQ1 using grounded theory. Grounded theory provides a lens through which data can be interpreted qualitatively, accounting for the similarities and differences that occur within a data set (Walker & Myrick, 2006). Otherwise known as constant comparison theory, this methodology works to organize quantitative data into themes or concepts to further explore the different ways words, language, and meaning emerge to understand a specific experience (Manning & Kunkel, 2014). Qualitative methodology enhances the original research question by capturing how women were making meaning in their sexual experiences and the different ways that meaning was made when using a self script. Additionally, adding thematic analysis captured the feelings, emotions, and experiences that further add richness and information to work in tandem with quantitative data (Manning & Kunkel, 2014; Walker & Myrick, 2006).

Research Question 1: Script Prioritization

Research question one asked, "Whose script (self, partner, relationship) is prioritized in sexual experiences with women who have endometriosis?" RQ1 was tested with a goodness-of-fit chi-square to ascertain if a significant difference exists between the coded script prioritizations observed and theoretical chance. Results were significant χ^2 (2, N = 78) = 99.36, p < .001. An examination of cells indicates 78 observations coded as "self," 16 observations coded as "partner," and three (3) observations coded as "relationship." The total 97 script references were found within the 90 posts, meaning that for some posts more than one script appeared and was accounted for. Given fewer than five (5) observations exist for the relationship category, results of this test are noted with a bit of caution.

Regarding the results of RQ1, the data demonstrate an overwhelming focus on the "self" script. Although a public subreddit was examined for this investigation and those who participated on the board chose to post to a public board, pseudo names are nevertheless used when giving post examples. Similarly, posts offered as examples include minor verbiage adjustments to quotes to support poster anonymity. The grounded theory analysis of the data related to RQ1 resulted in four primary themes emerging, reflecting manners in which women with endometriosis prioritize themselves and their health. The four themes and frequency of appearance in the data are as follows: accounting and adjusting for pain (18); avoiding sexual activity (36); reframing expectations (12); and, exploring solo-pleasure (7). There were four self scripts that did not fit into any category. Each of these aforementioned themes is further explicated below.

Accounting and Adjusting for Pain

Many women discuss incorporating pain relief methods to continue having sexual encounters with their partners. Pain was accounted for in a variety of ways, including self-care acts before and after sex, being mindful of positioning during sex, and using things that helped with pain such as lubrication or pain medication. For example, Post17 explains, *"I have a pre sex prep list. It includes 20 mins of pelvic floor yoga, 20 mins of applying a heating pad to get my pelvic floor as happy as possible prior to sex. It can be a headache to take an hour to prep for sex, but I do find it makes a difference!"* Post7 also used self-care strategies and shares, *"I usually take a hot bath after to ease any pain that did occur."* In this way, taking a bath or doing pelvic floor exercises allows women to relax and feel a sense of agency over their sexual experiences. In addition to adding self-care before, during and after sexual encounters, women explained that exploring different positions was also key to being able to have sex with endometriosis. Post18 explains, *"What I found worked for me was being on top. I can control the depth and we are both able to get satisfaction from it."* Post19 echoes the positional strategy shared by Post18 and indicates, *"I prefer to go on top as I have more control."* Other users share like-themed strategies, *"Positions are also key, try different things, it helps me to be in control of the motion until I have adjusted to what's happening*," *"Some positions are better for me than others"* and, "*I have found with patience, lots of foreplay, slowing easing into penetration, lube, and caution at the angles we use, sex starts feeling mostly good instead of bad."*

Avoiding Sexual Activity

Another emergent theme in response to RQ1 and self script prioritization was avoiding sexual activity all together. Many women express sex causing too much pain and it is in their best interest to listen to their pain and not do anything to exacerbate it. For example, Post8 shares, *"I'm not sexually active because it's too painful."* Post5 expresses that, *"Every time I*

have sex, I get this horrible dull pain in my entire pelvic area for hours afterward. It's gotten to the point where I don't do anything anymore." Additionally, Post6 notes, *"What has helped the most is just not having sex. I still miss it but not having it has been so good for me and my pain."*

Reframing Expectations

Reframing expectations around sex and intimacy with their partners is another way women prioritize themselves and is a third theme emerging during analyses. Post34 explains that, *"Our sex therapist has been helping me and my husband understand why sex is hard for me AND helps us find other ways to be sexually and emotionally intimate."* Similarly, Post87 writes, *"We have worked on building a positive and less goal orientated (as in sex must always lead to orgasm). Our counselor recommended we look into Tantric Sex. It has been a game changer for us! It helped us reframe our sexual experience together that is more enjoyable for us, even if he isn't inside me."* Women express other means of physical intimacy that didn't give them pain such as cuddling, taking baths together, or kissing. Post15 finds that, "*Reframing my expectations is helping somewhat. Right now, my partner and I are working on physical intimacy in other ways (like nightly make-out sessions)."*

Exploring Solo Pleasure

Lastly, women who prioritize their sexual scripts find ways to explore pleasure alone. Post58 says, *"Getting a toy and finding ways to explore what feels good for you without causing pain and without the pressure to perform makes a huge difference."* Post66 echoes this sentiment by sharing, *"I started trying things by myself first and it has helped me. Get to know what you like and don't like. It's going to make you feel more comfortable in bed*."

While the women's experiences explored in this investigation overwhelmingly demonstrate privileging their own health, it is important to acknowledge the less frequent voices

of women that discuss prioritizing their partner over themselves. Post2 explains that she continued to have sex despite her pain due to her partner's insistence. She says, "*My partner didn't believe my pain. I did a lot out of obligation while being coerced, guilted and somewhat forced."* Post72 also shares a similar experience*:*

> *I'm doing my best to have sex with him every day even if it means going to work all day with pain that leaves me physically sick at work. He still treats me like it's not enough. He asks for sex all the time regardless of my energy levels, mental state, and pain. It is making me feel absolutely useless.*

While occurring less frequently, prioritizing one's partner appeared 16 times in the data. Women who prioritized their partner discussed giving pleasure to their partners when they didn't feel like having sex. For example, Post4 writes, *"…when I'm not really feeling it but still want to make my partner feel good, I go for oral sex and just decline when he offers to reciprocate it."* Post23 shares a similar view saying, *"Sometimes I try to work through the pain because I am stubborn and want to focus on my partner."* Post26 discloses the dilemma she faces managing her pain and the expectations of having sex in a relationship: *"I would be quite happy being asexual if I wasn't with my partner but since I plan on staying with him (possibly forever) I can't live with this and have to start getting answers."* Furthermore, Post77 says, *"I have a boyfriend of two years and I put up with sex for him, but it isn't fun."* Post70 writes, *"I knew I wanted to have sex but really more for him,"* which sums up a majority of the statements women shared about keeping their partner's pleasure in mind when navigating endometriosis. In addition to giving pleasure to their partners, women who prioritized their partners discussed feeling obligated or manipulated by their partners. For instance, Post72 comments, "*I'm doing my very best to have sex with him every day"* and Post3 shares, *"I did a lot out of obligation."*

For the few women who discussed privileging their relationship over their health, they discussed wanting to make sure they didn't lose their relationship. For example, *"I try to hide it [pain] sometimes just because I don't want my partner to leave me or view me as worthless* [Post86]*."* Post5 echoes this idea saying, *"...I don't have him to get frustrated and leave because I like him a great deal and want to keep him."* Lastly for relationship prioritization, Post67 discusses that "*Numbing cream inside me and my partner wears a condom which greatly reduces painful sensations during sex. Once I decided I didn't need to feel pleasure during sex this method became so helpful for our relationship."*

Research Question 2: Scripts and Health Related Outcomes

Research question two asked, "What, if any, is the relationship between the prioritized script and valence of outcome for physical, relational, and emotional health (positive/negative)?" To test RQ2, a 3 (self script, partner script, relational script) X 6 (physical health with positive valence, physical health with negative valence, emotional health with positive valence, emotional health with negative valence, relational health with positive valence, relational health with negative valence) chi-square test of independence was conducted. Results were nonsignificant, χ^2 (10, 155) = 12.068, p = .28. It should be noted that several cells indicate < 5 datapoints. That said, as displayed in the frequency table below, health outcomes are most strongly aligned with the self script with strong representation for an association between the self script and negatively valenced physical health outcomes and negatively valenced emotional health outcomes, in particular.

Table 1: Scripts and Health Related Outcomes

	Physical Health /Positive	Physical Health /Negative	Emotional Health/Positive	Emotional Health/Negative	Relational Health /Positive	Relational Health/Negative
Self Script	15	53	9	33	16	5
Partner Script	0	11	0	7	1	3
Relational Script	0	2	0	0	0	0

While the statistical test results for RQ2 are nonsignificant, the findings do provide insight into what health outcomes most frequently associate with what script is being exercised. Indeed, the results say much about what is—and what isn't—being experienced and are nevertheless worthy of note. Most prevalent in the findings is the association between prioritizing the self script and negatively valenced physical health and negatively valenced emotional health outcomes. Most of the women who exercised their self script had negative physical health outcomes. For instance:

> *I can't have sex without feeling like there's a block in the way and it feels really uncomfortable. Also, with sex sometimes my vagina burns really bad and it feels almost gross like an infection. And this has just gotten to the point where I can't actually have sex anymore* – Post1

Many others list their negative physical experiences such as *"My partner and I don't have penetrative sex because I'm in pain"* [Post17], *"I didn't have sex for almost a year and a half because of the pain"* [Post29], and "*Sex is extremely painful for me that's why I've just stopped"* [Post28]. For the women who experienced positive physical health outcomes, they

discuss prioritizing their pleasure through non-penetrative activities such as *"foreplay" "oral sex"* and *"cuddling"*. Additionally, Post18 shares how she avoided certain positions that brought her pain and worked with her partner to find positions that allowed her to experience pleasure: *"What worked for me and my partner was for him to be on top. We are both able to get satisfaction from it and we come back to this move for pleasure."* However, not all women who do prioritize themselves or pleasure have positive outcomes. For example, Post51 discusses negative physical pain and negative emotional outcomes when adjusting sex to her needs saying, *"I have pain with sex and it's really difficult for me. I feel like I've let my partner down when we can't have sex. I still want intimacy though. So we try to do cuddling, massages, and oral so that there is still physical intimacy."*

Next, emotional health outcomes are discussed. The decision to prioritize one's own self script associates with a mix of positive and negative emotional outcomes; yet, negative health outcomes emerge from the data almost 4x more frequently than positive emotional health outcomes. Post30 writes, *"Sex is out of the question now because it's too painful. I was such a confident person before endo kicked in, I just want to know when I will get my life back. I'm so sad."* Post16 explains that the pain anxiety is what's stopping her from having sex saying, *"I'm pretty open with my boyfriend about my pain and I think it helps him to understand why we're not being as intimate. Pain anxiety plays a big part in it for me."*

The negative physical and emotional outcomes appear in the some of the same posts for women: *"Penetration hurts a little but that's mostly fine for me. But when I orgasm, I am fine for 20 seconds then I'm in EXTREME pain as if it's the first day on my period and I'm passing a large blood clot. I honestly don't have sex anymore because I'm so scared of this happening* [Post48]." In a similar way, Post24 writes, *"Painful sex is a new addition to my symptoms. I tried*

different times but I can't have sex anymore. It's crazy-making and so frustrating." Similar in sentiment, Post53 shares, *"I'm feeling very down about my sex life. It hurts almost every time and I am so anxious about the thought of sex that I avoid it. My husband is very understanding but I'm so pissed off and angry that we can't have spontaneous sex anymore."*

While positive emotional experiences present less frequently, some women do experience positive outcomes when putting their health first. The women who prioritize their self script and experience positive emotional outcomes discuss how their lives improved by taking care of themselves. Post21 states, *"I decided a few months ago that I would stop having sex and it's been one of the most positive and liberating decisions I've ever made in my life. I am fine with cuddling."* Post50 talks about her progress in pelvic floor physical therapy saying, *"I haven't had sex for 3 years but I am working on making progress with dilators and feeling optimistic."*

Lastly, the outcomes for relational health are mentioned. More positive relational health outcomes appear in the data than do negative relational health outcomes as related to the self script. Post19 says:

> *I prefer to go on top as I have more control. We experiment with positions and look things up, but it's all been a bit too much. We've bought the OhNut today and are looking into a pillow wedge. I'm so happy he is caring and patient and going through this with me. We're reading all the comments about sex with endo together*

Other posts discuss how the partner is *"understanding" "accepting"* and *"supportive"* of doing what is best for the women whether it is not having sex or finding ways to adjust or reframe sexual experiences together.

The negative relational health outcomes appear to demonstrate what happens when women do stand in their power and exercise their agency yet may not receive the support that

they need from their partners. For instance, Post57 shares, *"Lately, my partner has been questioning if I am cheating on him or even love him because I haven't engaged in sex and said no to every proposal during the last 7 months. He says he [is] okay not having sex but sometimes he makes resentful comments, and it hurts."* Another post also illustrates negative emotional valence in tandem with negative relational health:

> *I suffer from extreme endometriosis. My fiancé gets annoyed with me and isn't understanding at all. He expects sex every night and when I explain how much pain I am in it seems like he couldn't care less. I laid my foot down last night and refused to have sex and it started a huge fight. I feel worthless like I am unable to do anything and not good enough* [Post27].

Additional Analyses

Based on the data and emergent themes and examples, a third research question was added to deconstruct the relationship more pointedly between message valence and health outcome. Eleven neutral codes had emerged during coding for the physical health category only (zero observations are noted for both emotional health and relational health), but were not included in RQ2 testing given RQ2 focused on positive and negative valence. Therefore, neutral codes are recognized in this additional analysis. Specifically, "What is the relationship between message valence (positive/negative) and health outcome (physical health, emotional health, relational health)?" To test RQ3, a 3 (physical health, emotional health, relational health) X 3 (positive, negative, neutral) chi-square test of independence was conducted to determine if, as one moves across categories of physical, emotional, and relational health, shifts in outcome valence (positive/negative/neutral) differ beyond theoretical chance. Results are significant but

must be interpreted with caution given cells exist within fewer than < 5 items, χ^2 (4, 166) = 37.467, $p < .001$. Cell frequencies are as follows:

Table 2: Valence of Health Outcomes

	Physical Health	Emotional Health	Relational Health
Positive	15	9	17
Negative	66	40	8
Neutral	11	0	0

The results of RQ3 indicate that an association exists among physical, emotional, and relational health and positive, negative, and neutral outcomes. Specifically, outcomes most frequently related to a women's physical and emotional health are much more negative in nature, whereas the frequency of outcomes related to a woman's relational health are more positive in nature. Results suggest that relational health outcomes are twice as likely to be positive (versus negative) in nature. The resulting associations are further explicated below.

Valence Outcomes

Physical Health

The majority of response frequency for physical health is negative in nature. Below, examples illustrate the negative physical health response women experience in sexual activity. Most women express the physical pain that occurs during sexual activity. Post57 says, "*Sex is so painful, it makes me extremely nauseous*". Others followed this idea saying, *"Sometimes I have to stop my boyfriend in the middle of sex because I'm about to throw up from pain* [Post81]*"* and "*The pain that sex induces if they push in the wrong spot is excruciating* [Post86]*"* Others describe the pain from sex as "*physical agony*" and "*felt like my body was being ripped in half."* Frequently occurring negatively valenced descriptors and terms used include *"pain," "sex*

hurts," "sex stings," "sex is extremely painful" and having sex with endometriosis as *"the most painful experiences ever had."*

On the other hand, a handful of women express experiencing positive physical health. Albeit much fewer in number, the women who did express positive outcomes are able to have orgasms in their encounters. Post79 says, "S*ometimes I am able to manage getting comfortable enough to have an orgasm."* Specific actions also increase pleasure for women. For example, *"Foreplay feels amazing and really turns me on* [Post63]*" and "...being on top makes sex enjoyable* [Post18]*."* It is important to note that some of the positive physical health codes are followed by or co-exist with negative physical health outcomes. For instance, *"I like to climax before we start, this sometimes backfires because I also get orgasm cramps but mostly it helps a lot* [Post21]*"* Similarly, a user writes, "…*as we keep going, I can start to change positions without much pain. There are times where if he starts to go to the right (where a lot of endo was removed) it hurts, and we have to reset. Also, if I can orgasm before we get into these positions, I'm a happier camper* [Post22]*."*

While the neutral valence was only found for the physical health category, the 11 neutral posts express a physical experience that did not fall in the category of negative or positive. What emerges in the posts are expressions of the body feeling neither good nor bad, yet still acknowledging how the body was feeling. In this way, neutral physical health was defined as "not the body feeling good or the body feeling bad, such as feeling "less pain" or "more comfortable" but isn't necessarily experiencing pleasure". To illustrate, one woman stated that, "*Other forms of intimacy can be a lot less painful and still enjoyable* [Post23]*."* Neutral also expressed women's body or pain feeling "*okay*". For example, "*If we go slow, then it's okay and doesn't cause intense pain* [Post14]*."* Additionally, women discuss doing certain things that help

make their "pain less" so they are able to have sex, yet they are not experiencing pleasure or horrible pain.

Emotional Health

As messaging shifts from physical health in nature to emotional health in nature, the messaging valence continues to be primarily negative in nature. Many women try to explain the emotions felt when navigating pain in their sexual lives. Post80 talks about how isolating and lonely it can be:

> *I hate having sex. I just sit there and wait for it to be over unless I'm wasted. No one in my life can fathom what having painful sex is like. Sometimes I wonder if my inability to express love in a physical way is affecting my ability to be open and vulnerable about love, at all. Am I crazy??? Does anyone else feel seriously...stunted emotionally…because of all this?*

Post41 also shares feelings of isolation, writing. *"I really feel like I am missing out on something everyone else has/can experience and it's dampening my quality of life significantly."* In addition to isolation, many of the responses go beyond frustration and demonstrate significant mental health crises such as panic attacks and depression. Post65 says, *"I've been so traumatized by pain and procedures that I have no interest in having sex anymore. I often get PTSD symptoms during intercourse or have panic attacks."* Post2, "*I now have negative reactions to anyone touching me. It's definitely a form of traumatic response. I completely freeze and shut down.*" Post33 discusses that the emotions are so awful, *"I don't know what to do anymore and honestly most of the time I don't want to be alive anymore. I just want to stop hurting. I'm so tired of this."*

Along with isolation, depression and suicidal thoughts, women with endometriosis discuss the feelings of anxiety that came with having sex, otherwise known as pain anxiety. Many women wrote about *"feeling terrified," "scared"* or *"mental anguish"* in anticipating the pain and *"incredible frustration."* One woman writes:

> *So after 2 weeks of recovery from endo surgery, I am now cleared to put things in my vagina. I should feel excited about this but I'm finding I feel anxious. I know my husband wants to have sex and I do too but I'm having performance anxiety about it. And then there's the possibility of pain. One of the biggest reasons I got surgery was because of how painful sex has been for me. I guess I'm worried that it'll still be painful. I know I'll feel really discouraged if it still hurts* [Post31].

Women also experienced guilt when putting their needs first. For instance, *"I feel worthless and not good enough"* and *"I always feel guilty for not being able to have sex with my husband"* are commonly shared sentiments from the women.

Fewer women on the subreddit speak about having positive emotional health, but few who did describe it as follows. Women who experience positive emotional health talk about how *"Stopping having sex has been one of the most positive and liberating decisions* [Post21]." Similarly, a user writes that *"Never having sex again has improved my life enormously* [Post12]*."* Women who are able to have sex without pain talk about how happy they are to be able to engage in a normal activity. Post84 shares, *"I'm so happy I was able to have sex again!"*

Relational Health

As messaging shifts from physical health in nature to emotional health in nature, a shift is noted in the valence of the messaging. Specifically, communication shifts from being more negative to positive, particularly for relational health. Women who have supportive partners

express feeling seen, heard, and validated in their pain and health needs. For example, Post79 writes, "*My husband is patient with me and always willing to go slow and try different positions or stop if we need to."* Post88 explains a similar sentiment*, "My boyfriend, who is hardly empathetic, is super kind about the issue. He totally understands when I'm in pain and he supported me getting treatment and helping me stand up for myself to doctors. He adjusts as needed and we try different positions that work for us.* Similarly, Post9 shares, *"My current partner is incredibly mindful of how I am feeling, so our communication about sex is great which is really helpful!"*

On the other hand, the negative relational health codes suggest sexual coercion, invalidation, and signs of abusive behavior. Post72 shares her story saying, "*My partner has been with me since right before I got sick and he constantly compares what I used to be able to do sexually to what I can do now. How do I get him to realize how severe the pain from sex really is? It's making me feel absolutely useless."* In the same way, Post74 says, *"I used to have a partner who put his needs above mine before and I remember having sex while profusely bleeding and being uncomfortable and I decided I would much rather be alone than ever go through this again."* Lastly, Post57 conveys that *"My partner has been questioning if I am cheating on him or if I even love him because I haven't engaged in sex and said no to every proposal in the last 7 months. Sometimes he makes resentful comments and it hurts."*

Chapter 5: Discussion

A paucity of studies exist that examine how women with endometriosis experience sexual encounters (Cole et al., 2021; Nosek 1996). The purpose of this study was to understand the sexual script privileging of women with endometriosis and associated physical, emotional, and relational outcomes and message valence. The results of the self being the dominant script and health outcomes being associated with each other have implications for traditional sexual script theory and the biopsychosocial well-being of women. The findings inform sexual script theory and communication's role in health outcomes, relational coping strategies, and online health.

Theoretical Implications

According to the traditional sexual script and sexual script theory, women are often conditioned to privilege their male partners' needs above their own and use self-silencing as a main coping strategy (Byers, 1996; Byers & O'Sullivan, 2013; Cole et al., 2021; Simon & Gagnon, 1984; 1986). According to traditional sexual scripts, women are expected to put the man's needs first and are more likely to engage in unwanted behavior to please their partner (Mahar et al., 2020). However, the women in this study reflect a prioritization of their needs rather than those of their partners. What these findings suggest is a shifting as related to challenges associated with traditional sexual scripts and gender expectations. In other words, women are exercising their agency more and prioritizing their self and needs; yet, are also experiencing negative health outcomes. Specifically, women express feeling proud about standing in their power while managing proximal and distal emotions such as guilt, anxiety, helplessness, uselessness, and despair. A similar pattern is found from communication conflict scholars that report positive emotions when initially expressing one's needs and desires. For example, Malis and Roloff (2006) found that as time went on, partners who expressed conflict

initially later experience more negative outcomes such as stress, intrusive thoughts, and more avoidance. What this suggests, particularly as related to this investigation, is that women often experience negative feelings (e.g., dissonance, guilt, anxiety, depression) and/or consequences (e.g., personal physical/mental/emotional health is adversely impacted, partner becomes upset, relationship suffers) for standing up for their needs in relationships (Cupach et al., 2010; Mahar et al., 2020; Malis & Roloff, 2006). That said, given the statistical tests in this investigation were ones of association and not directional or causal in nature, an alternative interpretation of the findings is that the experience of poor physical, emotional, or relational health, for example, is associated with prioritizing a particular script. For example, a woman might feel depressed (emotional health) or experience bodily pain (physical health) and make the decision that they are tired of feeling this way and decide to prioritize themselves for once (self script) in the hope that it alleviates those feelings. Future research can further address and unpack the dynamics of scripts and health outcomes.

There are a few possibilities as to why women who prioritize the self script may be experiencing negative physical and emotional health. First, women may experience negative consequences because exercising agency might be considered as going against the grain of the traditional sexual script or cultural script expectations. In this way, speaking out and working to create new relational norms that account for women's health and pain may bring conflict into the relationship and contribute to avoidance strategies and withdrawal patterns, further isolating women in their illness journey (Cupach et al., 2010).

Given that the cultural and societal sexual scripts for women promote privileging the male partner's needs above their own and using self-silencing as a main coping strategy, women might experience stigmatization for going against the traditional sexual script (Byers, 1996) or

cultural script expectations (e.g., Simon & Gagnon, 1984; 1986). By exercising more agency, women are resisting societal expectations of what it means to be a woman. For example, women discussed feeling shame and guilt for not being able to meet their partner's needs when they had to stop having sex to manage their own pain. When women prioritize their health, they might be breaking societal expectations of being passive and reactive versus proactive, thereby experiencing negative emotions like shame and/or guilt.

Furthermore, women experience a double standard when it comes to their sexual health and communicating their needs. For instance, cultural scripts, as well as the TSS, promote a passive sexuality for women while normalizing self-silencing to avoid conflict and to prioritize men's needs first. When women adhere to the cultural values assigned to being a woman and repress their needs, research has found it is detrimental to their health (Sormanti, 2010). On the other hand, this study highlights that when women do express their needs and resist the traditional cultural gender notions, they also experience negative health consequences, particularly in the domains of physical and emotional health. As a culture and society, gender expectations are worthy of address, specifically in sexual encounters to promote more equitable experiences and better health outcomes for women. The study reflects the difficulties women face when prioritizing themselves due to resisting the traditional and cultural sexual scripts and double standards. One scholar offers a framework called intimate justice to account for how gender and racial expectations and sexual stigma impact people's sexual behavior, especially regarding what one believes they deserve in their sex lives (McClelland, 2010). While traditional and sexual scripts remain considerations in gender expectations today, more equitable scripts are necessary to account for the experiences of women and sexual and gender minorities.

Along with cultural scripts and stigma contributing to the negative health outcomes, women might be experiencing negative emotional health when prioritizing themselves because they are not able to engage in normal activities like sexual intimacy. As with women's being conditioned to keep the peace, per traditional and sexual scripts, women are also conditioned, particularly from traditional, conservative viewpoints, to "do their duty" as a relational partner. For example, well-known conservative author and radio host Dennis Prager (who co-hosted a fundraiser for Senator Mitch McConnell) was quoted in 2008 as remarking that wives have an obligation to sleep with their husbands whether in the mood not, just as husbands have an obligation to go to work (Jaffe, 2014). Sentiments such as these can contribute to perceptions about expectations.

Similarly, women might experience emotional distress because they must stop having sex to avoid pain or take care of their bodies yet, when doing so, are not having the normalcy of what sex looked like before having endometriosis. While adjusting for pain within sexual encounters allowed women to continue having sex with their partner and maintain engaging in normal life experiences, avoiding sex meant not engaging in activity. Meana and Lykins (2009) explain that physical pain is made worse when women are not able to engage in their normal activities which results in feelings of isolation, depression, and anxiety, which are, of course, also related to emotional and relational health. Thus, when women put their needs first, they are feeling isolated from the norms and expectations of womanhood. Moreover, if the women are conditioned to embrace more traditional and/or conservative views, they might also feel dissonance regarding what "expected partnerhood" looks like sexually speaking. These layers of feelings can compound, thereby contributing to a greater abundance of negative health outcomes. In sum, while prioritizing one's health by avoiding the activity of sex, women might nevertheless

experience negative emotional health outcomes because they are mourning the loss of their life before chronic illness. However, by acknowledging the presence of pain while still working to find ways to experience pleasure and sexual intimacy, women can enhance their emotional health.

Alternatively, when women reframe with their partner their expectations of what affection and sexual health look like in the context of chronic illness, they have more positive relational health outcomes. Positive relational health contributes to women feeling validated in their pain and experience support rather than isolation when prioritizing themselves. While going against traditional sexual scripts might cause stigma, women experience positive relational health when feeling supported in their interpersonal scripts and encounters. What this suggests is that while a cultural shift around gender is necessary to celebrate women prioritizing their health, women can get positive validation from their interpersonal communication, or relational partners.

On the other hand, another possible explanation, as noted earlier, could be that women may prioritize themselves *because* the pain is so horrible rather than experiencing negative health outcomes due to self-prioritization. As the posts convey regarding their physical symptoms, reflected is the decision to stop having sex as one strategy to avoid their pain. It could be possible that the physical pain a woman experiences might influence enacting a self script, specifically the strategy of abstaining from sex, which could then lead to negative outcomes such as guilt (Cole et al., 2021). The relationship between avoidance and negative heath variables has been supported in previous literature, that is people who experience painful sex tend to use the strategy of avoidance as to not make their pain worse (Bair et al., 2003; Thomtén & Linton, 2013). Furthermore, avoidance has been found as a predictor for negative emotions such as

shame and guilt and increase sexual dysfunction (Thomtén & Linton, 2013). Bair et al.'s (2003) research is congruent with these findings which found how avoidance, or negative behavioral emotion regulation, results in an array of negative effects such as worse pain and mood. In this case, prioritizing oneself could be a reaction to the physical negative health women had; and, to cope with the pain, some women had to do things to put themselves first. And then, the negative emotional health consequences that appear could be due to avoidance. Specifically, in this study, women may be making themselves feel worse because they believe the traditional sexual script regardless of if a partner is place pressure on them or not. Since women didn't have as many negative relational outcomes, the presence of negative physical and emotional health could be explained by this idea.

Overall, it is critical to note the variety of explanations regarding the prevalence of the self script and consider previous research that may indicate why negative health outcomes arise in tandem with the self script. Of interest for future research, particularly when examining these phenomena longitudinally, would be how scripts influence health and how health influences scripts. For example, might decisions at Time 1 in a relationship affect decisions at Time 2 in a relationship? That is, if a woman prioritizes herself (self script), but ultimately experiences negative relational outcomes (relational health), will she continue to follow a self script prioritization in future sexual decisions? Or, might she believe and decide that because her relationship (relational health) was adversely affected by her decision, that she should pivot and engage in sex (even if she has reservations about it) to appease her partner (partner script). As demonstrated, the potential exists for associative shifts, directionality, or circuitous patterns to present and are worthy of further investigation.

The last theoretical implication should consider the context of Reddit. Specifically, according to the traditional sexual script, women are conditioned to prioritize men over themselves (Byers, 1996). However, the data from this study reflect the exact opposite, that women reported making decisions that had what was best for their health in mind. A possible explanation for women's decision dynamics might be that the data were collected from an online site. That is, research indicates that many users go to Reddit for a space to discuss topics that are taboo or difficult to find information about from institutions or social structures (Ammari et al., 2019; Andalibi & Forte, 2018). Additionally, Reddit is a forum that allows specific communities to gather anonymously, making it easier to go against cultural norms or expectations (Sowles et al., 2018). For example, relational health research reflects women have a difficulty expressing their needs and putting their needs first due to cultural expectations about what it means to be a woman (Sormanti, 2010). What this suggests is that even though this study found a focus on the self script, offline women may still be following the traditional sexual script by prioritizing their partners or relationships. With this in mind, research that draws from online forums or investigating online communication must account for the limitations of generalizing the findings to the world offline (Proferes et al., 2021). In other words, while women online were putting themselves first, it could very well be that they did so because of acceptance of taboo topics and anonymity enabled a space allowing women to go against cultural norms. Additionally, research on the implications of research done via Reddit acknowledges that conversational patterns online may not be conducive with what happens on other media sites or offline, thus further calling for the work to be generalizable to the Reddit community rather than take as reflections of offline realities (Proferes et al., 2021).

Practical Implications

Given that relational health is more positively valenced in this investigation than physical and emotional health, what the findings suggest is that communication between partners about sex is critical to the sexual health and overall well-being of women with endometriosis. Women in relationships, especially those with chronic illness, benefit greatly from supportive relational communication (Wahl et al., 2021). Given more than 50% of women with endometriosis have reported feeling misunderstood and invalidated by their partners, communication becomes the way that partners can support women's endometriosis journey (Moradi et al., 2014). The women in the study who did have relational support appear to experience more positive emotional and physical health. Women expressed receiving support by feeling listened to, understood, and empathized with by their partners. Additionally, women explained that having their partner who validated their pain and worked with them to cope with the distress contributed to a greater sense of relational health and well-being (Lichtman et al., 1987). Specific things couples did was reframing expectations about what sex means and focusing on types of affection that don't induce pain are key strategies this study's findings suggest. Not only does this allow partners to display intimacy and affection without inducing extreme pain for the women, but it also eases anxiety and helps women feel more comfortable with their bodies (Delaney, 2019). In this way, communication works to validate the experiences of women and provide them emotional support that positively associates with greater physical health outcomes.

In line with biopsychosocial considerations as related to pain, women's physical pain is influenced by emotional and relational factors. What this association implies is that emotional and relational support can improve the physical pain that women experience. At the individual level, women with endometriosis who prioritize the self and their own self-care are far more emotionally, physically, and relationally healthy (Sormanti, 2010). As the results of this

investigation indicate, prioritizing the self can look like a multitude of things, with some experiences contributing more toward positive health benefits than others. For example, previous research highlights the positive impact re-framing expectations has on couples as they navigate sexual health with health diagnosis (Delaney, 2019; Lichtman et al., 1987; Zenmore & Shepel, 1989). Literature around painful sex has also discovered that changing positions can be a helpful strategy for women to continue to engage in sexual activity without causing them pain (Meana & Lykins, 2009). In this way, the positive outcomes and emotions that appeared in the self script could be tied to re-framing expectations and making self-care adjustments, which allow women to gain agency over their experiences and work through the experience of pain while still being able to engage in some level of sexual activity. On the other hand, avoiding sexual activity and self-pleasure might lead to more of the negative emotional outcomes, as previously discussed effects of coping with avoidance (Bair et al., 2003; Thomtén & Linton, 2013). Overall, the four themes that appear in the self script demonstrate the need for women to put their selves first, yet at the same time highlight the nuances within the different ways the self script is enacted that could help or further harm women's sexual health.

In terms of sexual scripts, it is important to note women are better served when having relational support, but they also need to have support from cultural scripts. In this way, imperative is that cultural institutions such as education, medical facilitates, and families support women and marginalized health groups by putting their needs first to combat the negative consequences of stigma. As indicated in this study, many women with endometriosis face an uphill battle across levels of sexual scripts. At the cultural level, challenges exists with healthcare workers, society, etc. understanding and validating their voice as being in the throes of a legitimate and painful experience. At the interpersonal script level, women shared feeling

tension, anxiety and the like when partners are not supportive of the woman's condition and experience. Finally, at the intrapsychic script level, whereas many women shared prioritizing their own script and standing in their power, many nevertheless felt proximal or distal feelings of dissonance, despair, anxiety, guilt and depression. Indeed, glimmers of light in the project demonstrate that when women engage in self-care and also receive the care and support from health providers, partners and society as a whole, outcomes are positive and encouraging.

This investigation's findings also hold practical implications for the use of online communication. In a world where women are doubted in their pain from medical communities, doctors, and even family and partners, women can turn to online forums such as Reddit to be affirmed and find suggestions to improve their well-being. While the stigma of sex and chronic illness might make having conversations about pain difficult, Reddit and like platforms serve to offer a community space to give guidance about stigmatized conditions. Women can turn to Reddit to address stigmatized issues to not only receive support but to also receive helpful recommendations that are then enacted in real life (Nobles et al., 2018; Record et al., 2018). Reading posts about other women prioritizing themselves can inspire women to enact health behaviors that validate their pain and experiences. For example, giving tips about self-care like adjusting positions and reframing expectations are concrete behaviors that women can enact in their own lives to promote their wellness. Additionally, reading women's stories about helpful behaviors promotes and encourages women to continue to prioritize their health and well-being. Furthermore, conversations around sexual health and chronic illness must continue to be normalized offline so that women are able to get the medical and mental support they need when navigating endometriosis.

Limitations

While the study analyzed 90 posts and stories from women with endometriosis, there are a few limitations worthy of address. The first limitation arises from the platform of Reddit. The women who posted the stories self-selected to share, which means that it is not necessarily representative of the entire endometriosis community. Many users of Reddit are "lurkers" rather than posters, or people who do not actively post on the website but use it to read and search for information, so the findings do not consider the experiences of the women who do not share their experiences online. Additionally, because the posts were created by anonymous users, certain variables were not able to be accounted for such as age, race, ethnicity, and religion. Given interpersonal sexual scripts are related to cultural scripts, one's culture can play a major role in the way one conceptualizes and enacts sexual behavior. The study would benefit from understanding different populations of women with endometriosis to understand how different identities and cultures influence their sexual scripts prioritization and valence of emotional, physical, and relational health.

Another potential limitation is not knowing the relationship type of the women in the Reddit posts. In relational research, the stages of dating, relationship length and relationship type are factors that influence the way in which one communication about taboo topics (Baxter & Wilmot, 1985). Partners experience an overwhelming amount of uncertainty at the beginning and middle stages of dating versus people who are in ongoing relationships, and this must be taken into consideration (Umphrey & Sherblom, 2001). In the same way, communication about sex between partners also differs based on the commitment level (Lehmiller et al., 2012; Theiss, 2011). Given the posts did not disclose specific information about the type and length of relationship, such factors must be noted as limitations.

Additionally, the study did not find statistical significance between the script used and the types/valences of health outcomes; thus association cannot be assumed. There are many factors that go into one's health outcomes, yet the role of sexual scripts and gender expectations must continue to be studied. That said, what wasn't present in certain, categorical frequency counts speaks volumes as well as patterns in valence. Lastly, the method of direct content analysis does have a limitation. Scholars note that direct content analysis might hyper focus on theory which may blind coders to consider the contextual components of the subject matter (Hsieh & Shannon, 2005). Given the codes were specifically looking at emotional, physical, and relational health, women's health outcomes might be influenced by other factors that were not measured in the study.

Future Directions

To make the results of the study generalizable to a specific population, people from the forum with a uterus who do not identify as women were not included because demographic data was not collected. The gender of the posters in the study were assumed as women based on pronouns used in the posts. Future studies must consider how different gender identities and sexual orientations might provide different experiences. Future studies can also consider the way relationship type (hookups, commitment, friends with benefits, etc.) influence sexual scripts of women with endometriosis and their health outcomes. Finally, more research is warranted to better understand the relationship between sexual scripts and health outcomes. In order to do this, the research questions and theoretical framework could be applied to people with endometriosis through interviews or via survey to gather more stories and experiences of people with endometriosis from a variety of backgrounds to identify other variables and contexts that may relate to the valence of health outcomes. Future studies can address different cultural,

interpersonal, and intrapsychic scripts women have as well as the health outcomes that might be associated with each script.

As mentioned previously, future research could consider looking into the associative, directional, and circuitous dynamics and the interplay of script decisions and relationships among health variables. For example, if women are privileging themselves because of their pain, then what outcomes are associated in response to such prioritization? Alternatively, even though this investigation uncovered utterances primarily suggesting that script prioritization inferred certain health outcomes, the data also demonstrate that health issues can affect what script is prioritized. Also of interest is if decisions manifest and are practiced over time. For example, if the health outcome for a certain script prioritization turns out to be less than desirable, would the individual make the same script decision over time? Similarly, might health experiences relate to particular script prioritizations over time? Longitudinal research regarding women's health experiences in this realm is of interest. Investigating choices and patterns could be informed by relational maintenance research. For example, Dindia and Baxter (1987) found that strategies individuals used to repair relationships can move to become ongoing relational maintenance strategies (e.g., "Our relationship suffered because we didn't spend time together. We made an effort to spend more time together to repair our relationship and we now practice weekly 'date nights' as a relational maintenance strategy"). Dindia and Baxter's (1987) work would be an excellent framework to further understand relational strategies in the context of sexual encounters and chronic illness. In other words, health outcomes that exist prior to a sexual encounter can affect later decisions, particularly those of script privileging and vice versa. Future studies could further investigate the direction and relationship between scripts and health outcomes.

Additionally, more research is required to identify the cultural scripts and messages currently at work to understand how sexual behaviors and communication might be influenced by new messages. While the traditional sexual script theory encourages specific gender roles and expectations, there is a call for new sexual scripts to evolve and account for the progression being made to account for the fluidity of gender and sexuality. For example, a return to ideas of gender from biosocial theory that acknowledge the role of societal expectations on forming gender norms and rules rather than gender being a biological predisposition (Cloninger, 1986). Using such frameworks, future research would help understand how to shift cultural scripts so that women can demonstrate agency and empowerment without experiencing negative physical and emotional consequences. In a similar way, future studies may look at script privileging longitudinally, to decipher if over time, women stick with their decision to put themselves first, or if relational pressure or social norms may impact the longevity of their prioritization.

Lastly, while this study solely focused on the experiences of women, the research would benefit from studying the partner's perspective, specifically the strategies and communication patterns that partners use to account for the way that partner's communication impacts the individual. Given that relational health is associated with emotional and physical health, scholars are encouraged to continue to examine and find practical applications for partners to implement into their own lives.

Conclusion

This study examined the relationship between sexual script use and health outcomes in sexual encounters for women with endometriosis. The findings of this investigation demonstrate some headway in recent decades in terms of women exercising their agency, which suggests a shift from passivity to proactivity. That said, however, findings suggest that women experience

negative physical and emotional health outcomes when prioritizing themselves, which highlights the need for sexual scripts to evolve at the cultural, interpersonal, and intrapsychic levels. By prioritizing the "self" in sexual encounters and coping with the pain with strategies like self-care, solo pleasure, and reframing expectations, women with endometriosis can begin to engage in strategies that elevate their emotional, relational, and physical health. In previous health research, scholars also discuss the biopsychosocial model of pain (Rush et al., 2019). This study contributes to such literature by illuminating how relational health, emotional health, and physical health are related variables, thereby suggesting that by focusing on improving women's relational and emotional health, their physical pain might lessen. The results of the study indicate that prioritizing one's health is critical to overall well-being, yet certain strategies appear to be more beneficial than others.

Furthermore, relational health is a significant area in which women's physical and emotional health can improve. Relational communication can be used to support women struggling and to reframe expectations for women in general, so they don't experience negative consequences for prioritizing their health first. While prioritizing oneself and self-silencing can lead to feelings of isolation and depression, communication can work to normalize the stigma of sexual health and chronic illness to remove barriers for women to receive the support they need. While women use online communication and forums such as Reddit to receive health information, the stigma in sexual health communication also benefits from address offline because stigma and gender expectations can contribute to adversely affecting the physical and emotional well-being of women. Thus, communication may serve as a powerful tool to overcome the barriers of stigma and help women express their lived experiences, thereby improving their overall sexual health and wellbeing.

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Curriculum Vitae

Madi Wiese – imadiwiese@gmail.com

Education

M.A. University of Nevada, Las Vegas, Communication Studies **Expected Spring 2022**
Thesis Title: "Communicating pain unseen: Addressing health outcomes in sexual activity for women with endometriosis"
Advisor: Dr. Tara Emmers-Sommer
Track: Relational communication

B.A. California Polytechnic State University SLO, Communication Studies **2019**
Title: "Make America pure again: Girlhood, whiteness, & virginity in *Blockers*"
Advisor: Dr. Emily Ryalls
Minor: Women, Gender, & Sexuality Studies

Research Interests

Sex Communication, Relational Communication, Sexual health, Chronic illness, Gender, Women's health, Health and well-being, Mixed Methods

Research Experience

University of Nevada, Las Vegas **Spring 2021**
Graduate Research Assistant

- Collaborated with Dr. Bloomfield's thematic analysis of climate denier rhetoric

Competitively Selected Conference Presentations

Wiese, M. (2022, Feb.). *What the body holds in pain: Reconstructing dialectics to uncover internal truth* [Paper presentation]. Western States National Communication Association Conference, Portland, OR, United States.

Wiese, M. (2021, Nov.). *The time has come: A case for sexual pleasure as communication research* [Paper presentation]. National Communication Association Conference, Seattle, WA, United States.

Wiese, M. (2021, Sept.). *Women's sexual health with endometriosis* [Paper presentation]. Rhetoric of Health and Medicine Symposium, Virtual.

Wiese, M. (2020, Feb.). *Are you kidding? The horror of patriarchy: A comparative film analysis of race and female agency in abstinence cinema* [Paper presentation]. Far West Popular Culture Conference, Las Vegas, NV, United States.

Wiese, (2019, Mar.). *There's no place like home: A metaphor rhetorical analysis on Erika Lust's ethical porn site* [Paper presentation]. California State University Gender, Sexuality, and Race Undergraduate Conference, Fresno, CA, United States.

Competitively Selected Summer Institutes

Rhetoric Society of America's Summer Institute - Risk and Public Health **2021**
The Kinsey Institute - Human Sexuality Summer Intensive **2021**

Teaching Experience

University of Nevada, Las Vegas **Fall 2021-Spring 2022**
Graduate Teaching Assistant

- COM 101: Oral Communication (Online, 2 semesters, 6 sections)

University of Nevada, Las Vegas **Fall 2020-Spring 2021**
Graduate Teaching Assistant

- COM 102: Interpersonal Communication (Online, 2 semesters, 6 sections)

Guest Lectures

University of Nevada, Las Vegas **Fall 2021**
COM 302: Relational Communication

- *The scripts we use, the roles we play: Using sexual script theory to understand our sexual attitudes and behaviors*

University of Nevada, Las Vegas **Fall 2020**
COM 302: Relational Communication.

- *What's your sexual attitude? A critical conversation about how we understand sex*

Service

University of Nevada, Las Vegas **Spring 2021**
Undergraduate Mentor

- Advised undergraduate students on the graduate school application process

California Polytechnic State University, SLO **2019**
Volunteer Performer, Cal Poly Gender Equity Center

- Wrote and performed narrative on sexual assault and gender-based violence

California Polytechnic State University, SLO **2016-2019**
Campus Ambassador

- Guided prospective students about Cal Poly' s campus culture and college experience, constantly polishing public speaking and interpersonal skills through campus tours and providing resources

Grants

Graduate and Professional Student Association Travel Grant, UNLV ($500)
Student Caucus Travel Grant, National Communication Association ($300)
Graduate Student Travel Grant, Department of Communication Studies, UNLV ($500)

Awards

Undergraduate Research Excellence Award **2019**
Cal Poly SLO Academic Excellence Scholarship **2015-2019**

Graduate Award of Outstanding Research **2022**

Relevant Professional Experience

Erika Lust Cinema, Barcelona, Spain **Summer 2018**
Research Assistant

- Performed research on sex worker's rights and the ethical porn industry
- Promoted the organization through writing/publishing press releases, event coordination, and media reach outs

Whatcom County Relational Education **2010-2015**
Founder & Sexual Health Educator

- Created non-profit organization and mentorship program for high school girls to learn about healthy relationships and body image
- Facilitated over 75 workshops, presented at 10 national conferences, coordinated 4 trade shows

Professional Affiliations

National Communication Association **2020-Present**
Western States Communication Association **2020-2021**
Society of the Scientific Study of Sexuality **2020-2021**