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April 5, 2022

“Part of Being a Girl”: Analyzing TikTok Narratives of Reproductive Health Care

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An abstract of  
a thesis submitted to the Faculty of Emory College of Arts and Sciences  
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## Abstract

### “Part of Being a Girl”: Analyzing TikTok Narratives of Reproductive Health Care By Amanda Dranch

This study intends to fill the gap in research on the subjective experiences of patients assigned female at birth (AFAB) in receiving reproductive health care. I review literature on how gender stereotypes have contributed to perceptions of women and how they influence health care professionals' (HCPs) evaluation and subsequent treatment of AFAB patients. I also explore how people with intersectional identities (i.e., LGBTQ individuals, people of color, people with lower socioeconomic status) experience reproductive health care. Eight relevant hashtags were searched on the social media platform, TikTok, to gather AFAB people's narratives about their reproductive health care experiences. A total of 78 videos were extracted for analysis. After transcribing the videos, the patterns of behavior exhibited by HCPs according to users' narratives were examined. Seven themes arose: dismissal, unhelpful solutions, withholding help, normalization, unprofessionalism, diagnostic delay, and positive experiences. Analysis focuses on the different ways in which HCPs exhibited these themes and how users felt about their experiences based on their narratives and how they shared them. The implications of unequal power dynamics and intersectionality are also explored.

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## INTRODUCTION

“Women’s health” is a specialty within medicine that focuses on diagnosing and treating conditions that affect the physical and emotional health of women (Anon 2022), or people with anatomy traditionally associated with the female sex. Women’s health care encompasses services in the areas of gynecology (female reproductive health) and obstetrics (pregnancy and childbirth), including the diagnosis of endometriosis, Polycystic Ovary Syndrome, reproductive cancers, and (in)fertility; preventative care, screening services, and procedures such as blood tests, imaging tests, and biopsies; and sterilization procedures such as hysterectomy and tubal ligation (Anon 2022). Unsurprisingly given the gender disparities pervasive in our society, many people assigned female at birth (AFAB) (including cisgender women, some nonbinary people, and transgender men) seeking health care are often unsatisfied with the quality of care that they receive. Some deal with this dissatisfaction by turning to social media, such as “TikTok,” to share their experiences and confirm by interacting with others whether they just had bad luck or experienced a common phenomenon.

As I took note in early 2021 of the frequency with which videos on reproductive health care experiences came up on my TikTok account’s “For You” page, the content of those videos, and their respective comments, I noticed a pattern emerging. It appeared that many AFAB people who sought reproductive health care experienced similar issues that may be indicative of a wider problem in the realm of this branch of medicine. This realization led me to begin my research by asking: what are the experiences of AFAB people in receiving reproductive health care? How do AFAB people feel about the quality of reproductive health care that they receive? Along the same vein, how do healthcare professionals (HCPs) treat the AFAB people that seek their reproductive health care, and what might be influencing their perceptions of their patients and

their subsequent decisions? I hypothesized that experiences of gender discrimination would be prevalent among AFAB people seeking reproductive health care. In this thesis, I review literature on intersectionality and power as theoretical lenses, health care disparities by gender, the history of gender stereotypes in medicine, and empirical research on the perceptions and treatment of women and other AFAB people in health care settings. For my research, I sought the answers to these questions with a relatively novel method of qualitative research by using social media content analysis. By analyzing AFAB people's narratives about their reproductive health care experiences, I identify common themes and come to understand the reasons why AFAB people tend to share similar experiences. My aim is not to demonize HCPs; I do not presume to know their true thoughts, feelings, and intentions, nor to determine what kind of care should or should not be given. Provider perspectives are important and deserve to be brought to light, but they are not a part of this work. Rather, I aim to bring attention to typically covert narratives about the challenges and aggravations of care-seeking from care seekers' perspectives.

#### *Topic Overview: Gender Disparities in Pain Care*

Existing empirical studies on gender disparities in health and health care are limited and relatively recent. Until around the 1990s, women were largely excluded from clinical research studies and discussions about their bodies and the health care that they receive (Hoffmann and Tarzian 2003; Young, Fisher, and Kirkman 2016). Despite an increase in research being conducted on this topic, among the many perspectives that have yet to be brought to light in an empirical study is that of patients' experiences of gender-biased diagnosing (Smith 2011).

Despite this omission, the differential medical treatment of cisgender women and men with regard to their pain is well-documented. Research has shown that physicians across a variety of fields treat women and men differently for the same ailments without a medical reason

(Samulowitz et al. 2018). Women have to wait longer to receive pain medication than men — 16 minutes longer, on average — if they receive any pain medication at all (Chen et al. 2008). The medication that women do receive is less effective and infrequently the strong kinds such as opioids (Samulowitz et al. 2018). Chen et al. (2008) show that the groups most likely to receive opioid analgesia were men, older patients, non-Black patients, and patients with higher triage acuity (i.e., severity) and reported pain. Women received fewer opiate prescriptions than men regardless of provider's gender and even when controlling for race, triage class, and gender-specific diagnoses (Chen et al. 2008). Instead of being treated directly for their pain, women are more frequently treated with antidepressants or mental health referrals (Samulowitz et al. 2018). The tendency for physicians to prescribe these alternative treatments may imply that they believe that women's pain will dissipate if their mental health improves; that is, that their pain is psychological.

Yet evidence suggests that women's pain is not wholly dependent on their mental well-being. Women biologically feel more pain or are more sensitive to it (Hoffmann and Tarzian 2003; Lloyd, Paganini, and ten Brinke 2020; Samulowitz et al. 2018), are *perceived* to be more sensitive to pain (Lloyd et al. 2020), and experience pain more frequently than men (Hoffmann and Tarzian 2003). Also, compared to men, women report similar or more pain intensity (Chen et al. 2008; Hoffmann and Tarzian 2003; Lloyd et al. 2020), are diagnosed with chronic pain more often (Hoffmann and Tarzian 2003; Samulowitz et al. 2018), and seek more health care support (Lloyd et al. 2020). Nonetheless, women are less likely than men to receive analgesia (Chen et al. 2008), to receive accurate, intensive, effective, and adequate treatment (Hoffmann and Tarzian 2003; Lloyd et al. 2020; Samulowitz et al. 2018), and to be taken seriously (Hoffmann and Tarzian 2003; Samulowitz et al. 2018) — all despite the aforementioned findings that

women are considered more sensitive to pain. The position of women in society and within clinical practice and research means that they are placed at a significant disadvantage for appropriate pain management.

*Theoretical Framework: Intersectionality and Power*

The idea of intersectionality originated within Black feminist thought which challenged the assumption that women are a monolith (Ruiz et al. 2021). For example, while the patriarchy affects all women, the intersections of gender, race, and class come with additional forms of oppression (Ruiz et al. 2021). Intersectionality theory posits that occupying multiple disadvantaged demographic categories can result in experiences such as oppression, disadvantage, and power imbalances that are particular to such individuals (O'Connor, Bright, and Bruner 2019). Intersectionality sheds light on how intersecting forms of oppression that result from holding multiple social identities can result in social inequalities and negatively impact the health of marginalized social groups (Lapalme, Haines-Saah, and Frohlich 2020).

While power is typically associated with the ability to use force and control material resources, Goodyear-Smith and Buetow (2001) also identify “mind power,” which “depends on obtaining and exchanging knowledge and information” (p. 449), and “social power,” which involves the capacity to decide whether or not to use one’s power, particularly by “supplying or withholding the means required to fulfil one’s own and others’ needs and desires” (p. 449-450). In a medical context, this can result in doctors monopolizing knowledge and not acknowledging patients’ preferences or expertise on their own bodies. In order for patients to have their health needs met, they must possess some amount of power, but according to Goodyear-Smith and Buetow (2001), doctors may have the upper hand in the realms of money, knowledge, and social authority. The authors suggest that such power may incentivize doctors to recommend

inappropriate or unnecessary treatments, be satisfied with providing inadequate care, withhold medical information, “play God” by being selective about the care they provide, “assume the moral superiority of their own value positions and hence exert undue influence, or offer ‘inferior care due to stereotyping’” (p. 453-455). The authors cite race, gender, and socioeconomic status discrimination as ways that doctors can reduce access to and quality of healthcare.

Lapalme et al. (2020) assert that intersectionality can be a lens through which we can investigate "how power relationships (re)-produce social inequalities" (p. 494). Power relationships do not only consist of intersecting social groups (i.e., multiple demographic categories) but intersecting systems of power, such as heteropatriarchy and white supremacy. The authors note that health research using an intersectional lens has only focused on the fact that “intersecting social groups...experience privilege and/or oppression” and not that they do so “as a result of these social structures” (p. 495). Thus, “how intersecting structural forces perpetuate social inequalities” must be investigated (p. 495). The health system is one example of a social structure in which marginalized groups face oppression *by* more powerful groups *because of* the nature of that social structure. Health care providers have power over patients, and this power difference is increased when patients hold disadvantaged intersectional identities.

## RELEVANT LITERATURE

The prevalence of disparate medical treatment makes it highly unlikely that it is just happenstance; some other factors must be at play. The influence of patient characteristics on the quality of health care has been widely studied, and the general conclusion is that certain groups of people, notably women and people of color, nearly always receive less adequate care than their white male counterparts (Knoy 2019). In this literature review, I build on prior work investigating the manifestation of gender stereotypes in health care. In the first section, I discuss

the content of gender stereotypes in the healthcare domain, how they originated, and how they persist today. In the second section, I present research that demonstrates women's experiences in receiving reproductive health care, namely for PCOS and endometriosis. I also discuss how low-income people, racial minorities, and LGBTQ individuals face additional barriers to quality reproductive health care. The theoretical lens of intersectionality demonstrates how having membership in multiple identity groups can exacerbate experiences during care. The theoretical lens of power demonstrates the hierarchical nature of health care settings and how it renders patients vulnerable to abuses at the hands of their medical providers. The literature review informs my research as I investigate AFAB people's experiences with reproductive health care. I aim to show how multiple forces work together to create disadvantages for AFAB people in reproductive health care settings and lead to consequences for their mental and physical health.

### *The History of Gender Stereotypes in Medicine*

*Origin of the mind-body association.* Sexist beliefs about women, their bodies, their health, and their pain tolerance have been pervasive throughout history and around the world. Feminist authors attribute the disparate treatment of women in health care to a long cultural history wherein women are regarded as having limited reasoning capacity and “unreflective, emotional, or immature” opinions (Hoffmann and Tarzian 2003:20). Such ideas find their origin in the history of women's health problems as they have been attributed to their reproductive organs, particularly the uterus. The word “hysteria,” used colloquially today to describe the condition of being extremely emotional, is derived from the Greek word “hystera” which translates to “uterus” (Munch 2004:104). The ancient Greeks believed that the uterus was responsible not only for women's diseases (Munch 2004) but for their psychology and emotions (Smith 2011). “Hysteria” means “wandering uterus” and comes from the notion that when a

woman was “hysterical,” it was because her uterus was literally wandering around inside her body, causing the symptoms she complained about and what was perceived as erratic behavior (Bachmann 1990:41, qtd. in Munch 2004:104-105).

With this kind of origin, it is clear how women’s physical health, especially their reproductive health, became associated with their psychological health. The “wandering uterus” myth has been disproven, but its interrelationship with emotions has persisted. The attribution of women’s health issues to their reproductive organs has simply taken a different form and has contributed to the preservation of the societal belief that women are “innately emotional or psychologically susceptible” (Smith 2011:2). It is thus no wonder why “the emotional outbursts and sensory disturbances associated with hysteria [are considered] to be more common in women” (Munch 2004:104-105). Hysteria, originating from a myth about the uterus, developed into a long-standing notion that the female body is connected to emotions, thus hysteria describes “psychologically disturbed women” (Smith 2011:2). These historical associations between women and emotionality have contributed to the development of some of the most prevalent *gender stereotypes*, or culturally standardized beliefs about the differences between women and men with regard to traits, behaviors, and other attributes, as well as the phenomenon of diagnosing women’s health problems as *psychosomatic*, or psychologically caused (Smith 2011).

*Gender stereotype formation and persistence.* Recognizing how gender stereotypes bleed into perceptions of women in medical contexts reveals that stereotypes are not just passive beliefs; they have consequences for people’s lives. The cognitive mechanisms and processes involved in the formation of stereotypes (Rothbart et al. 1978) help to shape an understanding of why stereotypes in medicine require attention and scrutiny.

Conceptions of particular social groups are formed as people learn stereotypes from their

social environments. Culture transmits prejudices and stereotypes, and members of cultures learn those ideas (Stone and Moskowitz 2011). Stereotype learning, specifically regarding gender roles, can be attributed to socialization as it “shapes how individuals cognitively assess and create social reality” and “superimposes male-female differences on virtually every aspect of human experience,” including emotional expression (Lafky et al. 1996:379-380). Gender stereotypes are produced and reproduced because they are “embedded in social, political, and economic institutions” (Lafky et al. 1996:380). Given that ideas about gender, as well as other human characteristics, are so embedded in people’s everyday lives and surroundings, it is likely that health care professionals are not unaffected by such forces and may carry their beliefs with them in their work. Social psychology research shows that when people encounter someone to which held stereotypes apply, their beliefs about what members of those groups are like are activated (Devine 1989; Stone and Moskowitz 2011). Because stereotypes are unconsciously embedded in memory, they are easily accessible and likely to be used to respond in situations involving a member of a stereotyped group (Moskowitz et al. 2012). Using information retrieved from memory, people make judgments and form an impression of and interact with a target individual of a group (Stone and Moskowitz 2011; Rothbart et al. 1978). If health care professionals believe in stereotypes about women’s traits and attributes, these beliefs may affect the way that they perceive and subsequently treat AFAB patients.

*Emotionality and psychosomatic diagnosis.* Gender stereotypes about emotionality remained even as Western medicine became more informed. Reproductive conditions such as menstrual cramps were scientifically proven to be caused by biological processes in the 1940s, yet medical students in the 1970s were still being taught that these conditions were emotionally caused (Smith 2011). Physicians commonly told women that experiencing fluctuating emotions



during their menstrual periods, a phenomenon known today as premenstrual syndrome, was “‘all in their heads’ and not due to any physiologic change” (McIlhany 1985, qtd. in Munch 2004:105). Women were also psychologized by the attribution of their discontent to their renunciation of gender roles. Proponents of classical psychoanalytic theory held that female reproductive issues, especially menstrual pain, morning sickness, and infertility, were caused by women’s “rejection of the feminine role” and “ambivalence about childbearing” (Munch 2004:104; Smith 2011:2). Pregnant women who vomited were thought to be experiencing “intrapsychic conflicts, such as hysteria, sexual frigidity, psychological immaturity, and a rejection of femininity” (Munch 2004:105). If women had difficulties with labor and delivery, they were purported to be “immature or emotionally disturbed” (Munch 2004:105). Every aspect of women’s reproductive lives was strictly scrutinized, and women were socially punished for not adhering to gender role expectations.

Medical textbooks even captured such sentiments. The 1972 textbook *Gynecology and Obstetrics, Current Diagnosis and Treatment* claimed that nausea stemmed from the “resentment and ambivalence of women ill prepared for motherhood” (Munch 2004:105). Other textbooks perpetuated stereotypical ideas of women, claiming that they complain, exaggerate, and lie, and consistently associated patients described as “psychogenic” or “hypochondriac” with women (Smith 2011:4-5). A gynecology textbook from 1971 read, “‘many women, wittingly or unwittingly, exaggerate the severity of their complaints to gratify neurotic desires’” (Corea 1977, qtd. in Smith 2011:5). The fact that physicians were not just holding gender biases but teaching unsubstantiated ideas about women and presenting them as medical facts may imply conscious or unconscious discrimination.

*Intersectionality and the “nature” of women.* Women of color and those of low social

class were and still are the subject of additional stereotypes. While wealthy white women were seen as feminine and delicate, requiring and deserving the attention and care of a doctor, minority and lower-class women were not viewed as feminine and therefore did not receive as much attention or care (Munch 2004). Neglecting poor women's health was justified due to the belief that they had "coarser" natures, making them more tolerant of pain (Munch 2004:113). While belonging to the gender category "woman" was disadvantageous in and of itself, the addition of disadvantaged race and class categories subjected those with intersectional identities to additional stereotypes. Gender, race, and class stereotypes carried throughout history have given rise to beliefs about women — especially women of color and poor women — that evidence fails to support, yet widespread bias in the medical field persists as if evidence did support such beliefs.

#### *Contemporary Stereotype-Based Perceptions of Women*

*Differing conceptions of women and men.* Differences in the descriptions of women's and men's personality traits as perceived by physicians have been widely observed. An overarching theme in the content of gender stereotypes is that women are more emotional than men (Lloyd et al. 2020). For the same behavior that causes men to be portrayed and perceived as forceful or aggressive, women are portrayed and perceived as emotional, hysterical, and frequent complainers (Hoffmann and Tarzian 2003). Samulowitz et al.'s (2018) literature review study of women's and men's portrayals in medical contexts revealed that, whereas men were presented as stoic, autonomous, in control, and tolerating, denying, or not talking about pain, women were presented as more likely to talk about and report pain than men, hysterical, emotional, complaining, malingering or "fabricating their pain, as if it is all in [their] head[s]," and "rather are assigned psychological than somatic causes for their pain" (p. 5). Hoffmann and Tarzian

(2003) cite a study showing that, whereas men are more likely to be given pain medication, women are more likely to be given sedatives. Existing literature speculates that this difference exists because of ideas that compared to men, who are thought to be “stoic so that when they do complain of pain, ‘it’s real,’” women complain more, are not accurate reporters of their pain, and have higher pain tolerance or better coping skills (p. 13). These assumptions suggest that women are not credible, that they are not complaining of “real” pain, and that their pain does not need to be treated as vigorously.

Another theme in the content of gender stereotypes is that women are irrational. Rationality has gendered associations: because women are seen as more emotional than men and emotion is assumed to detract from rational thought, physicians expect women to “react irrationally and dramatically” due to emotion whereas they do not expect the same of men (Lloyd et al. 2020:200), likely because the emotionality stereotype is not associated with men. Research has shown that women’s expressions of emotion are more likely to be characterized as dramatizations and exaggerations than men’s (Lloyd et al. 2020), supporting the idea that physicians may either consciously or unconsciously employ gendered stereotypes related to emotionality and rationality in their evaluations of patients.

*Psychosomatic misdiagnosis.* The perception of women as emotional and irrational may have implications for their credibility in medical settings and, consequently, their medical diagnoses. Women’s pain is often not taken as seriously as men’s (Samulowitz et al. 2018), their reports of pain being frequently discounted by physicians as “‘emotional’ or ‘psychogenic’ and, therefore, ‘not real’” (Hoffmann and Tarzian 2003:21). Women are also more likely than men to have their pain or physical symptoms labeled psychosomatic or attributed to psychogenesis, regardless of whether that is the actual cause of their pain (Hoffmann and Tarzian 2003; Smith

2011). When physicians believe stereotypes such as those that paint women as emotional, irrational, exaggerating, or even lying, women may be “found” to have more psychosomatic illnesses — a misdiagnosis in many cases (Hoffmann and Tarzian 2003).

*Gender-biased diagnosing.* Stereotype-based conceptions of women contribute to what Munch (2004) calls “gender-biased diagnosing—a tendency for physicians and other health care professionals to mislabel women’s somatic complaints as non-serious and/or psychosomatic both in the presence of organic etiologic factors and when the underlying pathophysiological mechanism of the condition is unknown” (p. 102). This suggests that, rather than admitting that they do not know the cause of women’s symptoms and doing further research or testing, physicians default to attributing women’s pain to psychological issues when they do not have alternative explanations. The frequent occurrence of gender-biased diagnosing in medical contexts shows just how deeply stereotypes permeate physicians’ beliefs and subsequent decisions for treatment.

*Credibility.* Physicians must make inferences about the authenticity and intensity of a patient’s pain in order to treat it (Lloyd et al. 2020). Thus, judgments are not objective; they may be biased. Stereotypes of women as “emotionally reactive,” “irrational,” and “inauthentic” are robust and widely held by physicians (Lloyd et al. 2020:200). Stereotypes can “bleed into assumptions about authenticity,” leading physicians to believe that women exaggerate, dramatize, or lie about their pain, which often results in their displays or disclosures of pain being met with physicians’ skepticism or doubt (Hoffmann and Tarzian 2003; Lloyd et al. 2020:200). According to Samulowitz et al.’s (2018) literature review study, when conditions cannot be medically explained, it is often tied to professionals’ unwillingness to believe their

female patients' pain.

The idea that women are not credible has been medically legitimized by the diagnostic classification of “factitious disorder.” According to Smith (2011), “‘fictitious [*sic*] disorder,’ in which women are believed to deliberately simulate illness in order to use the sick role as a means of escape from social pressures and dissatisfaction with life, has been called today’s new and accepted version of hysteria, only in the form of a medically recognized ‘disorder’” (p. 3). With the “phenomenon” of women feigning illness for emotional reasons legitimized by the medical community, stereotypes surrounding women’s credibility acquire validity. Factitious disorder and the stereotypes that inspired it may be present in the minds of physicians, as can be surmised from their treatment of female patients.

*Compounded stereotypes.* Minorities, people with lower socioeconomic status, and other vulnerable groups bear the burden of additional stereotypes. Like gender stereotypes, race and class stereotypes affect physicians’ perceptions of how patients feel pain. O’Connell and Zampas (2019) write that characteristics such as “age, HIV status, race, ethnicity, disability, and sexual orientation or gender identity or expression” compound the effects of stereotypes and leave those with intersectional identities the most vulnerable to abuses in medical contexts (p. 117). For example, black people and those with low socioeconomic status are stereotyped as being less sensitive to pain and subsequently receive less intensive and accurate pain care (Lloyd et al. 2020). When people from lower socioeconomic backgrounds are taken less seriously by physicians, then in addition to barriers such as transport, cost, or language that hinder their ability to access healthcare services, they may face diagnostic delay (Markovic, Manderson, and

Warren 2008).

### *Treatment-Seeking Pathways*

Power dynamics are an important consideration in any setting, but they can be especially consequential in medical settings. The healthcare field is inevitably hierarchical, as physicians have the medical knowledge and treatments that patients depend on for their health (O’Connell and Zampas 2019). This power allows physicians to insert their personal beliefs into patient care, including those based on stereotypes, which leaves an opportunity for the denial of access or subjection to services and medical treatments (O’Connell and Zampas 2019).

Because of the stereotypes and biases that HCPs hold, women must subvert HCPs’ preconceived notions. They must convince healthcare professionals “that their subjective experience or sensibility is ‘real’ and requiring further attention” (Markovic et al. 2008:350). They must also prove that their symptoms are not normal and should be taken seriously (Pettersson and Berterö 2020). Markovic et al. (2008) note that the ready availability of over-the-counter, short-term period pain relief medications “reinforces the notion that ‘all’ women experience pain and therefore that such pain is ‘normal;’” thus, in consultations with healthcare professionals, women must “distinguish their experience of menstruation from those of other women” (p. 350). According to Hoffmann and Tarzian (2003), women may need to “prove that they are as sick as...similarly situated males” in order to reduce gender differences in treatment (p. 17).

Women are aware of gender stereotypes and biases in healthcare, so they “invest[] much work, time, and energy before or during the encounters in order to be perceived as a credible patient” (Werner and Malterud 2003:1412). Werner and Malterud’s (2003) study on women with chronic pain revealed that their female participants “have struggled to be perceived as

somatically ill, whilst simultaneously avoiding appearing mentally unbalanced” (p. 1414). By appearing too ill, disarranged, and weak, complaining too much, or expressing how they wanted to be examined and treated, women risked “being perceived as quarrelsome, whining...mentally disturbed...unable to manage” (p. 1415). By not complaining enough or complaining only of minor things, they risked not piquing the interest of their doctors. Appearing too healthy, smart, strong, driven, and determined “conflict[ed] with the image of an ‘ill’ patient;” thus, women who did so “risked being assessed by the doctor as someone functioning well in their everyday life” (p. 1415). Werner and Malterud’s participants had to understand how to “balance” their presentations to doctors. Because women are aware that doctors anticipate stereotyped displays of emotions, they use tactics “such as downplaying the severity of symptoms, only reporting certain health concerns, acting as rational as possible, and pre-planning their appearance for the doctor’s visit in order to be perceived as a more credible patient” (Smith 2011:12). Smith’s (2011) female participants reported downplaying the severity of their symptoms to their doctors more than twice as much as the male participants due to worrying about being perceived to be irrational (p. 18). This phenomenon of “doing pain” (Smith 2011:12) seems to be a response to women’s anticipation that they will not be believed by doctors.

#### *Treatment of Women in Reproductive Health Care*

Studies examining the subjective experiences of women receiving reproductive healthcare suggest that many of these worries are warranted. Medical professionals’ inability to identify the causes of reproductive conditions especially render women with reproductive disorders vulnerable to the “impact of gender stereotypes and attitudes” (Munch 2004:102). Two common reproductive health problems faced by women that studies have shown to have the most

difficulty getting diagnosed are Polycystic ovary syndrome (PCOS) and endometriosis.

*Polycystic ovary syndrome.* PCOS is an endocrine disorder — that is, a condition related to the hormone system (Copp et al. 2020; Gibson-Helm et al. 2016; Lee 2019) — “associated with a number of adverse reproductive, metabolic and psychological outcomes” (Copp et al. 2020:661). Symptoms of PCOS include “irregular or absent periods, lack of ovulation, weight gain, acne, excessive facial hair,” and PCOS is one of the “leading causes of infertility in the US” (Lee 2019:1186). The cause of PCOS is unclear, but is likely related to genetic and environmental factors (Copp et al. 2020). Treatment focuses on symptom reduction and lifestyle changes to “reduce the risk of associated comorbidities,” but a cure for PCOS does not currently exist (Copp et al. 2020:661). Data on the prevalence of PCOS among reproductive-aged women is variable, but the prevalence is likely as low as 4% and as high as 22.5% (Copp et al. 2020; Gibson-Helm et al. 2016; Lee 2019). These numbers may even be an underestimate of the number of women who have PCOS or are undiagnosed (Gibson-Helm et al. 2016).

The actual prevalence of PCOS is unknown for a number of reasons. Approaches to diagnosis are inconsistent and uncertain (Copp et al. 2020; Gibson-Helm et al. 2016). Doctors have tended to rely on expert consensus for diagnostic criteria rather than on clinical evidence, leading to debate on what constitutes a PCOS diagnosis (Copp et al. 2020). Furthermore, in order to establish the diagnosis of PCOS, HCPs must eliminate other etiological possibilities (Gibson-Helm et al. 2016). The symptoms of PCOS, however, are broad in severity and shared in common with many other conditions, making it difficult to rule out other possibilities and make a PCOS diagnosis (Copp et al. 2020). These issues have raised concerns about underdiagnosis. According to clinicians interviewed by Copp et al. (2020), concerns of misdiagnosis and overdiagnosis have been raised due to the lack of standardization and clarity in diagnostic



criteria, the commonality of polycystic ovaries unrelated to PCOS, and “mimicking conditions” including “stress, contraceptive use, Cushing’s syndrome, obesity, hypothalamic amenorrhea or disordered eating” (Copp et al. 2020:663; Gibson-Helm et al. 2016). Some clinicians felt that overdiagnosing is not as harmful as underdiagnosing because a diagnosis leads to conversations about leading a healthy lifestyle and symptom management, which are “beneficial for everyone and any medical treatment is justified by bothersome symptoms” (p. 663). Other clinicians felt that PCOS is “*overplayed*” since the diagnostic criteria could apply to many women (p. 663). Furthermore, while a diagnosis can be validating, it may have a negative psychological impact, inducing unnecessary anxiety and hopelessness (p. 666). Some clinicians even thought that PCOS may be a “societal phenomenon” due to increasing obesity rates, and that diagnosing PCOS just medicalizes it (p. 663). While clinicians recognized that patients may want a medical explanation, they felt that labels might “undermine[] patients’ sense of ‘agency’ and control over their weight” and possibly “*set[] them up for failure by giving them a label to something that they may not necessarily have and then the treatments probably won’t necessarily help their situation*” (p. 664). Because of uncertainties and the lack of recognition of this condition, many people with PCOS face diagnostic delay (Copp et al. 2020; Gibson Helm 2016). Gibson-Helm et al.’s (2016) study participants reported that it took “several months to years and consultations with multiple health professionals” to receive a PCOS diagnosis (p. 608). Being diagnosed early allows for early treatment that can prevent future complications such as infertility and metabolic issues, making underdiagnosis a concern (Copp et al. 2020).

Diagnostic delay is particularly problematic in light of PCOS’s association with infertility. Lee’s (2019) study on American women struggling with infertility revealed that in spite of early-presenting symptoms, “education and counseling about the fertility implications of

[reproductive conditions] were not provided until the women were actively trying to conceive,” engaged, or married, resulting in a delay in treatment and therefore reduced efficacy (p. 1193). One participant “felt that valuable information about fertility had been withheld from her because of doctors’ assumptions that she was not yet at the right stage of life to be concerned with childbearing” (p. 1190). Lee notes that the participants who were diagnosed early were “often treated only symptomatically and never counseled about options for preserving fertility” (p. 1193). Many participants expressed that they wished they had been diagnosed earlier because it would have allowed them to be “armed with information” and consider their futures differently (p. 1190). Doctors’ assumptions about patients’ “readiness” to worry about fertility affected their decisions for information sharing and treatment. Lee comments: “These experiences reveal that fertility counseling can be withheld not only from women who are deemed too young to be raising families, but also to those who do not fit conventional notions of motherhood in terms of marriage, stability, and social position” (p. 1190-1191).

*Endometriosis.* Endometriosis is a disorder of the reproductive system that occurs when endometrial tissue grows outside the uterus, causing symptoms such as “chronic pelvic pain, period pain, pain during intercourse, heavy periods, sub-fertility or infertility” (Markovic et al. 2018:350) and sometimes ovarian and fallopian tube scarring if it grows on the abdominal lining (Lee 2019). Like PCOS, the cause of endometriosis is uncertain, but “genetic, hormonal and environmental factors are all implicated” (Markovic et al. 2018:350). Also like PCOS, a cure for endometriosis does not exist, and treatment focuses on symptom management (Young et al. 2016:555). Some treatments are hormonal and aim to reduce or relieve symptoms like pain, such as oral contraceptives (Denny 2004; Hållstam et al. 2018; Markovic et al. 2018; Young et al. 2016). Surgical procedures such as ablations and hysterectomy are also available and aim to

surgically remove lesions, adhesions, and endometrial tissue (Denny 2004; Markovic et al. 2018; Young et al. 2016). Such treatments have shown to only provide short-term relief from symptoms (Denny 2004; Young et al. 2016) and sometimes exacerbate them (Markovic et al. 2018) with side effects (Denny 2004; Young et al. 2016) “such as weight gain, skin problems or emotional upset” (Hållstam et al. 2018:100). A diagnosis of endometriosis can only be made by laparoscopy, laparotomy, or histology (Markovic et al. 2018; Pettersson and Berterö 2020; Young et al. 2016). As with PCOS, data on the prevalence of endometriosis is variable, but according to Markovic et al. (2018), 4-15% of reproductive-aged women and 25-40% of infertile women have endometriosis.

Despite the prevalence of endometriosis, many women experience diagnostic delays ranging from 2 to 12 years (Ballard, Lowton, and Wright 2006; Grundström et al. 2018, Markovic et al. 2018). The reasons for this delay in diagnosis include a “gap between onset of symptoms and the woman’s presentation for medical advice” (Markovic et al. 2018:350). At the individual level, this may be due to difficulty accessing healthcare (Markovic et al. 2018), not being aware that endometriosis is an existing condition, or perceiving that menstrual pain is normal (Grundström et al. 2018), leading to a delay in their presentation to healthcare professionals (Markovic et al. 2018). At the medical level, diagnostic delay may be due to unreliable measures, tools, and procedures to objectively evaluate reported pain levels (Ballard et al. 2006; Markovic et al. 2018; Pettersson and Berterö 2020), “leading clinicians to dismiss women’s health complains or to attribute account of severity of pain to psychological factors” (Markovic et al. 2018:350). In Ballard et al.’s (2006) study, the failure of screening tests such as ultrasounds to diagnose endometriosis led doctors to conclude that “further investigation or treatment was unnecessary” and “raised further doubt surrounding the genuineness of

symptoms” (p. 1299).

Research on women’s subjective experiences in receiving reproductive health care confirms that the perceptions and actions of health care professionals are often responsible for diagnostic delay. Indeed, when women present their health concerns to their healthcare providers, they often face rejection, disregard, or dismissal (Ballard et al. 2006, Markovic et al. 2018). HCPs may not acknowledge women’s pain and exhibit disinterest, distance, or nonchalance (Grundström et al. 2018; Markovic et al. 2018; Pettersson and Berterö 2020). Doctors may doubt the genuineness, legitimacy, or severity of women’s symptoms and complaints (Ballard et al. 2006; Pettersson and Berterö 2020); for example, “physicians could question whether the pains really were proportional to the size of the lesions,” and some doctors even believe that menstrual pain is not real (Pettersson and Berterö 2020:538). They may discount the presence of any physiological problem (Markovic et al. 2018), disbelieve women (Grundström et al. 2018) and think that women imagine their pain, exaggerate their symptoms, or have low pain thresholds (Grundström et al. 2018; Pettersson and Berterö 2020). Discounting physiological causes could lead doctors to conclude that the problem is psychological; e.g., a symptom of depression (Denny 2004; Markovic et al. 2018; Pettersson and Berterö 2020). Women face being discredited and labeled as psychosomatic, their displays of frustration at being disbelieved only reinforcing this conclusion (Markovic et al. 2018).

The tendency of HCPs to make these conclusions when tests are inconclusive and symptoms do not cease may indicate what Grundström et al.’s (2018) participants thought about their HCPs: that they “lacked basic knowledge about endometriosis” (p. 208). Some HCPs tend to focus on looking for “easy explanation[s]” (Grundström et al. 2018:208) or resort to finding “simple causes” if HCPs’ patients’ issues persist after hormonal or analgesic treatment

(Pettersson and Berterö 2020:537). According to Pettersson and Berterö's (2020) study, HCPs "were not inclined to accept that women's symptoms could be caused by any gynecological disorder or illness" (p. 537). They did not search for any other underlying causes and instead judged symptoms as normal. The authors note that this could lead to making an incorrect diagnosis. Instead of searching for underlying causes of patients' problems, studies show that HCPs offer solutions that tend to be unhelpful, such as "lifestyle changes" like exercise (Ballard et al. 2006:1299; Pettersson and Berterö 2020:537). HCPs also tend to focus treatments on controlling and masking symptoms rather than finding an underlying cause and long-term solutions (Denny 2004; Lee 2019). Women are commonly offered contraceptives (Denny 2004) to "'regulate' or 'control'" women's periods (Ballard et al. 2006:1299) and associated pain (Pettersson and Berterö 2020). Arbitrary treatments such as painkillers and hormones only mask symptoms. Markovic et al.'s (2018) participants reported that as adolescents, their periods were treated by being given painkillers or hot water bottles, or by being sent home, and that teacher support "reinforced the belief that period pain should not cause concern" (p. 335). The authors note: "By temporarily excusing young women from performing their social roles, the teachers both validated their subjective experience (of pain), and reinforced belief in the normality of the experience" (p. 355).

The normalization and trivialization of women's reproductive health problems by HCPs may also contribute to diagnostic delay (Ballard et al. 2006; Markovic et al. 2018; Pettersson and Berterö 2020). Some patients are told that they are just the "unlucky" ones (Denny 2004:644; Grundström et al. 2018:208; Pettersson and Berterö 2020:537). Others are told that menstrual pain is "a woman's issue" (Pettersson and Berterö 2020:540), "part of being a woman" (Pettersson and Berterö 2020:537-538; Denny 2004:642; Grundström et al. 2018), or just "'what

a woman has to put up with” (Markovic et al. 2018:356), and therefore women should just “endure it” (Markovic et al. 2018:356), “bear it” (Denny. 2004:642), or “cope with” it (Ballard et al. 2006:1299). Studies show that some HCPs blame patients, act insensitively (Pettersson and Berterö 2020), lack empathy (Grundström et al. 2018), and make women feel “humiliated, even abused” (Hållstam et al. 2018:100). Many women report feeling that if they had been acknowledged or taken seriously earlier, they could have saved themselves suffering and stress (Grundström et al. 2018; Markovic et al. 2018).

Although there is a lack of concrete evidence linking infertility and endometriosis (Young et al. 2016), the nature of endometriosis usually leads to discussions about fertility. Studies show that doctors and patients often have conflicting interests, usually an undue focus on fertility on the part of doctors. Care for conception difficulties may be offered spontaneously by the doctor without the woman’s request or suitability (Young et al. 2016). Sometimes recommendations turn into “pushing” women to conceive without acknowledging patients who expressed that they did not want to conceive (Young et al. 2016:559). Some doctors prioritized patients’ fertility over endometriosis care and symptom relief (Young et al. 2016). Other doctors “present[ed] pregnancy and hysterectomy as ‘treatment’ options” (Young et al. 2016:559). Young et al.’s (2016) participants said that doctors told them that pregnancy would fix endometriosis or reduce its symptoms.

Many women with endometriosis who seek sterilization experience strong opposition from doctors. Young et al.’s (2016) study showed that many doctors refused to investigate for endometriosis or perform surgery such as hysterectomy. Refusal to perform sterilization procedures was perceived by women as an assumption that they “would regret this decision after inevitably changing their minds in favour of motherhood” (p. 559). Patient age played a central

role in doctors' decisions. One of Young et al.'s (2016) participants reported that she was unable to afford a doctor willing to perform a hysterectomy, "and those she could afford refused an elective hysterectomy for a childless woman under 30" (p. 559). Lee's (2019) interviewees shared that physicians tended "to ignore or avoid discussions about possible fertility implications, revealing an assumption that they must not yet be concerned with childbearing" (p. 1191). Doctors' undue focus on fertility seems to be connected to their assumptions about what women want or need at particular stages of their lives.

### *The Impact of Intersectional Identity on Reproductive Health Care*

*Gender and sexual minorities.* Studies have demonstrated that stereotypes and ideologies surrounding the female gender identity and body make their way into health care and are sometimes employed by HCPs during interactions with AFAB patients. Those with intersectional identities (that is, multiple identities held simultaneously, including those within the categories of gender, sexual orientation, race, ethnicity, or class) may face their own respective stereotypes and discriminatory treatment. Gender and sexual minorities face additional barriers to reproductive health care than cisgender and heterosexual individuals. Wingo, Ingraham, and Roberts (2018) identify several barriers to quality reproductive health care that LGBTQ individuals encounter when seeking such care, including a lack of provider knowledge about LGBTQ-specific health, LGBTQ erasure, and discrimination — all of which impact health care-seeking behavior among LGBTQ individuals.

Wingo et al.'s (2018) study reveals that providers often lack competence about the kind of health services and information that are relevant to LGBTQ patients. The authors note that providers are "largely unprepared or unresponsive to family formation methods or sexual behaviors that fall outside of cis- or heteronormative expectations" (p. 355). According to their

participants, providers often made “behavioral assumptions” and “inquired imprecisely about sexual activity” during consultations in which providers needed to assess risks associated with their patients’ sexual history (p. 354). Unprepared providers who could not provide proper guidance, useful information, or adequate support and resources made participants feel “confused, invisible, and lacking practical information...anomalous, hindering their ability to receive relevant health care” (p. 354).

LGBTQ erasure in Wingo et al.’s study can be understood as the lack of acknowledgement of LGBTQ identity, which manifests in the use of cisheteronormative language and expectations. Questions about sexual activity, gender and sexual identity were designed to accommodate responses expected of cisgender and heterosexual patients, making it impossible for LGBTQ patients to answer accurately or to communicate about risks. For example, participants cited non-inclusive and outdated care protocols such as intake forms that asked about the “father of the baby” or “male partner” (p. 353).

A recurring theme in reproductive health care studies is providers’ undue focus on fertility. Wingo et al.’s study shows that providers steered conversations toward the topic of fertility, even when participants were only seeking help with acute health concerns. Providers often made assumptions about their patients’ risk of pregnancy or interest in fertility, and participants felt that this got in the way of their health care. The authors note that reproductive health care’s emphasis on womanhood and childbearing “made participants feel like their own health concerns were not as important to providers as filling child-bearing expectations externally ascribed to them” and alienates individuals who need reproductive services, who are not interested in childbearing, who are not at risk of pregnancy, and especially those who do not identify as female; e.g., the feminization of pregnancy and the framing of reproductive care as



“women’s care” (p. 355). In sum, “assumptions about sexual activity and pregnancy, and childbearing desire created barriers to obtaining useful sexual and reproductive health guidance” (p. 355) and constituted LGBTQ erasure.

LGBTQ individuals also face discrimination in the form of identity invalidation and interrogation. Wingo et al.’s (2018) transgender male participants reported that providers made homophobic or transphobic remarks, misgendered them (i.e., used incorrect pronouns), and asked questions about their identity that were not relevant to the care that they were seeking. Transgender and nonbinary participants reported that their providers were largely ignorant about transgender-related health issues and that their decision to pursue gender-affirming care were scrutinized and sometimes rejected. The authors describe the actions of one provider as “obstruct[ing] access to requested medical care by not providing a referral to an appropriate provider or engaging with the patient about their medical needs” (p. 354). Experiencing such discrimination when seeking reproductive health care, such as harassment and inappropriate treatment, can impact health-seeking behavior. For example, transgender men and cisgender women who identify as lesbian or bisexual are less likely than their cisgender and heterosexual counterparts to receive Pap smear tests. This may be indicative of either HCPs withholding this routine care or these individuals not seeking routine care as often because of the fear of discrimination. Wingo et al. note that experiencing discrimination in medical care settings “made participants feel both uncomfortably visible and unwelcome in reproductive health care spaces” (p. 354).

*Racial and ethnic minorities.* Female racial and ethnic minorities’ quality of health and health care is significantly poorer than that of their white male counterparts. Women of color are disproportionately affected by preventable health problems. They have low rates of routine care,

including preventative health screening tests such as Pap smears and breast exams (Ross et al. 2001). They also have low rates of contraceptive use, HPV vaccination, and STI care such as HIV tests and prevention prescriptions (Sutton et al. 2021). Women of color have high rates of reproductive tract infections (RTIs) including HIV/AIDS and STDs (Ross et al. 2001), reproductive cancers and breast cancer (Ross et al. 2001; Sutton et al. 2021), preterm deliveries, low birth rate children, maternal morbidity, and maternal mortality (Sutton et al. 2021). According to Sutton et al. (2021), “Black women and American Indian or Alaska Native women are 3.3 and 2.5 times more likely to die from pregnancy-related causes than White women, respectively,” and “clinician-level biases and racism often contributed to delayed or absent care that led to deaths” (p. 229).

Horrifyingly, women of color have a long history of being subjected to forced sterilization. Sutton et al. (2021) write that “clinicians must be aware of the historical legacy of abuse and eugenics in which women of color have been disproportionately sterilized without their consent (compared with White women) as a result of explicit bigotry” (p. 228). Although women of color have low rates of contraceptive use, population control is pervasive among many racial and ethnic minority groups. According to Ross et al. (2001), accounts show that doctors pressure female patients, especially poor Black women, to accept unrequested birth control methods. Additionally, a 1970 fertility study showed that “20% of all Chicana women had been sterilized” (p. 84). Native American women not only receive inadequate health care, but are coerced into temporary sterilization via a contraceptive (p. 84).

These statistics are among the limited amount of information and knowledge about the health of women of color available (Ross et al. 2001). The absence of data on women of color may be due to a “[d]eficiency in comprehensive research regarding the reproductive health of

women of color and current as well as historic lack of support in the medical community, as a whole, for effectively addressing the conditions faced by women of color” (p. 81). Reproductive health information and support resources such as counseling are especially lacking, leading to a lack of fertility awareness among women in general but especially among women of color (Lee 2019).

Women of color face many barriers to care that may account for their poorer health. Some factors that act as barriers to quality health and health care for people of color are racism, poverty, low social status, low education levels, rapid urbanization, neglect of health care delivery systems, and population control (Ross et al. 2001). Sociocultural constraints are also a barrier to accessing reproductive health services. For example, “[c]ultural taboos surrounding sexuality and pregnancy” such as anatomy, menstruation, sex, or RTIs “are prevalent among Asian/Pacific Islander Americans” (Ross et al. 2001:84). Such factors act in tandem to “reduce[] women’s decision-making power regarding their own sexuality, and constrain[] their ability to seek quality reproductive health care” (Ross et al. 2001:80).

*Socioeconomic status.* Class status has a significant impact on the people’s quality of health and the healthcare that they receive. For example, fertility is impacted by exposure to particular risks such as “occupational hazards, environmental risks, and lifestyle factors, including smoking and obesity...and delays in treatment of reproductive tract infections, including those that are sexually transmitted” — risks to which minority, working-class, and underprivileged populations are more likely to be exposed (Lee 2019:1187). The addition of other disadvantaged identities such as being a woman of color often results in exacerbated health and health care quality. Compared to middle-class or upper-class educated white women, low-income, less educated, and racial and ethnic minority women are more likely to be infertile and

less likely to have successful treatment outcomes (Lee 2019).

Reproductive health care varies according to different intersections of race/ethnicity and social class (Downing, LaVeist, and Bullock 2007). While white middle- or upper-class reproduction is encouraged, the reproduction of low-income, minority, and immigrant populations is discouraged and controlled (Downing et al. 2007; Lee 2019). Stereotypes about low-income women include being “dishonest, dependent, lazy, disinterested in education, and promiscuous” (Downing et al. 2007:1803). Downing et al. (2007) write that these negative stereotypes about low-income women render them vulnerable to discrimination in reproductive health care settings. According to their study, the only significant predictors of HCPs discussing options to restrict reproduction were being a low-income Latina or African American woman, and these individuals were more likely than middle-class White women to be discouraged from having children during their pregnancies or advised to restrict their childbearing (p. 1805). Downing et al. claim that this phenomenon is not necessarily intentional or conscious, but may result from “larger societal attitudes and stereotypes about the effectiveness of low-income parents” (p. 1806).

The impact of intersectional identity on reproductive health care is evident. People with disadvantaged intersectional identities face identity-based stereotypes and discrimination, barriers within healthcare and in their personal lives, control over their bodies, poorer health, and poorer quality of health care than people with less disadvantaged identities. The lack of research on and knowledge about the health and health needs of people with intersectional identities, as well as the fact that the healthcare system is designed to accommodate cisgender heterosexual individuals, contribute to these problems.

## RESEARCH METHODS

### *The Internet as a Narrative Source*

As a “comprehensive electronic archive of written material” (Keim-Malpass et al. 2014:1687), the Internet offers instant access to a vast amount of information on almost any topic. For people with questions on topics that may be taboo, complex, or relatively uncommon such as illnesses, the Internet is an especially useful tool. Social media has become a popular platform for people to share their experiences with or knowledge on health problems, advocate for those who experience the same thing, provide support, and access information by researching it online or by asking other social media users (Chou et al. 2011; Keim-Malpass et al. 2014). While the Internet has created opportunities for widespread communication and information learning among ordinary people, the most notable benefit of the Internet for social scientists and researchers is the vast availability and constant influx of new information on people and their interactions that can be quantitatively and qualitatively analyzed. As a place where patients can document and make sense of their health experiences (Han and Wiley 2013), social media becomes home to illness narratives rich with themes that can inform the medical community, especially regarding more covert issues. Narratives on social media are distinct from those extracted from interviews and surveys in that they are not just between researcher and subject, but between sharer and an audience who may be interested in participating in a conversation (Han and Wiley 2013). The awareness of the potential for audience members to be active may shape how people share their information.

TikTok, founded in 2016, is a social media platform in which people create and watch “TikToks”: short videos between a few seconds to three minutes that individual users post and share to the wider TikTok community. Users can include background music and special effects

(Zhu et al. 2019) which can be used to complement the content they create. Sound “can also function as a story builder and can be used to deliver a specific message” (Serrano, Papakyriakopoulos, and Hegelich 2020:258), hence “TikToks become vehicles for personal narratives” (Hautea et al. 2021:12). For healthcare professionals and patients, TikToks can be used to share information, promote health messages, and empower patients (Zhu et al. 2019).

The uniqueness of this mode of illness narrative sharing must not go unexplored. I developed my methods of data collection by researching empirical studies that have analyzed illness narratives online and those that have used TikTok as a data source. Because social media analysis is relatively new and TikTok is much newer, the number of studies using TikTok as a data source for any study, let alone for illness narratives, were limited. Nevertheless, their methods served as a baseline for my approach to collecting narrative data on TikTok.

### *Identifying Data Sets*

To identify data sets from online sources, researchers have taken many different approaches. Some researchers take their samples from sources dedicated to very specific and relevant causes. In a comprehensive study using TikTok for content analysis, Zhu et al. (2019) identified official (verified) Chinese Provincial Health Committee accounts to find out how they deliver health information. In another TikTok study, Li et al. (2021) reviewed all videos on TikTok’s COVID-19 information hub posted since November 2019 and identified videos related to COVID-19, determined by the inclusion of specific hashtags or mentions of COVID-19 or coronavirus in the audio or text. Other researchers incorporate a “snowball method” to find more data that may be useful. To understand women’s experiences with cancer, Keim-Malpass et al. (2013) obtained a convenience sample of cancer blogs through a modified snowball approach. They identified nine blogs from a list of cancer blogs on a website and found more blogs by

following young adult cancer survivors on Twitter. This efficient method of obtaining data sets ensures that most, if not all, posts will be relevant.

Researchers who want to find data sets from social media can also conduct searches by entering search terms or hashtags into social media platforms' built-in search engines. Some platforms allow searching through recent posts and others display popular posts, which has implications for consistency when collecting data from different platforms. Moreover, there are no best practice tools or guidelines for systematically searching on social media to date (Small 2011), but the different approaches that researchers have taken can be somewhat of a guide. Chou et al. (2011) extracted videos from YouTube using two search terms: "cancer survivor" and "cancer stories" and chose the top 20 clips according to YouTube's ranking algorithm to analyze. Small (2011) looked through "Tweets," user posts on Twitter, tagged with the most relevant and highly ranked hashtag. To gather illness narratives in chronic pain expressions, Gonzalez-Podello and Tarr (2016) searched images on the social media site Flickr that were tagged with "chronic pain," and then used the photostreams of users who used that tag to search for related terms and specific ailments. On Tumblr, they followed users whose profiles or blogs were presented as being related to chronic pain.

Searching by hashtag may be more useful than searching by keyword. Users who tag their content with hashtags can be assumed to intend to contribute to a wider conversation on the topic. This is implicit in the fact that many social media platforms provide users with the ability to search for posts by hashtag — it suggests that users may be interested in seeing what other social media users have to say on a particular topic. That being said, searching by hashtag can be useful for researchers who want to analyze narratives. TikTok in particular displays the most popular videos to users first when conducting a hashtag search (Serrano et al. 2020). Hautea et

al. (2021) identified TikTok videos on climate change by looking through a sample of the top 50 videos under TikTok's official climate change campaign hashtag, then identified a list of the most used and visible hashtags in climate-related videos, determined by TikTok's publicly displayed official view count record, and chose the top two in addition to the campaign hashtag. One who searches by hashtag can encounter problems such as that of Hautea et al. (2021), who had 51 posts in their sample that used climate-related hashtags but were unrelated to climate or environmental topics. This "demonstrat[ed] that a large portion of popular TikToks using climate hashtags were not actually about climate, meaning message content cannot be inferred from hashtags alone; and [revealed] a widespread strategic use of TikTok affordances, which is to 'hijack' popular hashtags to draw attention to content unrelated to the hashtags' original purpose" (p. 7). Although searching with hashtags risks finding relevant content, it does widen the scope of potential content to be analyzed. In addition, the aspect of hashtag searching on TikTok that showcases the most popular videos first may act as a filter for irrelevant content to some degree, as popularity could indicate audience interest or agreement.

### *Inclusion Criteria*

Researchers must decide what should be included and what should be excluded from their sample in order to obtain content most relevant to their research questions. Researchers that are mainly concerned with general discussions on a topic may simply select the most convenient data, such as Massey et al. (2020) who took the top 10 results for each search term that appeared on YouTube. Other researchers have more specific goals in mind. To understand how people express their chronic pain experiences on social media, Gonzalez-Podello and Tarr (2016) only included illness narratives that came from a post by a single individual discussing their personal experience with pain, as indicated by either the user's profile or photo description. Keim-



Malpass et al. (2013) specified that the title of the blogs or the blog authors' bibliographies had to state that the blog was related to the cancer experiences and indicate details of the diagnosis to ensure that it matched inclusion criteria. Since their population of interest was young women with cancer, Keim-Malpass et al. (2013) opted to only include a sample of women between the ages of 20 and 39 years with an illness blog dedicated to sharing their experience with cancer. Massey et al. (2020) excluded duplicate videos, videos that were not in English, and videos that did not present their specific subject of interest.

Language and context are also important considerations. Hautea et al. (2021) excluded non-English TikToks because the authors would not be able to interpret meaning from them, and Keim-Malpass et al. (2013) limited their sample to blogs in English and from the United States so that differences in healthcare systems would not confound analysis. Because social media platforms are used for more purposes than just personal expression, researchers identify and choose to exclude content that is commercial or intended for entertainment or advertising, news broadcasts, public service announcements, scripted, among other unrelated types of information sharing (Gonzalez-Podello and Tarr 2016; Chou et al. 2011). Blogs or data that are not publicly accessible are also excluded to preserve privacy (Keim-Malpass et al. 2014; Hautea et al. 2021).

### *Data Collection*

Online data collection methods tend to involve conducting a search through identified data sets and determining which pieces of content fall under specified inclusion criteria that can then be selected for analysis. Original datasets range from hundreds to thousands and are usually cut down significantly. Researchers specify the range of post creation dates included in their datasets (Gonzalez-Podello and Tarr 2016; Hautea et al. 2021) and the date ranges when searches were conducted (Carrotte et al. 2017; Chou et al. 2011; Massey et al. 2020). Searches may be

conducted at multiple points: Carrotte et al. (2017) searched Instagram, Tumblr, Facebook, and Twitter posts with the #fitspo hashtag at 3 randomly generated timeslots, and extracted them using screenshots. Researchers must be sure to take steps to prevent confounding factors from affecting their search. Massey et al. (2020) used an account “created on an incognito (private) browser to ensure browsing history did not influence the results” (p. 2).

### *Coding*

Researchers’ codebooks for social media analysis develop in different ways. Identifying user characteristics like age, race or ethnicity, and gender without having the ability to ask is both an accuracy and ethical challenge, and delineating subjective categories is another. Massey et al. (2020) chose to estimate age ranges. Categories were younger than 18, 18-25, and older than 25. For race, they coded people as white, black, other, or cannot be determined. This type of racial categorization is extremely limited and its salience to their research questions is questionable, but there are studies for which knowing the race or ethnicity of human subjects is relevant to the research questions.

Coding videos can take on a wide range of forms and can become complicated since many qualitative data are subjective and variable. Coding video types involves determining the mode of information distribution. Li et al. (2021:261) coded their video types as “acting, animated infographic, documentary, news, oral speech, pictorial slide-show and TikTok dance,” while Zhu et al. (2019) coded their video types as cartoon, situational comedy, documentary, TV program, or news report. Some researchers code “characters” in the videos, such as individual, retailer, manufacturer, or group organization (Massey et al. 2020), politician, news organization, journalist, individual, blogger, or cannot tell (Small 2011), or healthcare provider, general public, public figure, TV program, or no characters (Zhu et al. 2019).

### *Methods Used in the Current Study*

*Identifying data sets.* I created a TikTok account exclusively for this research to ensure that past account history would not affect the videos that come up and so that data would be all in one location. I began by entering #womenshealth into TikTok's "Discover" search feature and clicking the "Hashtags" tab. Since videos are "tagged" intentionally by the users that post them, this search method was used to increase the likelihood that the videos that came up would be relevant to my search term. After going through 300 videos under #womenshealth, I used a "snowballing" method to identify other relevant hashtags that appeared frequently in the captions of these videos alongside my initial search term. Relevant hashtags included specific reproductive health issues and variations of the same word or term. I chose ones that were broad (#reproductivehealthcare, #pelvicpain, #periodpain, #obgyn) and specific (#pcos, #polycysticovarysyndrome, #endometriosis). Although #endo may have been helpful to search as a shortened version of endometriosis, the majority of videos that came up were related to an "esports" player with the same name, so I chose not to search with #endo as I did not believe that I would be able to gather enough videos related to endometriosis.

*Inclusion criteria.* Human subjects protections were considered in the development of my research methods. I also only included videos that users chose to share in the public domain. I took steps to be respectful of users' privacy and to be mindful of the fact that I was analyzing their personal narratives. Besides general demographic information such as approximate age, gender, and racial category, I did not disclose easily traceable identifiers such as descriptions of users' appearances, affiliations, or usernames. My hashtag search terms are frequently searched and frequently used in posted videos, so the videos that I collected are likely to be buried among thousands of more recent videos and thus virtually impossible to find on the basis of results

shared in this thesis.

Included videos were published publicly between January 2020 and my search dates within September and October 2021. If the same video came up under more than one of my hashtags, I did not count it again as one of the 300 videos that I looked through under each hashtag. I collected the narratives of TikTok users who have been or were currently patients seeking reproductive health care (hereby referred to as “User [#]”). The user had to be discussing a personal experience or an observation about HCPs’ treatment of patients’ sexual and reproductive health issues that appeared to have special relevance to the user based on the content of the video. This could include specific encounters, multiple experiences, or experiences in general. Because my goal is not to compare the differences in health-seeking experiences around the world, and because consolidating the experiences of people who function under different healthcare systems could potentially confound my findings, I only extracted videos by users who lived in the United States. To avoid misunderstanding or misrepresenting users’ narratives, I only extracted videos in the English language.

I included narratives from users who were assigned female at birth (AFAB). This encompassed people who identify as cisgender women, nonbinary or gender-nonconforming people, or transgender men. Even if the user did not identify as female, I included their videos in my sample as long as 1) the user discussed or demonstrated a personal experience of coming to a health care provider (HCP) with a reproductive health problem that only people with typical female reproductive anatomy (e.g. a uterus, ovaries) can experience, and 2) the video included any of my hashtags and met the rest of my inclusion criteria. Although non-cisgender people face very specific healthcare challenges that may be different from that of cisgender women, HCPs’ perceptions of them and standards of care for bodies like theirs may render their reproductive

health care-seeking experiences similar to that of cisgender women and thus just as relevant to my research questions. It is also beneficial to explore those specific healthcare experiences.

My age demographic of interest was users between the ages of 16 and 35. This range captures people discussing long-term health issues and fertility or pregnancy as well as the most common demographic of TikTok users, which are people aged 16 to 24 (Ahlse, Nilsson, and Sandström 2020). The video had to be original or a “stitch” (when a user shows a portion of someone else’s video, usually one that is asking a question to the audience, and essentially “responds” to it), but not a “duet” (when a user shows their video and another user’s video side by side simultaneously, which would be unlikely to bring forward an illness narrative that would be useful for my research questions).

*Data collection.* Many TikTok users tag their videos with multiple hashtags, which may or may not be particularly relevant to the video content, to appeal to a broader audience and/or have their video become more popular. Because I expected that many videos would be irrelevant or would not fall under my inclusion criteria, I chose to sift through a large number of videos to ensure that my sample size would be adequate. Data were collected between September 14th, 2021, and October 19th, 2021 on the iOS TikTok app. I watched 300 videos under each of my selected hashtags and added videos that seemed to meet my inclusion criteria to my TikTok account’s “Favorites” folder. To begin extracting usable videos that met all of my inclusion criteria, I entered data into a Google Sheets document and completed initial labeling of the users’ username, the date that the video was uploaded, the video link, and the inclusion criteria met. The final sample included 78 individual videos.

*Coding.* My initial codebook was informed by codebooks developed by researchers who conducted social media content analysis. I randomly sampled two eligible videos from each

hashtag in order to begin the process of developing my final codebook. The coding scheme consists of 4 dimensions and several subdimensions: user characteristics, video content, video narrative mode, and themes.

The user characteristics dimension includes multiple variables. The age of users, either specifically stated by the user in the video or on their profile, inferred from their account content, or estimated from appearance, was recorded as ranges from 16-20, 21-29, and 30-35. User characteristics also included race/ethnicity (white or racialized minority) and gender to differentiate the experiences of those hypothesized to be the most and least likely to face discrimination in healthcare based on past research. For race/ethnicity, I decided that it would not be appropriate nor accurate to make judgments based on phenotype and place people into mutually exclusive categories, so I coded users' race/ethnicity as white or racialized minority based on my best judgment and/or specification somewhere in the user's TikTok profile or video. For gender, I coded users as cisgender female, nonbinary or gender-nonconforming, or transgender male. Users were assumed to be cisgender females unless otherwise specified in their profile, since people who are not cisgender may be more likely to mention this through stating pronouns or noting their transgender identity in their profile biography or hashtags. Sexual orientation was not coded because it cannot reasonably be determined as it is not visually discernible nor is it likely to be disclosed by every or many users.

The video content dimension concerns items that can be extracted directly from the video itself. To understand how users express their experiences, I coded their emotions. The final emotions were organized by level of positive or negative, and took users' intended connotations into consideration: happy, humorous (positive), neutral/no emotion, humorous (negative), frustrated, anxious/fearful, sad, angry. The number and percentage of videos depicting each were

recorded. This category was determined by basic emotion cues such as facial expressions, vocal tone, and speech volume. If users used music or sounds in their videos, I initially recorded the song or sound title, then took note of the specific lyrics, words, or sound effects. I recorded the caption text and hashtags included in it. The number of videos that fell under each category that I created were recorded and finalized after the initial analysis of the videos.

The video narrative mode category is similar to how “narrative mode” is used to describe the mode of storytelling in literature, except in this study, it describes *how* users tell their stories. This includes:

- 1) Experience sharing: Videos in which the user directly communicates their personal experience or a general observation about reproductive health care experiences with their audience. The user can either be speaking to the audience, recording their experience, or putting words on the screen.
- 2) Acting: Videos that feature the user acting in a skit or reenacting their experiences. There is a clear indication of roles (e.g., Patient (user), Doctor, Mom).
- 3) Other: Videos that indirectly communicate users’ experiences using alternative methods such as pairing their story with an audio clip, song, dance, and/or screen text. These videos are distinct from the first two categories in that the aforementioned extra factors drive the narrative. In this sense, videos in this category “show” rather than “tell,” as the user implies that something happened in real life.

The coding for this portion was finalized after watching the initial set of videos. After my codebook was finalized and after reviewing and transcribing all eligible videos, I coded the overarching themes and subthemes that emerged in the videos. I included definitions and explanations for what I looked for and specified the number and percentage of videos that fell

into these theme categories. By identifying themes and messages present in groups of videos, I shed light on how AFAB people's reproductive health care experiences are not unique, but possible indications of systemic issues in reproductive health care and society at large.

## RESULTS

After coding all videos, seven major themes arose: Dismissal (n = 56), Unhelpful Solutions (n = 37), Withholding Help (n = 33), Normalization (n = 14), Unprofessionalism (n = 72), Diagnostic Delay (n = 15), and Positive Experiences (n = 15). I categorized each theme into sub-themes or specific concepts (Appendix 2).

### *Description of the Sample*

My sample consists of 78 videos and only 59 individual users, as several users had more than one of their videos come up in my search and meet my inclusion criteria. The majority of users in my sample were between the ages of 21 and 29, cisgender women, and non-racialized minorities (Table 1).

*Table 1.* Sample Description

<b>Characteristic</b>	<b>Frequency (Total = 59)</b>
<b>Gender</b>	
Cisgender Female	89.8% (53)
Non-Binary	8.5% (5)
Transgender Male	1.7% (1)
<b>Race</b>	
White	86.4% (51)
Racialized Minority	13.6% (8)
<b>Age Range</b>	
16-20	5.1% (3)



21-29	72.9% (43)
30-35	22.0% (13)

### *Format, Style, and Content*

TikToks are videos between 15 seconds and 3 minutes long that individual users can record, cut into shorter clips, overlay with audio clips, music, visual effects, or screen text, and post publicly or privately on the TikTok app. Screen text may be utilized to give the audience context to the video. For example, some users put the text “POV:” (i.e., Point of View) at the top of the screen, followed by a description of what the audience should imagine they are experiencing while watching the video. Screen text can also function as a label when placed over the body of the user in the video to indicate to the audience who they should imagine the user to be. Audio and music clips are taken from existing videos uploaded on the app or from the app’s audio/commercial music library. The words or lyrics are often used to drive the narrative. For example, User 40 (Video 59) put screen text at the top of her video that read, “When I have to explain my endo treatment to my general ob/gyn.” The audio playing in her video was that of a man speaking hoarsely: “Sir? Sir? Sir, are you there?” User 40 mouthed along to the audio, as if it was she who was speaking. The audio drove her narrative by symbolizing her reaction to the situation.

Users can also make videos interacting with other users’ videos and comments via “duets,” “stitches,” and video “replies.” Duets are not featured in my study, but several users “stitched” others’ videos in order to add their own commentary. Through “stitching,” multiple users can hop on the bandwagon, so to speak, and share anecdotes that show how common and diverse experiences on the topic can be. A short clip of the stitched video plays before users add their own footage. For example, User 48 (Video 65) stitched the video of another user who asked

the audience to “tell me your age and something you can’t do.” User 48 played the clip of this person making that statement before appearing herself on the screen to share her response. Users can also make video “replies” to comments. These comments show up on the screen of their video and are linked in the “comments” section. This method of engagement allows users to interact with other users who chose not to make videos, but to communicate directly with the user by writing and posting a comment on their video.

Users also have the option to add captions and/or hashtags to their videos. Captions sometimes function to clarify content in videos, provide context, add commentary, or ask the audience questions. Hashtags make videos more visible, as I was able to find them by searching for videos under particular hashtags using TikTok’s search feature. They also give context to what the user’s video is about. Some hashtags, however, do not give contextual information. For example, my hashtag search terms were #womenshealth, #reproductivehealthcare, #pelvicpain, #periodpain, #obgyn, #pcos, #polycysticovarysyndrome, and #endometriosis, but not all of these were the most frequently used hashtags in my sample (Appendix 1). While some of the most popular hashtags were topical (e.g., #endometriosis, #pcos, #womenshealth, #chronicillness), other hashtags, such as #fyp and #stitch, are meant to increase video visibility and popularity. The hashtag #fyp stands for “for you page,” which is the main screen that TikTok displays to users when they open the app.

Users in my sample utilized different narrative styles to share their experiences (Table 2). Most videos (43.6%) were straightforward narratives in which users set up their devices and recorded themselves talking directly to the audience. In videos coded as “acting,” users reenacted their experiences by roleplaying as different characters, with screen text serving to specify who the user is imitating. For example, User 2 (Video 3) put screen text at the top that read, “POV:

you go to the gyno for your annual check-up” to give context to the content of her video (Figure 1). She acted as a gynecologist while the audience took the “point of view” of the patient that the gynecologist was interacting with. Other users relied on the screen text to tell their story instead of speaking and used their facial expressions, body movements, audio clips, or music with lyrics as an accompaniment or a further narrative driver. These videos were coded as “other.” For example, User 48 created multiple videos in which they roleplayed as different characters (a “mean patient advocate” and a “mean endo advocate”) and rapped to a track of music to share their story from a different point of view.

Figure 1. User 2, Video 3



Various emotions and tones were displayed in the videos in my sample, primarily humor and frustration (Table 2). Humor was utilized in both a negative and a positive sense. While some humorous videos made light of unfortunate situations and experiences, others were more

sarcastic and critical. Videos coded as happy and angry often featured passion and energy. Some users shared their experiences to vent or spread awareness. Such narratives mostly fell on the negative end of the emotion/tone spectrum.

*Table 2. Format, Style, and Content of TikTok Videos*

<b>Video Narrative</b>	<b>Frequency (Total = 78)</b>
Experience sharing	43.6% (34)
Acting	25.6% (20)
Other	30.8% (24)
<b>Emotion/Tone</b>	
Happy	9.0% (7)
Humorous (positive)	12.8% (10)
Neutral/No Emotion	6.4% (5)
Humorous (negative)	30.8% (24)
Frustrated	20.5% (16)
Anxious/Scared	5.1% (4)
Sad	11.5% (9)
Angry	3.9% (3)

### *Themes*

Seven themes were inductively derived from the sample (n = 78): dismissal (23.3%), unhelpful solutions (15.4%), withholding help (13.8%), normalization (5.8%), unprofessionalism (30.0%), diagnostic delay (6.3%), and positive experiences (5.4%) (Appendix 2). These themes (defined in Appendix 3) were developed using a grounded theory approach to analyzing video content (audio/visual/textual) on user experiences in seeking reproductive health care. In their TikTok videos, users shared or demonstrated their experiences. In the following sections, I discuss the various ways in which users experienced being “dismissed”: literally by being sent

home, and figuratively by having their experiences, problems, concerns, questions, and propositions downplayed, ignored, denied, disbelieved, and misattributed. I show how the solutions offered by HCPs were considered partially or wholly unhelpful to users due to being arbitrarily offered, intended to mask rather than solve problems, and being unwanted due to underlying medical or personal reasons. Users' narratives revealed that medical help was withheld from them in the form of refusing services and withholding information, especially by failing to mention existing treatments that users may otherwise not know about. I note the relation of refusing services to an undue focus on fertility and cisheteronormativity. I also show how this resulted in a delay in assistance for users, which sometimes had detrimental consequences for their health. I show how the normalization of reproductive health issues, notably menstrual pain, leads to a lack of concern on the part of HCPs which can further contribute to a delay in assistance. I show how users' HCPs acted unprofessionally by failing to adhere to standards of care: being discourteous, doing what they may perceive to be malpractice (hurting users, performing procedures that were not consented to or not medically necessary), lacking medical knowledge that is expected of them, not showing compassion or empathy and instead exhibiting obvious signs of disinterest toward the users, and failing to do their duties as HCPs. I show how all of these problems lead to diagnostic delay. Finally, I shift to the positive experiences that users had, and show how users framed these experiences as surprising because of their rarity.

### *Dismissal*

The manner in which users experienced dismissal varied. User 28 (Video 32), for example, was dismissed by being sent home by their ER doctor despite their persisting symptoms. Other users experienced forms of dismissal that put an affective rather than physical distance between them and their HCPs. HCPs exhibited this affective distance by verbally,

tacitly or in effect “dismissing” users and their health concerns. My analysis of videos discussing experiences of dismissal indicated that users’ problems had not been properly considered or dealt with, if at all, due to the dismissive attitudes of their HCPs.

*Downplaying.* Many users indicated that their HCPs made it seem like their health concerns, problems, and experiences of discomfort or pain were not as severe as they expressed or felt, or that their health issues should not warrant worrying. Some HCPs sorely understated the intensity of pain involved in undergoing routine and surgical procedures:

*User 7 “stitches” a video of a midwife opening a speculum.*

“Yet again, I would like to bring up how when I went in for my first Pap smear, the nurse had the audacity to say that if I was sexually active, *that* wasn’t supposed to hurt? I don’t know what kind of relations *you’re* having, Karen, but THAT’S. NOT. IT!” (User 7, Video 8)

*User 58 describes how her gynecologist performed a Pap smear on User 58 to compare the pain to getting an IUD inserted.*

“ . . . anyways, she sticks the thing in she pulls it out she goes ‘okay you did really good! Now getting an IUD will be like *that*...except a LITTLE MORE PAINFUL.’” [screaming] (User 58, Video 77)

*The gynecologist suggests that User 50 get a hysterectomy for her pelvic pain.*

P: “But that’s like a major surgery, right?”

HCP: “[Well] ‘technically,’ it’s a major surgery. You’ll be in the hospital a few days.” (User 50, Video 68)

User 7 and User 58 vented their frustration about their HCPs’ nonchalance about their pain.

Raising their voices and enunciating their words functioned to emphasize the absurdity of their HCPs’ claims that a Pap smear is not (that) painful. User 50’s reenactment of her gynecologist claiming that a hysterectomy would not be a major surgery is satirical. She raised her eyebrows, rolled her eyes, flipped the palm of her hand, and made “air quotes” with her fingers to convey a flippant attitude about the seriousness of the surgery. User 50’s gynecologist character contrasted hers during this encounter, which featured facial expressions and a vocal tone of worry and confusion.

Several users described how their symptoms, including vomiting, dehydration, excessive

menstrual bleeding, abnormally frequent need to change menstrual products and leave school, a pelvic infection, and especially extreme pain, did not elicit a serious or urgent response from HCPs. Many HCPs claimed that users' symptoms were "not that severe" (User 28, Video 32), suggesting that they did not consider users' issues worth urgently or thoroughly investigating:

"Diagnosed with polycystic ovarian syndrome and endometriosis at 14 years old, I would literally have cysts rupture while I was in chorus class, go to the hospital, and they'd be like, 'girl, take an aspirin. You'll be fine.' . . . Had absolutely terrible pain, went to the hospital, my stomach started getting bigger and bigger and bigger, and they were like 'you're fine, sit, we don't have a bed for you.' Uh, but they found out I, it was internal bleeding from a cyst that bled into my stomach. Ouch!" (User 22, Video 24)

The disenchanted tone in User 22's voice as she made her final comment about what the expansion of her stomach ended up being a symptom of, followed by a sarcastic "ouch," suggests that User 22 felt that her HCPs, in hindsight, should have been more alarmed given the symptoms she presented and her long history of reproductive health problems.

Downplaying seemed to be a result of a communication disconnect between the users and their HCPs. This disconnect was not the fault of the users — who, through words or expressions of pain or concern, clearly conveyed what they intended to convey — but the HCPs, who failed to grasp or take seriously the severity of users' health concerns, problems, and experiences.

*Ignoring.* Many videos showed that HCPs ignored or did not acknowledge what users communicated to them. The phrase "not listening" and variations thereof were commonly used to describe this form of dismissal. Expressions of users' wants, needs, and concerns were often met with inapt or unrelated responses:

"I went to the gynecologist last week for the first time ever 'cause I've always had debilitating periods and wanted to know what was wrong . . . I explained to the doctor that I just got off hormonal birth control because the side effects were wreaking havoc on my body. She then lists out all the hormonal birth control options I should get started on so I don't have bad periods again. She said and I quote, 'the goal is to not have a period.' I told her I instead wanted to focus on re-balancing my hormones through diet, and would like a hormone screening to determine the route I wanted to go and gain insight. Then she tells me 'they don't do hormone screenings.'" (User 30, Video 36)

User 30's gynecologist ignored what she said about her negative experience with birth control and her desire to follow an alternative treatment plan. User 30's explanation that hormonal birth control was not a suitable option for her seemed to be clear, but the HCP responded by suggesting more hormonal birth control options. The gynecologist comes off as not having actually "listened" to her patient when she claimed that "*the goal is not to have a period*" (emphasis added) despite User 30 never having expressed that this was *her* goal.

Users were often ignored by HCPs when they offered their theories as to what the problem might be. After User 54 (Video 72) had a blood test and a pregnancy test, her HCPs finally "went on to do a transvaginal ultrasound because I kept telling them 'I'm pretty sure this is a cyst.'" The use of the word "kept" suggests that this imaging test had to be requested multiple times before her HCPs agreed to perform it. Similarly, User 21 (Video 23) had to repeatedly request that her doctors do a hysteroscopy. Her symptom of daily menstrual bleeding for over two years led her to suspect that her polyps, which she had removed in 2017, had returned:

" . . . they found exactly what I knew they would find. Exactly what I told doctors to look for back in 2019 . . . just as I thought, just as I suspected, and just as I presented to my doctors in the past, they're back. And there's more. There's *so* much more." (User 21, Video 23)

User 21's relapse of polyps could have been prevented or mitigated sooner had her doctors taken her suspicions seriously. User 54's and User 21's HCPs may not have thought to accept the users' requests because they assumed that, as medical professionals, they were more medically knowledgeable. Nevertheless, perhaps the persistence of these users should have signaled to the HCPs that they are more familiar with their own bodies and medical history.

*Denial & disbelief.* Users' assertions of their experiences were not only ignored, but disbelieved. Users wondered why their HCPs did not find them credible. They used similar vocabulary to describe how HCPs denied the validity of their health problems, asserted that no



problem existed in spite of their complaints, or told them that their assertion of the problem was incorrect. When users finally encountered an HCP who took them seriously, they felt “validated.” When they did not, they felt “gaslit” and “invalidated”:

“ [The doctor] completely ignored my medical history, invalidated my pain, and made me feel like shit. She actually told me I didn’t look sick and I left feeling totally gaslit.” (User 31, Video 37)

Medical gaslighting can be understood in this context as users’ shared experience of being made to question their own realities by their HCPs. The videos in my sample contain numerous instances of HCPs expressing doubt toward users’ claims about their subjective experiences or denying the existence of their health problems altogether. HCPs expressed this by asserting that “nothing is wrong” with the user. For example, User 18 (Video 19) had bloodwork done to test for PCOS with an OBGYN and the results came back normal. She nevertheless felt that something was still wrong because her pain persisted, so she asked if her primary doctor could do further testing and mentioned that her OBGYN had suggested that she get an ultrasound to test for PCOS. The doctor repeatedly refused because she didn’t believe her patient: “It’s not PCOS, I’m not testing any further for that because your bloodwork was normal . . . you’re fine, don’t worry about it.” The constant denial of User 18’s persisting problem, coupled with the refusal to find out why, evidences the doctor’s complete lack of trust in her patient.

User 50 (Video 67) appropriately tagged her video #medicalgaslighting:

P: “So I just did not like how I felt on that birth control, so I was just wondering if there was maybe other options.”

Screen Text: male gyno

HCP: “What do you mean? You didn’t like it, what...[sighing] what’s wrong with the birth control?”

P: “Well, I had chronic headaches and nausea and, this is a little embarrassing, but I gained like a ton of weight on it.”

HCP: [scoffing] “No, listen. Birth control does not make you gain weight.”

P: “But it’s hormones. Doesn’t that make some people gain weight?”

HCP: [chuckling] “No, hon, listen. Let me fill you in on a little secret, okay? Birth control does *not* make you gain that much weight. Women are lying, they’re making that up.”

P: “Why would...why would women be lying, why would they be making that [up]?”

HCP: “So women get on birth control, right? Mokay, and then they’re just *lazy*, and they don’t work out, and they don’t eat right, and they’re looking for someone to blame, and who do they blame? Birth control.”

P: “No, that doesn’t, that doesn’t seem right. Where did you get your degree from?”

HCP: “Just don’t be a lazy cow and you’ll be fine.” (User 50, Video 67)

User 50’s gynecologist not only ignored most of the birth control side effects that she mentioned were bothering her, but he also gaslighted her about her experience of gaining weight on her birth control — that is, he made her question the reality of her subjective experience. By making the overarching claim that women who gain weight on birth control are liars who do not want to take responsibility for their exercise and eating habits, User 50’s gynecologist indirectly claimed the same about her. This communicates to User 50 that her gynecologist not only disbelieved her, but is biased against women who share the same experience. This also may signal to User 50 that trying to convince him of the validity of her problem would be futile.

Several users felt that their HCPs discredited them, making them out to be untrustworthy sources of information on their own health. Words and phrases that users reported were used by HCPs to describe them were “combative,” “argumentative,” “dramatic,” and “hypochondriac” — labels that strip users of their credibility and lead to statements or beliefs that they are “seeking attention,” “faking,” and therefore “lying.” User 42 made a sarcastic commentary on this phenomenon in her personal experience:

Screen text: What my first gyno heard when I told her about my pain

Audio: [User 42 mouthing along] “One of my favorite things to do, um, one of my many talents, one of my hobbies, is lying. I *love* lying. I love lying pathologically, I love lying through my teeth, and I love doing it every single day.” (User 42, Video 54)

The idea that HCPs automatically interpret what they hear from their patients as lies was reflected in many videos in my sample. User 28 illustrated their own experience of being disbelieved and considered untrustworthy:

*User 28 roleplays as a “mean patient advocate and raps along to a track of music.*

Screen text: THE MEAN PATIENT ADVOCATE | *\*based on a true story\**

“Ah yes, Dr. Phillips. We need to speak about the patient you sent home the other day? The one you didn’t believe was in pain. Well why don’t I refresh your memory, alright? The patient came in with a pelvic infection. You treated them as if they were seeking attention. Despite their pain, vomiting, dehydration, you said they were faking without hesitation. ‘You need to control your emotions dear, take some advil, it’s not that severe.’ Her entire pelvic region was inflamed, let me kick your balls and you say you’re not in pain. I don’t mean to be so unprofessional, doctor, but it literally says here you called them combative when *you’re* the one who refused testing. Then they left here *questioning* if they were crazy for seeking help...when they know their body inside and out.” (User 28, Video 32)

Gaslighting is evident in the last sentence. Despite knowing what feels right and wrong in their own body, User 28 was made to question their experience so much so that they wondered if they were “crazy” for seeking help for what they now wonder may be a fake problem. The same user expressed in Video 48 that they felt they were treated like they were “crazy for being upset that [the surgery] was canceled” at the last minute after five years of waiting. They claimed that the doctor said, “I don’t know why you’re so upset” and that he sat there “as if the patient is just being dramatic.” He also referred them to the psych ward, making it seem like they were mentally unfit and therefore not to be trusted regarding their claims about their own medical issues.

User 28’s videos stated how HCPs make them, and perhaps patients seeking reproductive health care in general, feel when HCPs deny the validity of their claims and disbelieve their accounts of their experiences. Other users who experienced instances of invalidation and gaslighting may also have internalized HCPs’ discrediting language toward them.

*Misattribution.* HCPs often attributed the reproductive health problems that users complained about to non-gynecological factors. Users’ narratives indicated that some HCPs psychologized their physical symptoms, claiming that their mental health or emotions were the cause. User 44 (Video 60) provided examples of the different responses she has received when seeking out a doctor for period pain, such as “you just have low pain tolerance!” and “all your

labs came back normal so the pain is likely more psychological!”

HCPs also attributed users’ experiences to other physical health problems. Users’ complaints, most often pain, were misattributed to weight, lack of exercise, poor diet, hormones from birth control, hormone fluctuation from PMS, cysts, having low pain tolerance, normal symptoms of PCOS, STDs, muscular pain, and even pain medication addiction. For example, when User 19 (Video 20) could not stop gaining weight, her doctor asked if she “tried working out and eating better.” Later, she was told that “it’s just the birth control hormones left in my body.” A new doctor finally diagnosed her with PCOS, revealing the true cause of her symptoms.

While some misattributions may hold some merit — that is, the explanations are in the realm of possibility, medically speaking — other HCPs’ misattributions evidence either a lack of accurate medical knowledge or a lack of motivation to provide an accurate explanation:

P: “I had my period about a week ago, and uh, halfway through it, I had this *horrible*, horrible pain that brought me to my knees, it felt like something inside of me was *exploding*, it hurt *so* bad.”

HCP: [incredulous] “It sounds like a cyst burst.”

P: “Okay, so is that...is that PCOS? Could we test further? [Another doctor] mentioned an internal ultrasound for that.”

HCP: [annoyed] “No, I’m not testing any further for PCOS. You don’t have it.”

P: “But you said a cyst could’ve burst?”

HCP: [condescending] “Yeah. Every month when you ovulate, a cyst forms and it bursts to release the egg, so that’s probably what happened. It’s not PCOS, I’m not testing any further for that because your bloodwork was normal!”

P: “But I was...*on my period*. So I would’ve already ovulated. This was *during* my period that this pain happened.”

HCP: “Okay, well I’m sure you don’t have PCOS, so let’s just do your exam and your pap, let’s take a look.” (User 18, Video 19)

“If you have PCOS and doctors keep telling you that you are bleeding for X amount of days because of your PCOS...get a new doctor, um, because...yes PCOS can cause abnormal menstruation, but, it’s typically lack of. Um, 800 plus days, any amount of abnormal bleeding...is...something’s *wrong*.” (User 21, Video 23)

Screen text: POV: You're in the ER suffering with Endometriosis Pelvic Floor Dysfunction, Multiple Sclerosis & Ehler Danlos.

HCP: “Oookay, Gabrielle, let’s take a llook! Alright we’ve got pelvic pain, uhuh [inhaling] Okay, interstitial cystitis...pelvic pain, bladder pain, urinary...*stuff*, ahahahaha, oookay, could you

be, are you pregnant? Okay, maybe an STD, maybe an STD. [Sucking air through teeth] Mmm, or, I know, it's a UTI! Maybe, right? Right? Okay, okay. We'll get you feeling better." (User 41, Video 53)

User 18's doctor's explanation for her pain — that a cyst burst *when* she ovulated — contradicted her experience of feeling the pain during her period, which is *after* she ovulated. Thus, the cause of the pain could not have been a cyst burst, but the doctor went on to deny that the cause was PCOS and performed routine exams that would not be able to diagnose complex issues. User 21 suggested that her doctors incorrectly attributed her long-term menstrual bleeding to PCOS not just because of disbelief, but because of misinformation. She learned after several years that she had polyps, so the misattribution of her 800+ day menstrual bleeding to usual symptoms of PCOS constituted a failure to detect something more dire. User 51's POV-style video may have been intended to be comical, but the message it sends echoes that of User 18, User 21, and several other users who experienced having their severe reproductive health issues misattributed to mildly or minimally severe issues.

*Key points.* Users' narratives of being dismissed by their HCPs revealed a disappointing tendency for HCPs to not put much thought into the problems that their patients presented to them. By downplaying the severity of health problems, ignoring users' suggestions, questions, and requests, denying the validity of their problems or not believing their claims, and misattributing side effects and symptoms to other problems, HCPs left users feeling confused, angry, disappointed, crazy, and fearful. This treatment may make patients believe that their problems are not important enough to warrant seeking help, or that it is not worth seeking help at all.

### *Unhelpful Solutions*

While being dismissed implies not being helped, sometimes HCPs' attempts to help users are just as unavailing. Users whose TikToks were coded as "Unhelpful Solutions" were those

who felt that the solutions or treatments offered by their HCPs were unhelpful in that they did not directly treat the problems that users wanted to solve. As with dismissal, my analysis of such videos indicates that users' problems were not solved. Often, this was because HCPs resorted to the easiest or most generic treatments, suggesting a lack of effort to find out what would best help their patients.

*Arbitrary treatments.* Treatments that HCPs offered users were often arbitrary in that they seemed to be offered without a specific medical reason or goal in mind. Some users were told to engage in activities and behaviors that would calm them down, like therapy, exercise, or “relaxing.” User 6 (Video 7), who dealt with pain while having sex, was told by a doctor to “drink wine, smoke a j[oint], use extra lub[e].” User 6 tagged her video #vaginismus and #dyspareunia, suggesting that she was dealing with medical issues that could not be solved using alcohol, recreational drugs, or non-medicinal products. The fact that these sorts of “treatments” were recommended rather than investigating the problem thoroughly to make diagnoses and prescribe medications suggests that these users' HCPs believed the problem to be psychological.

Other times, HCPs offered solutions in order to fix users' health issues, but their solutions were not adequate to ameliorate the complex reproductive health issues that users were dealing with. Several users were told to lose weight, change their diets, or go on birth control as means to treat PCOS or make periods come back:

Screen text: \*telling my doctor about my PCOS symptoms\* | \*realizing the only advice they have is to lose weight\* | “weight gain causes PCOS” | “Just take birth control or Metformin” (User 20, Video 21)

User 20 appeared disappointed that her doctor had such arbitrary suggestions to fix PCOS, a hormonal disorder, especially with something like Metformin, an anti-diabetic medication. Given that losing weight was such common advice from doctors to ameliorate PCOS, it may be that doctors have misconceptions about the causes and symptoms of PCOS.

Other users like User 47 (Video 63) were offered treatments that were completely off the mark with regard to ameliorating the problems that they presented to their HCPs:

“She was predictably unhelpful. Like most doctors, she tried to put me on birth control. I’ve explained in a previous video why I can’t do that. And then she said, ‘Well why not try the copper IUD for your menstrual cramps?’ Do you guys know what the main side effect of the copper IUD is? [Unintelligible mumbling] Cramps and severe menstrual pain! And then I’m more likely to violently yeet it out of my body.” (User 47, Video 63)

User 47’s primary concern was menstrual pain, but the treatment that her HCP offered, the copper IUD, is known to cause that very effect. This leaves us to wonder why User 47’s doctor would offer the copper IUD in the first place. Perhaps she was not aware or did not believe that IUDs cause menstrual pain. Alternatively, she may not have any better ideas because User 47 declined to take other types of birth control. In other words, instead of finding non-birth control methods to ameliorate her patient’s menstrual pain, the doctor insisted on a type of birth control that User 47 has not tried yet as another attempt to get her to accept that kind of treatment. The doctor recommended the copper IUD in spite of the fact that it would not only be ineffective for solving User 47’s problem, but make it significantly worse.

*Masking.* Many users perceived that their HCPs’ goals were not to uncover the underlying cause of their problems in order to find a long-term solution, but to simply reduce symptoms. Some users were told to pursue major “treatments” like a hysterectomy or pregnancy. Others were offered only short-term remedies like aspirin and ibuprofen, which are ineffective for alleviating severe pain. One of the most common masking treatments offered was birth control. Users were offered birth control to fix unbalanced hormones, period pain, and PCOS. User 1 (Video 2) noted that “anytime we go to the doctor with any concern about our menstrual health . . . the *only* option we have is birth control.” User 56 provided insight into why this may be:

“I was slapped with that shit [birth control] ten years ago to fix polycystic ovarian syndrome,

which a doctor told me the other day basically means that they don't know what's wrong with you, so that's super great." (User 56, Video 75)

User 56's commentary suggests that birth control is a default treatment, a cure-all remedy for anything related to reproductive health. As the users shared, birth control did not fix all of their problems, and their complaints imply that they wished they were given other options. User 15 went on a sarcastic rant about her thoughts on HCPs' tendency to default to birth control as a treatment:

"Awww, OH! Your period's so painful that you pass out and threw up and vomited at school? Oh, you almost weren't able to graduate high school 'cause you had to, you had to miss so much school? Oh, you got fired from your job, 'cause you were missing that much school because of period pain. I know what we'll do! I KNOW WHAT WE'LL DO! Here's this birth control pill, even though you have no, you're maybe not even sexually active, but here's this birth control pill that shuts down ovulation from happening. Let's just shut it off. Instead of balancing hormones, let's just shut it off! AH! Perfect idea! Oh, and then you trade the pain for anxiety, depression, issues with your gut health, food intolerances, sensitivities. It's just part of being a girl, right?" (User 15, Video 16)

User 15 seemed to have been particularly irked by the fact that HCPs only offer treatments that mask problems that people have with periods instead of coming up with solutions to "balanc[e] hormones" naturally, and that these treatments come with the price of hindering mental and gastrointestinal health.

Users' narratives revealed HCPs' tendency to resort to prescription drugs to mask symptoms rather than finding ways to improve well-being in other ways. They perceived that their HCPs were not open to alternative methods for diagnosis and treatment, nor were they concerned about side effects that their prescriptions caused.

*Unwanted treatment offer.* A lack of concern by HCPs about treatment side effects was a common reason that HCPs offered unwanted treatments to users. Users shared that they were offered treatments that had not worked for them in the past or that they could not or did not want to receive due to medical reasons or personal preferences. Several users' HCPs disregarded their



negative experiences with birth control:

“So I understand you’re having a hard time on the pill. *This* pill launched you into psychosis? Okay...And *this* pill made you gain 25 to 30 pounds? Normal. Average. So *might* I suggest a new pill that will actually do *both* of those things *plus* probably give you your period for two months' time? Yeah, like nonstop? Let’s give that a whirl, you know?” (User 2, Video 3)

In User 2’s comedic skit of a gynecologist’s encounter with a patient, it was clear that the gynecologist understood that many different kinds of birth control pills have caused bad side effects for the patient. User 2’s gynecologist character sarcastically commented: “Normal. Average” to imply that the real-life gynecologist was not at all concerned about these side effects. Nevertheless, the gynecologist offered another pill with additional side effects. Another user suggested that their doctor was overly persistent about using hormonal birth control:

“ . . . despite having suffered immensely from periods most of my life, both from the physical pain and the dysphoria they caused me as a nonbinary person, I was not offered this procedure [an endometrial ablation] until I made it clear to my doctor that I absolutely would not use hormonal birth control to resolve the bleeding because it makes me feel like shit, let alone would I be willing to use it for the rest of my life which was her solution at the time.” (User 3, Video 4)

User 3 was not offered an alternative to hormonal birth control “*until I made it clear to my doctor*” (emphasis added) that they would not accept this form of treatment. Their absolute refusal was the catalyst for the change in the doctor’s medical plan, not their lifelong suffering from period pain and gender dysphoria.

*Key points.* Users communicating their history and wishes to their HCPs was too often futile. Their HCPs did not take their personal wants, needs, limits, and boundaries into consideration. Instead of using the information provided by their patients to guide their treatment plans, HCPs were adamant about sticking to their initial plans. The haphazard approach taken by many HCPs in treating their patients left users just as lost as they would have been had they not sought out medical assistance.

### *Withholding Help*

The worst way that HCPs were unhelpful to users was when they did not try to help at all. Medical help can come in the form of procedures, medications, and information. Users' narratives indicate that various forms of medical help were withheld from them, whether in the short-term, long-term, or forever.

*Help refusal and undue focus on fertility.* Some users' HCPs refused to conduct tests or procedures requested by their patients. Users' narratives suggest that their HCPs' reasonings for refusing services were influenced by social and cultural norms, beliefs, and expectations. Age played a central role in many narratives. Interestingly, videos featuring help refusal revealed an undue focus on fertility on the part of HCPs. Many HCPs focused discussion and treatment on issues concerning fertility and having children, even when this topic was irrelevant, unwanted, or not medically necessary. Some HCPs refused to perform sterilization procedures because they preemptively assumed that the user may want children someday. Ciheteronormative and patriarchal ideology also influenced HCPs' decisions. HCPs often took users' potential future or current husband's needs into consideration and put them above that of their patient's:

HCP: "So I know that we told you before that you were just hormonal, but *now*, we know that you have PCOS."

P: "Oh, what does that mean?"

HCP: "Well, you'll probably never be able to have children, *and*, you're going to have so many problems, every single day, all of the time. Isn't that fun?"

P: "No! Why can't we just scoop out the whole kit and caboodle?"

HCP: "Of course not, you're 19. What if you wanted to have children?"

P: "You literally just said that I can never have children!"

HCP: "But what would your husband think?"

P: "*I'm a homosexual!*" (User 17, Video 18)

Screen text: Me: i dont [*sic*] want to have kids, please sterilize me | Doctor: youre to [*sic*] young to know that | Doctor: what if your husband wants kids | Doctor: Just get an iud so you can take it out later | Doctor: Everyone [*sic*] woman wants children you will change your mind (User 49, Video 66)

Despite being told that their PCOS may cause chronic problems and infertility, User 17's HCP

refused to surgically remove their reproductive organs because of their age. The reasoning provided was that they or their potential future spouse may want to have children, even though the HCP told the user that they may never even be able to have children due to their PCOS. Additionally, the assumption that this user would have a husband to consider was likely a result of cisheteronormativity. User 49's HCP's response to her request to be sterilized also cited age as acceptable reasoning. User 49, who was categorized in the 21-29 age range, was not refused sterilization because it would be medically unwise, but because of the doctor's assertion that User 49's age indicated a lack of capacity or maturity to decide that she did not want children. The responses mentioning a husband and what "every woman wants" show that the HCP was more concerned with the wants and needs of a man in the user's future life and not of her own wants and needs. The HCP also held her to a cultural expectation that as a woman, she should want children and that her assertion that she did not want children was invalid.

Sometimes age was not even used as a reason. One user was refused tubal ligation despite being a grown woman:

Stitch: "Tell me your age and something you can't do."  
 "So this is fun. I'm almost 29 years old and I cannot get my tubes tied without my husband's permission. 29 years old. No children, don't want children, don't have a husband. I want my tubes tied. Because I don't wanna get pregnant. Because I don't want children. And I'm not allowed to do it. Isn't that amazing? Men rule the world and it's just *so* great for us females!"  
 (User 48, Video 65)

User 48 was "not allowed" to get a sterilization procedure because permission from a husband was required. Her commentary about men "rul[ing] the world" and making it "*so* great" — that is, difficult, as implied by her sarcastic tone — for "us females" (and those with typical female reproductive anatomy) is a shared sentiment among users. Inspired by recent Texas abortion laws, User 3 shared their ideas about "forced fertility throughout our culture" to demonstrate society's insistence on childbearing:

“ . . . medicine is patriarchal and anyone born with a uterus is forced to remain fertile no matter the suffering it causes, unless of course it’s a woman of color who’s vulnerable and then she may be *forced* into a hysterectomy without her consent . . . this should be a choice, we should be allowed to opt out of fertility if we don’t want it.” (User 3, Video 4)

User 3’s comment that medicine is “patriarchal” insinuates that the societal dominance of men in positions of power is responsible for the lack of control that uterus owners have over their own bodies. Although this claim seems radical, the narratives of other users demonstrate that at least some patients AFAB are not allowed to exercise bodily autonomy for reasons that are medically irrelevant.

*Not offering.* User 3’s video demonstrated another theme in my sample’s narratives.

Some users shared that their HCPs did not offer information or resources that would have been useful to them. Many said that their HCPs did inform them about the possibility or existence of a medication, treatment, symptoms, or side effects. User 3 asserted that information related to sterilization is “withheld from everyone born with a uterus”:

“There is a simple non-surgical procedure that permanently stops periods without hormones or a hysterectomy and *none* of us are educated on it because we are not allowed to make decisions about our own bodies. It’s called ‘endometrial ablation’ and it is the best thing that has ever happened to me . . . So why aren’t we told about it? . . . The only people I know who have ever heard of this procedure are perimenopausal or menopausal, meaning *they* are *past* the *prime reproductive years*.” (User 3, Video 4)

User 3 said that the procedure they received is widely unheard of, as only people that they know who are infertile or less fertile have heard of it. This may suggest that information about endometrial ablation is only shared with patients for whom fertility is no longer as important.

User 3’s previous comment on patriarchal medicine suggests that the lack of easily accessible information on reproductive health procedures can be attributed to it. Other users were also aware of having information withheld from them:

“[One type of birth control] caused microtears during sex and I was wondering why sex was so *fucking* painful. Look online, sure enough, reviews of women say that. Your doctor don’t tell you though.” (User 9, Video 10)

Screen text: CC: “I was able to reverse my PCOS symptoms without birth control or Metformin” | Doctor: “how bizarre...” | Nurse: “how bizarre” | Cc: “Thanks for telling me that was a possibility! Had to learn from Tik Tok instead! (User 20, Video 30)

User 20 captioned her video, “it’s almost like they don’t want you to know!” suggesting something sinister. The doctor’s and nurse’s innocence in the matter implied by the “how bizarre” comment may either be a result of ignorance or disingenuity. As demonstrated by my analysis of the theme of dismissal and unhelpful solutions, HCPs often push medications like birth control onto their patients. It seems that users’ HCPs were either unaware of natural options or unmotivated to search for them.

Users also claimed that some of their HCPs did not offer medication or treatment to them. Several users claimed that they were not offered painkillers, numbing, or local anesthetics for painful procedures, including IUD insertion and an endometrial biopsy. Users were often not offered anything for their pain caused by their gynecological problems. For example, User 53 (Video 71) had a cyst for which “the medical plan of action is ‘just wait it out, it’ll go away on it’s [*sic*] own!’” even though her pain rendered her unable to work. Some users also felt that their medical options were intentionally withheld from them. User 1 (Video 2) lamented that birth control is the *only* option that doctors seem to offer for menstrual health concerns. User 3 had to wait and put in significant effort to be offered a procedure:

“I was not offered [an endometrial ablation] until I made it clear to my doctor that I absolutely would not use hormonal birth control to resolve the bleeding because it makes me feel like shit, let alone would I be willing to use it for the rest of my life which was her solution at the time . . . And I had been bleeding for over TWO MONTHS STRAIGHT before my doctor, whom I actually consider one of the good ones, offered me an ablation.” (User 3, Video 4)

They captioned their video, “Everyone with a #uterus deserves ALL of their medical options.” Perhaps HCPs relied on their patients to request these procedures themselves, assuming that they would ask if they wanted something. This, however, would require users to have the appropriate knowledge, and patients are not always informed about the possibilities. Thus, for HCPs to have

this expectation is unreasonable. Users' HCPs did not take the responsibility of informing their patients about their medical options or offering them anything until they insisted. Even then, many users had to go without any treatment at all.

*Assistance delay.* Sometimes it took a long time for the HCPs to provide help to the users. User 3 (Video 4) "suffered immensely from periods most of my life" and bled constantly for over two months before they were offered an endometrial ablation to stop their periods. User 21 (Video 23) had been telling her doctors to look for polyps for several years because she had a history of polyps and was concerned about her daily bleeding for over 800 days. Her doctors did not do so until recently when they found a large number of polyps — many more than before. Had they looked for polyps earlier, perhaps they would not have had to remove as many and User 21 could have avoided years of suffering.

User 28's medical help was also delayed. They were sent home because their doctor did not believe them. Roleplaying as an endometriosis advocate, they explain how this impacted their health:

"Thank goodness they came back on Saturday night because we found an abscess which gave us a fright. Now they're in emergency surgery. They're gonna lose their ovary 'cause you sent them home early. And their entire health is at risk because you didn't listen and had them dismissed."  
(User 28, Video 32)

Had the doctor evaluated this user earlier, they may not have had to lose an ovary. This user also made another video (Video 35) explaining that a doctor diagnosed them with severe endometriosis but kept postponing surgery. He sent them to a pain management doctor first, who told him: "'either you do surgery or put them on a pain pump because they're really sick.'" User 28 notes: "Not only did the surgery take 5 hours, I was stage IV endometriosis." The severity of their case may have been avoided had the doctor not waited to do the surgery. When this user (Video 48) expressed that they were upset that their HCP canceled a surgery for their

endometriosis that they waited five years to have done, the HCP referred them to the “psych ward . . . treating them like they are crazy for being upset that it was canceled” instead of finding another way to help them.

*Key points.* Withholding medical assistance from users — whether intentionally or unintentionally, or in the form of providing information or making an offer (or not) — had dire consequences for users’ mental and physical health. Cultural norms were used to support HCPs’ arguments for withholding help rather than medical reasons. HCPs’ preconceived notions about people’s ideals and values overshadowed users’ personal wants and needs. For example, HCPs automatically assumed that users wanted children or aimed to appease a spouse, and users’ arguments that such things were not personally valued were not respected or taken seriously, and were certainly not effective in convincing their HCPs. Suffering physically (e.g. pain) or mentally (e.g. gender dysphoria) was not a compelling enough reason to change HCPs’ minds. Withholding information and offers and delaying assistance forced users to endure more suffering than they would have, had HCPs been more informative or proactive in helping them.

#### *Normalization*

“Normalization” was a common phenomenon in my sample wherein users’ HCPs reduced their patients’ problems to something of little or no concern because of the commonality of those problems. By being told that “it’s normal[,] everyone has period pain” (User 44, Video 50), users gathered that they must deal with their gynecological problems because they are a universal experience, which implies that they are of no concern.

*Normalizing symptoms and side effects.* Many users were told by their HCPs that their symptoms were “normal,” including painful menstrual cramps, painful sex, heavy bleeding necessitating extremely frequently changing menstrual products, having longer than average

periods, vomiting, passing out, cystic acne, cysts, and significant weight gain. Side effects of medications that were normalized were mental health issues and gastrointestinal health.

While User 35 (Video 43) had “a severe painful sex disorder” that necessitated going to “vagina physical therapy,” she was told by “society” that sex should hurt the first time and by her gynecologist that “it’s common to experience pain during sex.” User 35 mouthed along to a song in her video whose lyrics repeat, “Okay! I believe you,” insinuating that she took her gynecologist’s word for it before receiving her diagnosis. She captioned her video, “[I don’t know] who needs to hear this but SEX IS NOT SUPPOSED TO HURT!!! If it does you might have #vaginismus, #vulvodynia, #endometriosis, etc.” Her video informs her audience that painful sex may be common, but it is not “normal” because it could be caused by gynecological disorders.

*Normalizing female gynecological problems.* Notably, many of the users’ experiences of having their problems normalized were centered around the notion of a typical “female” experience. The phrase “part of being a girl” was quoted verbatim by many different users. User 15 (Video 22) roleplayed as herself and her HCP:

Screen text: [Patient:] “I pass out every month because of period pain.” [HCP:] “Ok. Tell me more.” [Patient:] I throw up every month because of my cramps. [HCP:] Yeah! That’s normal! That’s just part of being a girl (User 15, Video 22)

The same user in Video 33 imitated doctors and how they tell patients to “just deal with it.” In my sample, there appeared to be an expectation that people who have uteruses and menstruate must endure extreme symptoms of periods to fulfill the “part of being a girl.” Discomfort was presented as an expectation and a measure of normalcy.

*Lack of concern.* One of the most demonstrative ways that users’ problems were normalized was when HCPs exhibited a lack of concern. Some of them did not seem to be alarmed at their patients’ accounts of extreme problems because they perceived those problems



to be normal. User 36 (Video 46) recounted being 15, explaining her horrible period symptoms to her gynecologist, and being asked, “And that’s an issue because?” User 22 (Video 24) recounted her chronic pain and cysts that took her out of school and made her go to the hospital. She was constantly told that she was fine and to take an aspirin or lose weight. User 32 (Video 31) mouthed along to a song to demonstrate how she believed HCPs respond to period symptoms:

Screen text: Patient: "My periods make me throw up, double over in pain, and bleed through my tampon every 30 minutes" Doctor:

Song: “That's tough. That's tough. That's tough. That's tough...”

Caption: Who's been told you're normal? (User 32, Video 41)

“That’s tough” was presented by User 32 to be a disingenuous display of sympathy, indicating that her doctor had no qualms about her incapacitating symptoms.

*Key points.* The normalization of gynecological problems was demonstrated by HCPs’ lack of concern and insinuation that users’ problems are normal because they are common. Severe pain and other debilitating and inconvenient problems associated with menstruation were justified on the basis that such experiences are “part of being a girl,” and if they will inevitably happen to menstruating patients, then no additional care is necessary. By conflating commonality with normalcy, HCPs allowed their patients to suffer in spite of the existence of medical solutions and explanations.

### *Unprofessionalism*

The most common theme in my sample was unprofessionalism. TikToks that signified unprofessionalism were those in which the users shared that their HCP did or said things during their consultations with users that do not meet the standard expectations of an HCP.

*Discourteousness.* Many users’ videos showed that their HCPs were discourteous or insensitive toward them, whether through gestures, emotions displayed, insinuations, or direct

statements and questions. Some users found that their HCPs were mean, hostile, or had a bad attitude. The tone of HCPs, as acted out by users in their videos, was often dry, incredulous, annoyed, or condescending. After getting bloodwork done by another doctor and receiving normal results, User 18 visited her “normal doctor” that displayed such an attitude:

P: “Sssso, I’m still not feeling right, uh, saw the other doctor a couple weeks ago, something’s still not right.”

HCP: [dry] “Okay, well your bloodwork’s normal.”

P: “Okay, well the other doctor mentioned it might be PCOS, um, is that something we could look into? Also I don’t know if this is related, but, I had my period about a week ago, and uh, halfway through it, I had this *horrible*, horrible pain that brought me to my knees, it felt like something inside of me was *exploding*, it hurt *so* bad.”

HCP: [incredulous] “It sounds like a cyst burst.”

P: “Okay, so is that...is that PCOS? Could we test further? She mentioned an internal ultrasound for that.”

HCP: [annoyed] “No, I’m not testing any further for PCOS. You don’t have it.”

P: “But you said a cyst could’ve burst?”

HCP: [condescending] “Yeah. Every month when you ovulate, a cyst forms and it bursts to release the egg, so that’s probably what happened. It’s not PCOS, I’m not testing any further for that because your bloodwork was normal!”

P: “But I was...*on my period*. So I would’ve already ovulated. This was *during* my period that this pain happened.”

HCP: “Okay, well I’m sure you don’t have PCOS, so let’s just do your exam and your pap, let’s take a look.”

Screen text: \*she starts my pap and scrapped at me for SEVERAL minutes, it was painful\*

P: “Ahh...mm...that...that hurts, a lot.”

HCP: [annoyed] “I’m almost done.” (User 18, Video 19)

Based on User 18’s acting, it seemed that the doctor was not concerned that their patient still felt unwell despite the normal bloodwork results, taking those results as an indication that nothing must be wrong. The doctor character came off as rude and unwilling to listen to or work with User 18 to find out what was really causing her symptoms.

Many users’ HCPs’ hostile treatment of them made them feel negative emotions. User 31’s doctor “made me feel like shit” (Video 37) and “made me feel so hopeless and angry” (Video 44). Many users were laughed at, scoffed at, or snickered at. User 54’s video (Video 72) demonstrated how her ER doctor lacked compassion:

“Um, turns out I had a seven and a half-centimeter hemorrhagic cyst on my left ovary, as well as

a two-centimeter simple cyst. I have a bleeding disorder, this is dangerous for me. The ER doc looked at me straight in the eyes while I am *bawling* in pain on the bed and goes, ‘You need to stop. Ovarian cysts don’t hurt.’” (User 54, Video 72)

Several users shared that their HCPs blamed them, telling them that it was their “fault” that they were experiencing symptoms and side effects. Users’ narratives indicated that HCPs framed this blame via if/then statements or insinuations, such that if the user changed their behavior, then they would not have their health problems. This was especially apparent in regard to weight. User 25 sarcastically commented on how poorly PCOS is handled and how people suffering from PCOS are treated:

“Yeah, hey, so, uh, there’s this medical condition, it affects 1 in 5 people assigned female at birth, um, that is the leading cause of infertility, 50% of us becoming diabetic by the age of *forty*...yeah. Uh, and, if left untreated can cause cancer and heart disease, but you know, um, but we’re ignored. Wait, wait, wait wait, no, no, we’re not ignored, we’re blamed...yeah. We’re blamed. We’re told it’s our fault ‘cause we’re...we’re fat. It’s a weight issue. So if we just, we just got off the weight, you know?” (User 25, Video 27)

User 50’s gynecologist (specified as male) told her that birth control does not make people gain weight and that people who take birth control only experience weight gain because “they’re just *lazy*, and they don’t work out, and they don’t eat right, and they’re looking for someone to blame . . . Just don’t be a lazy cow and you’ll be fine” (User 50, Video 67). User 22 (Video 24) was told to “stop eating so many carbs” every time she sought medical help for her PCOS-caused weight gain.

Weight was a prominent focus of users’ HCPs and lead to “fatshaming.” User 12’s HCP made her weight a central focus during a Pap smear:

Stitch: “What is the most unprofessional thing a doctor has ever said [to you]?”  
 “I’ve been waiting for this one. My last Pap smear was sooo traumatizing, because of this doctor who I had picked out because she had a background in women’s health and reproductive studies and all this stuff, I thought it was gonna be great. She starts out by *staring* at me, ‘cause I was about 60 pounds heavier, um, and she goes, ‘Oh, we have to get you healthy so you can have bab[ies]’ . . . She makes *several* more comments about my weight. She’s like, ‘I don’t think you can run on those knees.’” (User 12, Video 13)

User 12 was getting a routine procedure done by her doctor, not an overall health evaluation. For

this reason, the doctor's repeated focus on User 12's weight was medically unnecessary and uncalled for. The doctor assumed that User 12 wanted children and could not "run on those knees" just because of her weight. These comments and staring at the patient were forms of fatshaming, as they suggested that being heavy was something to scorn because it may or may not prevent her from being able to have children or to run. These were assumptions that were not only medically unfounded because they were untested, but also had nothing to do with the purpose of the visit.

Some users were "slutshamed" — that is, the HCP said or insinuated that they were promiscuous. User 46 (Video 62) was tested for STDs by two different gynecologists when she complained of low back pain and "some other symptoms that made me think it was maybe a 'female' problem." The second doctor asked how many partners she had, and when she responded that it was just one for the past five years, her doctor replied that her boyfriend might be cheating on her. Another user shared her experiences with multiple types of birth control and going to the doctor for birth control-caused bacterial vaginosis and a chronic yeast infection:

"Kept going to the doctor, the doctor basically called me a fucking whore every time, he kept making me get STD tests, even when I wasn't even fucking anybody." (User 9, Video 10)

User 9 said her doctor "basically" called her a "whore," meaning that he did not use that exact word, but insinuated it through his actions. This is evident by the fact that he had her get STD tests even when she told him that she was not sexually active.

Other HCPs were not so subtle. Users shared that their HCPs said things to them that were inappropriate, improper, or indecent. User 10 (Video 11) posted a video captioned "still shook to this day #outtاپocket" that read on the screen: "to my first gyn0 who prepped me for the speculum insertion by saying 'now this isn't going to feel nice and warm like your boyfriend.'" User 12 (Video 13), the user who was stared at for being "60 pounds heavier" and

told that she needs to help her become ““healthy so you can have bab[ies],”” also told her doctor that she was not planning on having children, to which the doctor asked if her husband knew that. Asking about a patient’s husband in this context is not only medically unnecessary, but an invasion of privacy. In the same video, User 12 shared what happened when the doctor had to give her a Pap smear:

“I’m already stressed, I’m tense, I don’t like doctors, so I was crying ‘cause I was trying to like, just [user blows out air], you know, breathe. Because I’m tense, the fucking thing isn’t going in, right? So she gets the- the *larger* size, and then when that hurts, and isn’t going in, she LAUGHS and makes a joke while I’m crying on the table about how she feels like she’s raping me.” (User 12, Video 13)

User 12 was already uncomfortable from the previous comments about her weight and the invasion of her privacy. While the doctor may not have picked up on her discomfort then, User 12 was evidently uncomfortable during the Pap smear due to her heavy breathing, crying, and pelvic floor tension preventing the speculum from entering her body. Despite these obvious signs of discomfort, the doctor did not take actions to alleviate User 12’s discomfort. She made User 12 more physically uncomfortable by getting a larger-sized speculum even though this was unnecessary given that the smaller size did not fit and caused User 12 pain. She also made User 12 more emotionally uncomfortable by “joking” that performing the Pap smear made the HCP feel like she was raping her patient. Given the power dynamic between a doctor and a patient, these actions indicate unprofessionalism. User 12 was left feeling violated physically and emotionally.

The insensitivity of HCPs clearly made a lasting impression on users, so much so that they decided to make TikToks about their negative experiences.

*Non-adherence to standards of care.* Some users experienced treatment from HCPs that could be perceived as medical malpractice. Several users shared experiences in which their HCPs did things that were nonconsensual (i.e., done without their permission) as well as medically

unnecessary. User 14 shared her story of having a procedure done without her knowledge or permission during an unrelated procedure:

Comment: Never forget everything in *The Handmaid's Tale* happens to real women in real life “This is exactly how I felt when I saw the scene where Ofglen has her clitoris removed. Um...what happened to me is functionally equivalent to that because the dorsal nerves of my clitoris were cut. They were cut in a clitoral hood reduction done without my consent during a labiaplasty when I was barely 18.” (User 14, Video 15)

User 14 replied to a comment referencing *The Handmaid's Tale*, a dystopian TV show based on a novel by Margaret Atwood, which features gender-based abuse such as forced surrogacy and bodily mutilation. One of the characters, Ofglen, had a clitorectomy performed on her against her will. User 14 supposedly consented to a labiaplasty, but not to a clitoral hood reduction, which resulted in having her nerves cut and likely rendered them nonfunctional. The fact that the OBGYN was working near User 14's clitoris when the requested procedure was supposed to be on her labia suggests that this mutilation was not an accident. User 14 went on to say that her OBGYN was celebrated for being a great doctor and was never held accountable for this action.

User 13 (Video 14) shared that her doctor gave her “18 or 19 stitches in my hoohah” when giving birth to her child resulted in a “grade 2 tear”:

“So for anyone who isn't aware, the ‘husband stitch’ is an extra stitch, or nine, that you can put in a woman after she has a baby, so everything down there is [clicking with tongue] you know, put togetha’. This is a real practice that people have actually done because you know, we love permanently altering women's bodies for men's pleasure. It has been widely criticized by gynecologists and OBs, the world around . . . The doctor who did all of my stitching got really fucking excited to have needle and thread in his hand apparently, and just went buck wild doing them.”

User 14 then described the resulting pain and her thoughts on the procedure:

“And um, needless to say, it felt like someone shoved a red hot fucking poker iron up my shit. So, doing that intentionally to a woman in a ‘husband stitch’ has gotta be the most disgusting, psychotic, repulsive fucking thing I have ever heard in my life because all bullshit aside, my kitty is fine and my daughter is beautiful, but that shit was the most painful thing I have ever experienced.” (User 13, Video 14)

“Husband stitches” are extra stitches to make the vagina tighter, supposedly for a man's pleasure

according to User 13, but at the expense of the patient's comfort. Although User 13 needed stitches for her grade 2 tear, she suggested that her doctor had given her more stitches than necessary. User 13's commentary on the nature of this intentional and nonconsensual action suggests that she perceived this to be malpractice because it was of no medical or personal benefit to her and only caused her pain.

Some HCPs performed procedures incorrectly which resulted in hurting or harming the users. Some users had their IUDs put in incorrectly, resulting in pain. Other users had painful pap smear experiences which they interpreted to have been performed in a way that would intentionally cause pain. It cannot be proven that these users' HCPs intentionally meant to harm their patients, but the fact that the means of conducting their procedures *could* have been performed in a much less painful way suggests that at the very least, the HCPs were not concerned enough to find a different method that suited their patients better.

*Lack of provider knowledge.* HCPs are generally expected to be knowledgeable about medicine and the body, but many users' interactions with HCPs revealed that some HCPs were not knowledgeable in these areas. User 40 made two videos about how she had to "educate my general ob/gyn on pelvic anatomy" (Video 58) and "explain my endo treatment to my general ob/gyn" (Video 59). Her captions revealed that she was shocked that she was more knowledgeable about pelvic anatomy and treatment for endometriosis than an OBGYN who is supposed to be an expert on these subjects. User 40's caption in Video 58 read, "I can understand forgetting anatomy over time, but the anatomy of your specialty?"

User 11 shared her experience trying to get help with her IUD:

"So I called a bunch of urgent cares, and none of them are 'outfitted to take care of IUDs.' One receptionist actually even said to me, 'is that the thing that goes in your arm?' So here I am at the ER. It's been seven hours. I finally saw the physician's assistant who took a look and then says, 'You know, I'm not really sure what it's supposed to look like.'" (User 11, Video 12)

For the urgent care receptionist to not know the difference between an IUD, which goes in the uterus, and a contraceptive implant, which goes in the arm, and for the ER physician's assistant to not know what IUDs are "supposed to look like," is surprising given their occupations. HCPs not having knowledge about some of the most common forms of birth control, especially on information as simple as the location and appearance of them, can be detrimental to patients seeking answers or help with their birth control.

It should also be expected that HCPs know or at least obtain essential information such as patients' medical information or history. Several users shared that their HCPs ignored or did not take into account their medical history despite having that information available, resulting in things like unnecessary testing or procedures and prescriptions. User 47 found her doctor's suggestion to use birth control baffling considering her medical history:

"[The doctor] was predictably unhelpful. Like most doctors, she tried to put me on birth control. I've explained in a previous video why I can't do that. And then she said, 'Well why not try the copper IUD for your menstrual cramps?' Do you guys know what the main side effect of the copper IUD is? [unintelligible mumbling] Cramps and severe menstrual pain! And then I'm more likely to violently yeet it out of my body, HA! Not all doctors are A students! Hmhm!" (User 47, Video 63)

The context suggests that User 47 had a history with birth control that rendered taking birth control medically unwise for her ("I've explained in a previous video why *I can't* do that" (emphasis added)). When the doctor suggested the copper IUD for menstrual cramps, User 47 smiled sarcastically while exclaiming that menstrual cramps and pain are the main side effects of using the copper IUD, in disbelief that the doctor would suggest it when she should know that it causes the very symptoms that User 47 wished to avoid. For User 47, ignorance resulted in being offered a copper IUD to ameliorate menstrual cramps while it is known to cause that symptom. User 47 implied that she found the doctor to be ignorant, or perhaps not that smart, by saying that "not all doctors are A students!"



This lack of knowledge often resulted in providing misinformation: User 20 (Video 21) was told that weight gain causes PCOS, User 28 (Video 48) was told that “endo” is caused by being overweight, and User 21 (Video 23) was told that PCOS was the cause of her experience of bleeding for over 800 days straight. She claimed: “yes PCOS can cause abnormal menstruation, but, it’s typically lack of.” User 20 (Video 21) was told that weight gain causes PCOS, and User 50 (Video 67) was told that birth control does *not* cause weight gain, so one of these women received misinformation. User 47’s (Video 63) doctor told her that inguinal hernias were “impossible to happen in women,” yet she did indeed have one. User 57 shared her experience of visiting the doctor for an annual check-up. Acting out the interaction, she shows that her doctor prescribed her birth control a year prior, but never gave the pharmacy her insurance information and did not call User 57 after months' worth of attempts to contact her. Thus, User 57 was not on birth control, and her doctor questioned “how you’re not pregnant right now”:

P: “Didn’t you tell me when I was 15 that I would never have a successful pregnancy because of the ovarian cysts that are in my uterus, on my fallopian tubes, etcetera? Did, isn’t, isn’t that the whole reason that you put me on birth control?”

HCP: “I *might* have said that but I didn’t make note of it in your file, so I really don’t know. I might’ve actually said that on *accident*.”

P: “You made me believe I was never gonna have a baby for my entire life...on *accident*?” (User 57, Video 76)

User 57, like many users, was misinformed by her HCP. To be told one piece of information and to experience something contrary to that information must have caused these users to feel negative emotions. Patients seek out HCPs to be informed about the causes of, symptoms of, and solutions to their health problems. One would expect that HCPs would provide accurate information given that they are supposed to be experts in medicine. When the people that patients trust give them false information, it may not only encourage distrust of HCPs but also confusion, ambivalence, or discomfort. In User 57’s case, it was disbelief and sadness. A woman

in her twenties had believed for several years that she would not be able to conceive a child because of the information that her doctor gave her. She expressed shock that her doctor admitted that this statement may have been “accidental,” suggesting that she expected her doctor, a medical professional, to be more careful about providing such life-changing information.

Many users expressed anger due to these blunders, while others dealt with it with humor. For example, User 52 (Video 70) shared that her male doctor asked her, “did you know you don’t have a uterus?!” The background audio that User 52 used features a recording of Donald Trump saying, “Wow, I didn’t know that, I just, uh, you’re telling me now for the first time.” User 52 mouthed along to this audio clip as it played, smiling and giving off the impression that she interpreted that sentence as sarcastic. She captioned the video, “no sh\*t sherlock I know I don’t have a uterus lmfao I was there for that surgery 😏👩.” The fact that the doctor asked urgently or in a surprised manner — as implied by the question mark followed by the exclamation point that User 52 put on the screen text — whether she was aware that she did not have a uterus, implies that he may not have looked at her medical history, which likely showed when a procedure to remove her uterus was done.

*Disinterest.* Some users felt that their HCPs exhibited apathy, not taking the time to figure out users’ health problems or making them feel cared for. Users expressed this by quoting, sometimes exaggeratedly, their HCPs delivering bad news in a nonchalant way, lacking empathy about their discomfort, sounding annoyed or bored, or otherwise seeming unengaged in the present interaction. User 50’s gynecologist sighed and scoffed during her visit (Video 67). User 59’s video (78) demonstrated how OBGYNs signal disinterest or a lack of care:

Screen text: Every OBGYN appointment when you're pregnant

HCP: [speaking quickly] “Hi, how are you doing? Have any questions? No? ‘kay good. Okay, lay back, let’s measure your belly, oh perfect, measure- measuring just on time. Let’s get that heartbeat. Beebeeb beep. Okay, good, she’s perfect. Alright, have any questions again? No? Okay, yeah. So, we’ll see you at your next appointment. Bye!”

Screen text: Me still laying wiping the gel off my belly (User 59, Video 78)

User 59 captioned her video, “You wait longer in the waiting room.” Her enactment of how OBGYN appointments play out for pregnant women ends with showing that the OBGYN said goodbye to her before she even wiped the ultrasound gel off of her abdomen. This video demonstrated her perception that OBGYNs must be disinterested when they rush their pregnant patients in this way.

User 50 (Video 67), who reenacts her consultation with her gynecologist (specified as male) in which she shares that she “did not like how I felt on that birth control” and requested to be informed about other options. Playing the role of her gynecologist, she asked with an incredulous, annoyed, and disinterested tone while rolling her eyes, sighing, and shaking her head, “What do you mean? You didn’t like it. What, [sighing], what’s wrong with the birth control?” The tone with which these questions were spoken suggests that the gynecologist was annoyed that the birth control was not satisfactory to his patient and now has to find out why.

*Dereliction.* Another form of unprofessionalism was symbolized through dereliction, or when HCPs did not fulfill the technical responsibilities of their job during consultations. User 2 (Video 3) created a comedic skit to show how gynecologists act during consultations, featuring her acting as an HCP who is distracted, doing a non-work-related thing during a visitation. In one part, User 2 said, “oh, hold on, my daughter’s Facetiming me. Call you back, okay? I’ve got a wide-open birth canal right in front of me, I can’t talk.” Although this video is likely satire, considering it’s recording in the form of a “point of view,” perhaps User 2 has experienced or knows others who have experienced a gynecologist answering their phone during a check-up and discussing the patient’s private information in a crude way.

Another failure to fulfill the technical responsibilities of a job was found in videos in which HCPs did not inquire about essential patient information or needs, such as symptoms,

sexual activity, and menstrual cycle questions (User 39, Video 51). User 57 was prescribed birth control but her doctor failed to follow up:

P: “. . . actually a year ago, uh, you, you put in a prescription for the pharmacy and they called you to confirm it and to get some insurance information from you and um, you never called them back so, they canceled the prescription.”

HCP: “Well why didn’t *you* call me? I would’ve filled it right away if you called me.”

P: “I did call you...For several weeks...For several *months*. You never called me back.” (User 57, Video 76)

This lack of inquiry and communication resulted in User 57 not getting her prescription. Other patients whose HCPs breached their duties also may have missed out on care that would have helped them.

*Key points.* Users’ dissatisfactory reproductive health care experiences were largely due to HCPs’ unprofessional behavior. HCPs’ tone of voice and comments came off as insulting, signaled a lack of empathy, and made the overall visit unpleasant for users. HCPs exhibited disrespect when they spoke down at users or blamed users for supposedly engaging in behavior like physical inactivity or promiscuity that may have caused the health problems they complained about. HCPs crossed professional boundaries when they made insensitive or inappropriate jokes during invasive physical examinations. HCPs seemed to not take their patients or their responsibility to uphold ethical standards seriously when they made jokes, acted disinterested or unengaged, were unprepared by not having the proper medical information and then providing their patients with misinformation, hurt their patients, and especially when they performed nonconsensual or medically unnecessary procedures. The trust that patients must put into their HCPs during medical consultations is violated when HCPs fail to act professionally. When patients are physically vulnerable and subjected to HCPs’ unprofessional behavior, their

health and safety are put at stake.

### *Diagnostic Delay*

The themes that I have raised thus far — dismissal, withholding help, normalization, unprofessionalism, and unhelpful solutions — were the culprits of users' experiences of diagnostic delay. Many user narratives indicated that it took a considerable amount of time to receive a diagnosis or a factual explanation for their medical issue. Users did not always state that they had experienced diagnostic delay, but they often insinuated it. Several users used the word “finally” followed by an explanation of what their diagnosis was, or that they had “finally” found an HCP that was willing to find out the correct diagnosis. Others ended their narratives with, “it was [diagnosis].”

For example, User 22 (Video 24) explained that she was diagnosed with PCOS and endometriosis when she was fourteen, but she continued to have problems throughout her twenties. At the end of the video, she claimed: “It was Hashimoto’s and hypothyroidism” while she had been told to take aspirin and stop eating carbohydrates the whole time. User 22’s HCPs had downplayed her symptoms and offered her unhelpful solutions for over a decade, leading to a significant delay in her diagnoses. User 37 (Video 47) also faced diagnostic delay as a result of dismissal. She explained her repeated issues of having her menstrual pain dismissed by her mother and doctors, who told her that nothing was wrong. In the caption, she wrote, “it was endometriosis that caused the pain.”

User 46 (Video 62) discussed how multiple gynecologists kept testing her for STDs when she came to them for lower back pain and other gynecologic problem symptoms. At the end of the video, she said: “Four years later, I find out I have endometriosis!” The misattribution of her reproductive health issues to STDs led to a diagnostic delay of four years. While User 46 was able to obtain a diagnosis eventually, had her gynecologists not insisted that she get STD tests,

and taken the negative results to mean that something else was wrong, she may have received a correct diagnosis and therefore treatment much sooner.

User 21 (Video 23) had a significant diagnostic delay with a dangerous consequence. She told her audience that she had polyps removed in 2017. In 2019, she told her doctors to look for polyps, but they did not. At the time of the video, User 21 had been consistently bleeding from her uterus for 829 days. When she went to the doctor for a hysteroscopy:

“ . . . they found exactly what I knew they would find. Exactly what I told doctors to look for back in 2019 . . . And just as I thought, just as I suspected, and just as I presented to my doctors in the past, my polyps that I, I had polyps removed in 2017, um, they’re back, and there’s more. There’s *so* much more.” (User 21, Video 23)

Perhaps if the doctors had listened to her before and not withheld assistance, User 21 may have been able to prevent the return of her polyps. Many users waited even longer and mentioned the ages at which they saw their HCPs. User 55 (Video 74) said that she wanted to get tested for PCOS at the age of 15, but was not diagnosed until the age of 25.

*Key points.* Users sought help from HCPs because they trusted their medical knowledge, but heeding their advice often proved to be time-wasting. Having their experiences dismissed or normalized, being offered unhelpful solutions or none at all, or working with providers who lacked accurate knowledge or motivation to find answers or solutions all contributed to diagnostic delay. As is apparent from user narratives, diagnostic delay led to years of suffering and feeling that users had been deprived of help that they could have received earlier.

### *Positive Experiences*

Despite the many negative interactions that my sample had with HCPs, some had positive experiences. Positive experiences were defined as interactions with HCPs that the users expressed were pleasant or had positive outcomes. Users greatly appreciated it when HCPs were respectful of their identity, privacy, or safety. User 4 (Video 5) was pleasantly surprised that her

nurse at Planned Parenthood asked for her pronouns and if it was safe to announce the name of the clinic in case she would want to hide it from her family or others. User 43 (Video 56) was invited by her endometriosis specialist to share her story with MIT students. He emphasized that it was her choice and, acknowledging HIPAA privacy laws, that she had the right to stay anonymous. User 43 expressed joyfully that he was “so, so respectful.”

Some HCPs seemed to genuinely want patients to feel comfortable, which many users were “surprised” about given prior experiences. Users described how relieved they felt when they “finally” found HCPs that listened to, reassured, comforted, and encouraged them. These experiences were validating because they had never or seldom had positive experiences with HCPs for their reproductive health problems, but now they found someone who cared. User 31 (Video 44) had previously had a bad experience with a doctor “who made me feel so hopeless and angry.” She was nervous to see a new doctor about a plan for her endometriosis but was pleased with how considerate she was: “My new doctor ended up being an actual angel. I literally teared up in the room. She actually made me believe my quality of life could improve one day.” User 43 also raved about her “amazing visit” with her specialist:

“Oh my gosh. Oh my gosh, I literally started crying in the room because like I’d never been so heard, so, like, *understood*. Understood what I was going through. And then after my appointment he was like, ‘You are literally textbook, like, endo warrior.’” (User 43, Video 56)

The utter joy that users expressed simply after positive social interactions and not even treatment shows that quality of health care matters and includes HCP attitude. Besides positive social interactions, users also appreciated HCPs who provided solutions or information that were effective or helpful. Users were just happy to get information, but to have tests and procedures scheduled and performed after not having had any effective treatment before was a major factor in users characterizing their experiences as positive.

User 18 (Video 19) explained to her OBGYN the difficulty she had getting pregnant

since coming off her birth control. Her doctor immediately began to look into the situation and conduct tests. After seeing her primary doctor who told her nothing was wrong despite her symptoms, User 18 went back to the OBGYN, who again immediately started looking into it.

The OBGYN reassured her that she would help User 18 get diagnosed and treated:

“Okay, well let’s go ahead with the internal ultrasound, let’s check you out. It also sounds like you’re making too much prolactin, so we’re gonna look into that too. That’s typically not a symptom of PCOS, but, I still want to look into everything, You could have multiple issues. But at the *bare* minimum, let’s rule it out. But *don’t* worry, no matter what’s going on, we’re gonna figure it out and we’re gonna find a way to get you pregnant.” (User 18, Video 19)

User 18 was eventually diagnosed with PCOS. By roleplaying, she illustrated how her OBGYN thoroughly and simply explained her diagnosis and why it was causing her to experience her symptoms. The OBGYN also assured User 18 that she would give her effective treatment. On the screen, User 18 wrote that she was able to overcome her symptoms and get pregnant after her OBGYN prescribed her medication, and claimed, “It is SO important to have a doctor that listens to you!” Listening was only the first step in the path to effective treatment.

*Key points.* Not all users had negative experiences in seeking reproductive health care, but positive experiences were few and far in between. Users who shared their positive reproductive health care experiences seemed extremely grateful and relieved, suggesting that their expectations had been exceeded. They framed their narratives as surprising situations, suggesting that they were rare. Videos that depicted positive experiences revealed the importance of kind treatment in addition to medical treatment. Listening to the user seemed to be a catalyst for actually finding out the problem. Showing empathy, encouraging users, and setting plans to find a diagnosis and the most effective treatment led users to find their experiences pleasant and helpful.



## DISCUSSION

### *Negative Experience Bias*

The experiences and health needs of AFAB people have been on the periphery of healthcare throughout the history of biomedicine. Their exclusion from clinical research studies, discussions on their health and health care, as well as the differential medical treatment of their pain are objective indicators of this. The neglect of AFAB people in healthcare has resulted in significant negative reproductive health care experiences and health outcomes, as demonstrated by the TikTok narratives I have presented.

It is important to acknowledge that although my sample consists of predominantly negative experiences, there were opportunities for sample bias that may have contributed to this. Videos that appeared in my hashtag search were based on TikTok's algorithm, which is influenced by video popularity (Serrano et al. 2020). Controversial content elicits strong emotions, which may not only make videos about negative experiences more likely to grab people's attention, but also motivate users to post this kind of content rather than positive, unproblematic experiences. The hashtags that I selected may also skew toward certain types of videos. People using hashtags like #PCOS or #endometriosis aim to contribute to a conversation on the topic or to seek solidarity with others who share similar experiences, but the nature of these disorders is inherently negative, so it is more likely that discussions about them will be similarly valenced. It is therefore unlikely that my findings are generalizable, but generalizability was not the goal of this study.

### *Traditional Versus Non-Traditional Methods*

Prior studies have utilized more traditional data collection methods such as surveys and interviews. The benefit of using these standardized research methods is that it allows researchers to elicit the exact kind of information that they are interested in analyzing. The drawback,

however, is that data are limited by the questions that researchers ask and the responses that participants are required to or think they should provide. Gathering data from people's personal social media content allows for more variability. TikTok users' ability to express themselves freely, creatively, and tell their stories on their own terms provides a richer look into how people frame their own experiences. Plenty of studies provide evidence of gender disparities in health and health care—these findings do not need further corroboration. What needs to be brought to light are AFAB people's self-made collective and subjective experiences in receiving reproductive healthcare, which is what I aimed to do by analyzing TikTok narratives.

### *Theoretical Lenses*

The theoretical lenses of intersectionality and power help us understand why the relationship between patients and HCPs matters. Social norms and values are constructed by society. Institutions reflect, propagate, and legitimize these ideas, concretizing hierarchies of social status and power. Intersectionality describes how one's social identities like race, class, gender, or sexual orientation intersect and overlap to create privileges for some groups and disadvantages for others—namely people of color, women, LGBTQ individuals, and people with lower socioeconomic status. Additionally, those who control material resources and information, such as HCPs with medical knowledge and access to treatments, have more power than those who depend on them, such as patients, especially those who have disadvantaged social identities. These theoretical lenses shed light on how the institution of medicine gives doctors power over patients, and society's privileging of particular identities puts AFAB individuals seeking health care at a disadvantage.

*Intersectionality.* Since the majority of my sample consisted of young, white, cisgender women, it was not possible to analyze the differences between experiences of AFAB individuals

with intersecting identities. While the narratives did not provide substantive evidence for the particular disadvantages faced by those with intersecting identities, the forces that contribute to disadvantages are clear when considering the results in context of the bigger picture. Research consistently demonstrates that medicine is centered around the health and experiences of white cisgender men. When white cisgender men are not present, white cisgender women receive second priority. Besides #womenshealth, the hashtags that I used to search for videos are facially identity-neutral (#reproductivehealthcare, #pelvicpain, #periodpain, #obgyn, #pcos, #polycysticovarysyndrome, #endometriosis), and yet the social hierarchy is ingrained in these terms and, by extension, the results that come up when searching with them.

For instance, when users discussed their observations about AFAB reproductive health care, most of them described “women’s” experiences, and only a couple used inclusive language like “people born with a uterus.” This is unsurprising given that the majority of people who are born with uteruses are cisgender women, but it leads to the question of why cisgender women dominate discussions about AFAB reproductive health care even though people with other gender identities share the same experiences. In the United States, drug companies must provide a comprehensive list of all possible side effects. If a medication has even a miniscule risk of death, this information cannot be left out. Why, then, is reproductive health care not all inclusive? Why do the experiences of the majority negate those of the minority?

Most videos that came up when doing my hashtag search were of white cisgender women. While differential healthcare access may partially contribute to this, it cannot reasonably be assumed that people of color and transgender or nonbinary people have so much less to contribute to conversations about AFAB reproductive health care. My sample mostly reflects the white, cisgender female, heterosexual experience. In order to find narratives that are not about

this demographic, I would have had to add modifiers to my search terms such as #blackwomenshealth or #lgbtqhealthcare. I did not need modifiers to find white cisgender women's experiences because they represent the norm from which others must depart. Nor did I need to create comparison groups or search for data with very specific hashtags to demonstrate how AFAB intersectionality plays into reproductive health care. The fact that white womanhood is the default speaks for itself.

*Power.* The analysis of my results mainly focuses on the overarching themes of the reproductive health care experiences of patients through the actions of health care providers. What should also be analyzed and discussed is the behavior of HCPs given the role they play in light of power dynamics.

As the knowledge holders and service providers of the relationship, HCPs have the power to decide how to evaluate and treat patients. This is not to say that HCPs choose to perceive users in particular ways, but that their personal perception of patients is the ultimate determinant, and only by being a trusting individual or by engaging with an especially persuasive patient will their perception change. This is especially problematic because of how deeply embedded stereotypes are in our society, especially in medicine. As discussed in the literature review, stereotypes are learned, internalized, and reproduced by being embedded in institutions. HCPs are not immune to this socialization and can unconsciously carry stereotypical beliefs into their clinical practice, affecting how they perceive and treat AFAB patients. Because of the unequal power dynamic between HCPs and patients, the fate of patients is ultimately in the hands of HCPs because they are the ones who can provide the services that patients need.

The consequences of this unequal power dynamic were evident in dozens of videos in my sample. The more severe users' symptoms were, the more unsettling it was that their HCPs

dismissed them. When users perceived their symptoms to require medical intervention and HCPs claimed that they were not “that severe” or were just “normal” symptoms of, for example, PCOS, users were essentially branded with attributes like weakness and being a complainer. Dismissal — specifically downplaying, denial, and disbelief — not only made users question their own character and perceptive capabilities, but functioned to silence users, especially when HCPs attributed users’ experiences to their psychological state. The strong association between AFAB people’s bodies and their psychology put their credibility at stake. This kind of treatment reflects the historical treatment of women in healthcare, when HCPs’ bias and use of stereotypes were much more blatant and explicit. Now they are more subtle, but we see the same stereotypes about women as emotional, irrational, exaggerators, and liars being employed by HCPs and affecting their access to quality health care. While instances of not being listened to, believed, or taken seriously could be attributed to the character of individual users, the fact that these experiences were shared by many and aligned with some of the most prevalent stereotypes about AFAB people is certainly suspect. Although users’ experiences are not shared by everyone who seeks reproductive healthcare, the patterns that arose suggest that there is a systemic issue present and support my hypothesis that gender discrimination is at play. While the intentions of these users’ HCPs were not necessarily sinister, the ultimate outcome was that they did not see eye-to-eye with their patients, and thus would not provide users the medical help that they needed. HCPs’ perceptions overruled users’ claims.

HCPs’ general attitudes toward medical problems also influenced their treatment of users. The normalization of symptoms and side effects signaled a defeatist, pessimistic attitude by HCPs. Although the conflation of commonality with normalcy may have influenced their judgment, HCPs may also have felt that the issues that users complained about were inevitable,

“just the way it is,” and therefore immutable. They might believe that if menstrual cramps are experienced by nearly everyone who menstruates, then no additional or special treatment is necessary. But one could argue the same about other common health problems that are gender-neutral such as heartburn or arthritis. Is the response to the many people who develop these health issues also to “just deal with it”? The mindset that normality justifies a health problem’s symptoms may contribute to my findings that many HCPs refused to do further testing, gave up on continuing to look for new solutions, dismissed users, or offered them unhelpful solutions. Normality or commonality should not signal to HCPs that patients must deal with their problems because they are inevitable, but that there is a very common problem that is unsolved and needs innovative thinkers to find solutions. As shown in videos coded as Positive Experiences, many patients’ reproductive health problems can be dealt with by being proactive, not by accepting unsuccessful outcomes.

Suffering conceived as something to be avoided and quickly relieved is not only a universal sentiment, but a goal specific to the field of healthcare. Yet some users’ HCPs were not fervently working toward this goal. Grundström et al. (2018) and Pettersson and Berterö (2020) found that HCPs resorted to finding “easy explanations” or “simple causes” if nothing else seemed to help the patient. Munch (2004) argues that HCPs’ tendency to misattribute women’s pain to other issues, namely psychological ones, can be a result of not having an alternative explanation for their patients’ conditions.

In my study, users’ expressed desires to explore other options were frequently disregarded by HCPs. HCPs seemed to be unmotivated or reluctant to do further investigation once their initial ideas proved ineffective. It was almost as if they were discouraged by users’ rejections of their suggestions or doubts about their expertise. Suggesting arbitrary treatments

like “relaxing” or exercising and prescribing medications like birth control to mask and suppress symptoms communicated that HCPs did not have a medical plan of action. When User 6 (Video 7) told her doctor that she experienced pain while having sex, she was told to try drinking alcohol and smoking marijuana. The doctor’s solution can be assumed to stem from the belief that mindstate-altering substances would fix User 6’s problem, suggesting that they thought the pain was psychological. This echoes the mind-body connection that heavily influenced medicine throughout history — the idea that reproductive health issues were psychologically caused and will go away by “fixing” the mind, suggesting the inherent problematicity of AFAB people’s psychology and the necessity of adhering to standards of medical normality, which are defined by the male mind: non-emotional. HCPs’ default to supposed cure-alls like birth control instead of searching for underlying causes and alternative treatments indicates a focus on short-term relief rather than long-term solutions. HCPs’ side of the story would have to be obtained to find out what influences their choices for treatment options. Perhaps they truly believe that their suggestions are effective, or there are norms and expectations at their medical practice to which they feel obligated to adhere. Although medical care is a service, many users did not receive the services they requested because of HCPs’ perceptions of what constitutes a problem worth solving. To reiterate, HCPs have the power to judge and to treat, so not listening rendered users’ requests fruitless.

HCPs’ perceptions of particular patients in addition to their personal worldviews affect the decisions that they make. Goodyear-Smith and Buetow’s (2001) idea of “mind power” and “social power” show how doctors have access to and possession of knowledge and resources that patients need, and the ability to decide whether or not to share with their patients. The authors also note that this power can be misused and give doctors the chance to “play God” by being one

of the sole decision-makers about the future of their patients through their own decisions, which can often be based on their personal moral beliefs, leaving room for prejudice, bias, and discriminatory treatment. Videos coded as Withholding Help revealed that such extra-medical factors influenced HCPs' perception and treatment of their patients. Many users' HCPs had the knowledge and resources that users sought but chose not to provide them. Other users' HCPs refused to conduct tests or procedures requested by their patients. While HCPs have the right to deny services to patients on moral or religious grounds due to medical conscience laws (Prairie, Wrye, and Murfree 2017), users' narratives revealed that their HCPs' reasonings for refusing services were not a matter of religion or strongly held personal beliefs, but of social and cultural norms, beliefs, assumptions, and expectations.

HCPs were very controlling of their AFAB patients' fertility. Most users in my sample expressed that they were not interested in or concerned with fertility and future children and simply wanted to end their suffering by getting sterilization procedures. This ideology baffled HCPs, who seemed to operate under a very traditional, cisheteronormative, patriarchal ideology when it came to fertility-related decisions. When users told their HCPs that they wanted, for example, a hysterectomy, their HCPs' immediate replies concerned potential or future husbands' opinions about it rather than patients' needs. There was also evidence of cultural norms about womanhood and parenthood, assuming that "every woman wants" to be a mother, and that those who get sterilized will inevitably regret it. This was especially true in regard to age, as HCPs made assumptions that there were ages that were "too young" to decide to become sterile, as youth is associated with immaturity. Historically, women have been regarded as less intellectually sharp than men, motivated by feelings rather than critical thought (Hoffmann and



Tarzian 2003), so one may wonder whether the same assumptions about maturity would be made about young men.

There certainly are justifiable reasons for refusing to perform sterilization procedures on religious, moral, or medical grounds. Sterilization is invasive and permanent. It may weigh on HCPs' consequences to be responsible for something that their patient could potentially regret. But is it an HCPs' job to decide on behalf of patients what is "best" for them regarding non-medical topics? Users in my sample who sought sterilization had been suffering for a long time and failing to find effective treatments. Their quality of life was reduced significantly because of their reproductive health issues. As consenting adults, they should be allowed to make decisions about their own bodies and hold themselves responsible if they regret their decisions. Several users expressed that they were upset that their bodily autonomy was being withheld from them, and that they did not have the option to "opt out" of childbearing. The treatment of people with uteruses as vessels for children is dehumanizing, and the idea that it is their responsibility to procreate is outdated and unnecessary. Allowing HCPs to decide what justifies sterilization and what reasons are valid and invalid based on culturally developed reasons is not only a violation of people's freedom but a violation of the responsibilities of an HCP, which is to prioritize care, symptom relief, and patients' expressed needs.

The most disturbing examples of unequal power dynamics were those coded as Unprofessionalism. "Unprofessionalism" is somewhat subjective but also informed by official norms and rules. HCPs must take a Hippocratic Oath to "do no harm" and uphold ethical standards. Like all professional work environments, certain behaviors are expected and other behaviors are prohibited. Furthermore, cultural norms inform appropriate behavior, including respecting people's boundaries. Many users in my sample had interactions with HCPs that

evidenced a lack of professionalism as just defined. Many HCPs seemed to be either unaware or uncaring of their excessive use of their power as they were unapologetically mean to their patients. Even if HCPs are stressed or have personal life issues, or if they have become numb to suffering and see patients as complaining and bothersome, their job entails a level of professionalism that is not a suggestion but a requirement. HCPs often blamed users for things that they could not necessarily control. Not all patients are educated on health facts that may be obvious to doctors, nor do all patients have the resources needed to become healthier like exercise, healthy food, or vitamin supplements. While HCPs have an ethical duty of care, their patients should be able to self-determine the life that they want to pursue and the level of pain that they can accept as part of that life.

The inappropriate comments made by some HCPs demonstrate some of the most shocking misuses of power. User 12 (Video 13) was angry that her HCP made a “joke” likening trying to insert a speculum inside her for a Pap smear to raping her and laughing as User 12 cried on the table. Strict professional and personal boundaries were crossed during this encounter. Although making jokes during uncomfortable physical exams may sometimes be acceptable to keep a patient calm, the content of this HCP’s joke was problematic. First, rape is a violent and violative act. If patients have trauma related to sexual assault or rape, this “joke” can be extremely detrimental to their mental health. Second, this joke was made during a procedure in which the HCP was required to insert an object inside the patient’s body, akin to the act about which the HCP was making a joke. User 12 told her audience that the speculum would not fit and the HCP replaced it with a larger-sized speculum, which does not make sense considering she expressed that she was in considerable pain. Third, the HCP misused her power during this physical exam. The patient-doctor relationship requires a great deal of trust, especially on the

part of the patient who must entrust their body and wellbeing to a virtual stranger. This means that the HCP must take on a responsibility to treat the patient's body kindly and respectfully, just as one would do with their own body. A Pap smear is a routine exam that people with cervixes must undergo several times throughout their life to ensure that they do not develop cancer or other reproductive health problems. For the HCP to violate this trust and traumatize User 12 so that every time she has to do a Pap smear she will be reminded of this event is objectively unacceptable.

Trust was also violated in the case of users who underwent nonconsensual and/or medically unnecessary procedures. User 14 (Video 15) trusted her OBGYN to give her a labiaplasty — the only procedure she consented to — and he took the liberty of cutting the dorsal nerves of her clitoris during a clitoral hood reduction — an irreversible procedure — without consulting User 14 and with no medical justification. How could the OBGYN have justified this extra procedure? He could not have possibly done so under the pretense of doing his job, considering that a labiaplasty and a clitoral hood reduction are performed on different parts of the vulva. User 14 also mentioned that he was a highly respected and successful OBGYN, so it is very unlikely that he made a foolish mistake. The only plausible explanation is that he did it intentionally, perhaps hoping that his patient would be too afraid to come forward given his reputation. Indeed, the most devastating part of User 14's narrative was that she never received justice, nor could she. The fact that her OBGYN had a great reputation in the medical community rendered her powerless. User 14 was only 18 years old when this event occurred, which would make her word even less credible. While many users were silenced because of HCPs' power to perceive, users like User 14 were silenced because of HCPs' power to act.

As I discussed in my literature review, AFAB patients anticipate HCPs' stereotype-based biases and prejudices, so they work to convince their HCPs of the genuineness and severity of their health problems. This may result in a feedback loop in which patients actively try to come off as credible to offset potential bias but are not convincing enough and cause HCPs to perceive them as disingenuous. Regardless, the danger of not being taken seriously and worrying that one does not appear credible may make patients think that their problems are not important or severe enough to warrant seeking medical help and thus dissuade them from doing so. This is a danger that must be avoided at all costs, even if it means taking the time to evaluate patients who may or may not have a physiological problem. There is not enough awareness about the experiences of AFAB people in seeking reproductive health care as told from their perspectives, nor are there extensive explorations of the influences of HCPs' perceptions of these patients. As it stands, many AFAB people experience delays in diagnosis and treatment, and the fact that positive experiences were rare in my sample suggests that these issues will not be ameliorated without action being taken.

## CONCLUSION

While TikTok is widely known for being a medium for entertainment, it is also a medium for information-sharing and community-building. The public, creative, and interactive nature of this social media platform makes it a valuable source of data that can be analyzed sociologically to better understand the personal lives of the newest generations. In this study, the reproductive health care experiences of young people assigned female at birth, as told through their personal TikTok accounts, were analyzed for themes that can inform us of wider societal, cultural, or institutional problems.

Before beginning my research, I sought the answers to several questions: What are the experiences of AFAB people in receiving reproductive health care? How do AFAB people feel about the quality of reproductive health care that they receive? Furthermore, how do healthcare professionals treat AFAB people that seek their reproductive health care, and what might be influencing their perceptions of their patients and their subsequent decisions?

In my literature review, I demonstrated how gender stereotypes have contributed to the gender disparities that we have seen in healthcare for millennia. I showed that an association between a woman's mind and her body developed out of misconceptions about human biology, which led to assumptions about AFAB people's health and their expressions of suffering that were both produced and reinforced by sexist stereotypes. I argue that stereotypical assumptions about women and subsequently anyone with typical female reproductive anatomy or who is perceived as female arise in medicine and contribute to patients' negative experiences in reproductive health care.

My data reveals that, broadly conceived, people assigned female at birth experience various forms of dismissal, being offered unhelpful solutions, having medical help withheld from them, having their experiences normalized and thus deemed un concerning, unprofessional behavior by their HCPs, and diagnostic delay. Many of these types of experiences overlapped with one another. The few positive experiences that were shared were framed as unusual, surprising, and relieving, suggesting past negative experiences. The majority of users in my study expressed dissatisfaction with the quality of reproductive health care that they received and suggested that they felt unjustly treated. Many users were keenly aware of the forces that may have influenced their HCPs such as cisheteronormativity, patriarchy, and patient-provider power imbalances. My analysis suggests that many of the ways that HCPs treated users, delineated in

each theme, were likely influenced by gender stereotypes. Other treatments suggested a lack of care, motivation, and respect for users' wants and needs.

### *Limitations*

Despite the abundant evidence of wide health and reproductive health care disparities between genders, races/ethnicities, and classes, there is a lack of research on patients' personal experiences in seeking and receiving reproductive health care. This study was limited by my ability to collect more detailed and accurate demographic data, notably on race/ethnicity and sexual orientation. Because I extracted videos from TikTok and did not directly collect this information from users, race was determined by phenotype only and combined into one category, "racialized minority." There were not enough people of color in my sample to make a generalization about their experiences, nor did any of them discuss race-related issues. While some LGBTQ users mentioned how their HCPs' cisheteronormative expectations showed in their medical suggestions, there were not enough data to compare their quality of health care to that of cisgender and heterosexual individuals. Because of these limitations, I was unable to speak on the impact of intersectionality on the experiences of users in my sample.

My study was also limited by my inclusion criteria. I only included videos that were posted publicly, which means that users were comfortable sharing their experiences, so there are likely many narratives that remain unheard. I also only included videos in the U.S. because of the distinctness of its healthcare system, but my selection was often based on my best judgment of users' accents and profiles. I was thus unable to confirm whether the health care encounters shared took place in or outside the U.S.

### *Future Directions*

Social media narrative analysis is a relatively new method of social science research. Social media is a popular platform for people, especially younger generations, to share experiences that they may not be comfortable sharing with others in person. Researchers should look to social media apps such as TikTok in order to gain insight into the personal and recreational lives of young people.

The experiences of LGBTQ people, low-income individuals, and people of color need further investigation. Existing research suggests that these groups have unique barriers to health care that are understudied. Since I was unable to differentiate their experiences from non-minority groups' experiences in my study, future studies should utilize research methods that would allow for such data collection.

Ascertaining what influences HCPs can only be surmised by their patients and theorized by researchers. Researchers may consider conducting a survey or interview to find out from HCPs' perspectives how they perceive different demographics of patients. Responses should be qualitatively analyzed to identify any links to stereotypes. HCPs should also be asked about their personal worldviews and their thoughts on the place of personal worldviews in health care decision-making.

## APPENDICES

*Appendix 1. Hashtags Used by Users*

<b>Hashtag(s)</b>	<b>Frequency</b>
#endometriosis	32
#pcos	24
#womenshealth	18
#fyp	16
#chronicillness	11
#pcosawareness, #pelvicpain	9
#pcosproblems, #stitch	8
#chronicpain, #endo	7
#obygn, #periodpain, #reproductivehealth, #womensrights	6
#iud, #mentalhealth	5
#birthcontrol, #endometriosisawareness, #foryou, #foryoupage, #greenscreen, #hormones, #polycysticovarysyndrome, #reproductiverights, #vaginismus	4
#adenomyosis, #comedy, #doctors, #feminism, #hashimotos, #hypothyroidism, #lgbtq, #medicalgaslighting, #pcosweightloss, #prochoice, #storytime, #ttc	3
#birthcontrolproblems, #bodilyautonomy, #doctor, #eds, #fypツ, #healthcare, #iminpain, #infertility, #invisibleillness, #meanendoadvocate, #medicalbattle, #pain, #pcod, #pcosdiagnosis, #pcosfighter, #periods, #pms, #pregnancy, #uterus, #viral, #weneeduniversalhealthcare	2
#1in10, #1in8, #28XTREMES, #3, #4, #ableism, #abnormal, #adhd, #allithinkaboutisyoud, #americanhealthcare, #ASOSFashionweek, #autism, #autoimmune, #baddoctor, #baddoctorstories, #bigpharma, #birthcontrolsideeffects, #birthcontrolstory, #bleeding, #cleargenius, #ColorCustomizer, #contraceptions, #contraceptive, #copperiud, #cramps, #crazy, #dayinmylifevlogs, #dejavu, #destigmatizepelvicpain, #disabled, #disabledtiktok, #doctoc, #doctorsoffice, #doctorsoftiktok, #doctorswhocare, #doctortiktok, #dyspareunia, #ehlerdanlos,	1



<p>#emergencyroom, #enby, #endofighter, #endometriosischeck, #endometriosisdiagnosis, #endowarrior, #endowarriors, #endowarriorstrong, #fertility, #festivefashion, #fybromyalgia, #fypage, #fypforyoupage, #gaslighting, #gaybabys, #girlproblems, #gooddoctor, #gossipgirlhere, #gynecologist, #gynecology, #Handmaidstale, #health, #healthissues, #heartsurgery, #help, #helpmeimpoor, #holistichealth, #hormoneimbalance, #husbandstitch, #hyperthyroid, #iCarlyAffirmation, #illdoitmyself, #imgettingripped, #imgettingrippedddtonighttt, #infertilityawareness, #insurance, #iudreplacement, #justgirlythings, #Learnhow, #levitating, #lgbt, #losangeleslife, #makeitstop, #mcdonalds, #MCDonaldsCCSing, #medicaid, #medical, #medicaltiktok, #medicaltrauma, #medicine, #meds, #medtok, #mittelschmerz, #momlife, #momsoftiktok, #momtok, #newdoctor, #nonbinary, #nope, #nutrition, #nuvaring, #nuvaringfail, #oof, #osdd, #outtاپocket, #ovariancyst, #painfulperiods, #painsbad, #papsmear, #patriarchy, #pcoslife, #pcosupportgirl, #pelvicfloor, #pelvicfloordysfunction, #pelvicfloorthrapy, #periodcramps, #periodproblems, #pfd, #pharmacy, #phonebattle, #plannedparenthood, #pleasehold, #polycysticovarysyndrome, #polyps, #postbirthcontrolsyndrome, #postpartum, #pots, #pourtoi, #pov, #povs, #pregnancyhourney, #pregnant, #PrimeDayShowPJParty, #pronouns, #refundglowup, #relatable, #remix, #reproductive, #sayquaynotkway, #selfdiagnosed, #shouldhavestayedinthedrafts, #sterilization, #stitchthis, #surgery, #takeabite, #texttospeech, #thepill, #theprom, #thrifting, #tiktokmom, #trans, #transgender, #trend, #truestory, #TrulyGlowingSelfieLove, #tryingtoconceive, #ttcjourney, #vaginismustherapy, #vivacleanhacks, #vulvodynia, #wellnessclub, #womanhood, #womenhealth, #womenpower, #womensbodies, #womensmarch, #womensupportingwomen, #xyzbca, #yourpainsreal, #yourpainsinvalid</p>	
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*Appendix 2. Themes and Sub-Themes Present in TikTok Videos*

Theme and Sub-Theme	Percentage of All Videos ( <i>n</i> )
<i>Dismissal</i>	23.3% (56)

1. Downplaying	2.5% (6)
2. Ignoring	2.9% (7)
3. Denial and disbelief	8.8% (21)
4. Misattribution	7.9% (19)
5. Physical dismissal	0.4% (1)
6. Other	0.8% (2)
<b><i>Unhelpful Solutions</i></b>	<b>15.4% (37)</b>
1. Arbitrary treatments	5.8% (14)
2. Masking	6.3% (15)
3. Unwanted treatment offer	3.3% (8)
<b><i>Withholding Help</i></b>	<b>13.8% (33)</b>
1. Help refusal and undue focus on fertility	7.1% (17)
2. Not informing	1.3% (3)
3. Not offering	2.9% (7)
4. Assistance delay	2.5% (6)
<b><i>Normalization</i></b>	<b>5.9% (14)</b>
1. Normalizing symptoms and side effects	2.5% (6)
2. Normalizing female gynecological problems	1.3% (3)
3. Lack of concern	2.1% (5)
<b><i>Unprofessionalism</i></b>	<b>30.1% (72)</b>
1. Discourteousness	10.4% (25)
2. Non-adherence to standards of care	4.6% (11)
3. Ignorance	6.7% (16)
4. Disinterest	2.5% (6)
5. Dereliction	1.3% (3)
6. Other	4.6% (11)
<b><i>Diagnostic Delay</i></b>	<b>6.3% (15)</b>
<b><i>Positive Experiences</i></b>	<b>5.5% (13)</b>
<b>Total percent (n)</b>	<b>100.3% (240)</b>

*Appendix 3. Theme Definitions*

<b>Theme</b>	<b>Definition</b>
Dismissal	When the HCP physically, verbally, tacitly or in effect “dismissed” the user and their health concerns.
Unhelpful Solutions	When the HCP offers unhelpful solutions to the user’s health problems.
Withholding Help	When the HCP does not provide help to the user in the short term, long term, or ever.
Normalization	When the HCP refuses the patient’s problem to something of little or no concern because of its commonality.
Unprofessionalism	When the HCP does or says things during their consultations with users that do not meet the standard expectations of HCPs.
Diagnostic Delay	When the user narrative indicates that it took a considerable amount of time for the user to receive a diagnosis or a factual explanation for their medical problem.
Positive Experiences	When the experience of the user in seeking reproductive health care has a positive outcome in the user’s view.

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