Networks of Endometriosis

An Analysis of the Social Media Practices of People with Endometriosis

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Abstract

Networks of Endometriosis: An Analysis of the Social Media Practices of People with Endometriosis

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Endometriosis is a chronic inflammatory condition that has been historically underfunded and mistreated despite affecting approximately 200 million people worldwide. In the face of this lacking care, increasing numbers of people with endometriosis have turned to social media, particularly Facebook and Instagram, in search of representation, information, and community. This dissertation is a multidisciplinary analysis of the social media practices of people with endometriosis on Facebook and Instagram between 2018-2022. Using ethnographic and small-data methods for social media analysis, this study highlights the voices of people with endometriosis to consider why and how they go online. The surveys and interviews conducted for this study show that people with endometriosis use social media for a wide range of practices, including information-sharing, community building, meaning-making, and advocacy. This research addresses the following research questions: how and why do people with endometriosis use social media; what draws them to these spaces and what pushes them away; and how do these practices both respond to histories of endometriosis as well as shape the future of the disease?

On social media, endometriosis is mediated not only through technology, but also through people, conflicts, businesses, discourses, and patient-centred stories. These *networks of endometriosis* are complex and difficult spaces, but these complexities often reflect already-existent, offline challenges surrounding endometriosis. As a patient-researcher and a person living with endometriosis, I have included my own auto-ethnographic research notes and excerpts from my medical journals within this work, in part to be transparent about my own bias and connections, as well as to illustrate some of the barriers that people with endometriosis face, whether in seeking out care or trying to be represented in research. In this dissertation I argue that, in the face of inadequate care, imperfect social media spaces have become a significant resource for many people with

endometriosis and this significance as well as these online contributions should not be dismissed. Rather, by including patient contributions such as these in our research—and validating the turn to social media—we can better understand the needs, values, and networks of the people living with this disease.

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Chapter 1: Mediating Endometriosis

"I started my Instagram after the first time a doctor said I can't do anything to help you."
(Morneault 2020b)

Prelude

December 19, 2017 & December 8, 2020

In the fall of 2017, a week into starting my PhD, I was diagnosed with a condition called endometriosis. I had suspected this diagnosis for a long time and had been experiencing symptoms since my menstrual cycle began at the age of nine. My primary symptoms were pain and fatigue which, by the time I was 23, had grown into every part of my life. I would wake up in pain and spend speechless nights on the bathroom floor. At some point in my 20s, after pain had taken away my ability to exercise or reliably get to school, I began Googling my symptoms and came across the word *endometriosis*. At this point, I had been to a dozen doctors since my symptoms began (GPs, gynecologists, gastroenterologists, hematologists, ER physicians) and, even though I had a perfect symptom profile for the disease, it was WebMD that finally gave me an accurate 'diagnosis.' I found out over the next few years of talking to other people with endometriosis that my story was in no way unique, that even nurses and doctors are not always aware of what endometriosis is (despite its prevalence), and that many of those with endometriosis rely on external sources like the internet to answer their questions.

Once I learned that endometriosis existed, I was simultaneously sure I had it and also full of doubt. More than ten years of medical dismissal and neglect had left me convinced that I was crazy and overreactive. The fact that I was on anti-depressants for clinical depression didn't help me seem reliable to doctors and I soon found out that, in order to receive adequate medical care, it was best not to mention my mental health history at all. I dug deeper with my endometriosis research by reading medical journals, joining Facebook groups, and following the hashtag #endometriosis on Instagram. Using these resources, I found out that the only way to confirm I had endometriosis was through surgery. So, on September 11, 2017, after months of trying to convince my doctors I had an illness I checked all the boxes for, I walked up the street from my apartment to the hospital and underwent a diagnostic laparoscopic surgery with ablation. In the days before I was diagnosed, I had been so scared of surgery. But surgery remains one of the easiest and most painless parts of my life with endometriosis. When they cut me open there was nothingness. Pain and fear have been everything else, before and after, in degrees.

When I woke up from the fog of anaesthetic my first question was, *Did they find endometriosis?* Since then, I have seen this exact question repeated in countless stories from people living with this disease. In my case, the answer was yes, and the relief I felt was overwhelming: I wasn't crazy, what I was feeling for over ten years was real, and it had a *name* I could tell people. What I didn't know at the time is that having a diagnosis would not prevent me from being dismissed. I also didn't know that ablation is not considered the most effective surgery for treating endometriosis (T. R. Jenkins 2009; Healey, Cheng, and Kaur 2014). Neither was I told that they had found and left endometriosis near my rectum, a fact I wouldn't discover until 2021 when I was assembling my medical records to search for another doctor.

When I continued to be in pain after surgery, my doctor told me that I "must just be one of those people who are always in pain" without a referral to a pain clinic or mention of pelvic physiotherapy, medical marijuana, or any of the available treatments for chronic pelvic pain. It was another year or two before I even learned that any of those options existed. My only choice at the time was to continue my own research until my referral for a new doctor went through, all while still dealing with debilitating pain and recovering from a surgery that had made things worse. The process of learning *what exactly endometriosis is* has not stopped since. Even in writing this dissertation, talking to experts, and reading as much medical research as I could, I have come to learn new things about my condition that my doctors have continually described as "unexplainable." The stories my interviewees and survey respondents shared with me, and which I explore within this dissertation, have never stopped being shocking, even when I recognize my own experiences in them. Each story on its own is troubling but, when they are brought together, they illustrate an endemic.

I begin this dissertation with my story not to prioritize my own experience, but as a starting path into describing the *network of experiences* that those living with endometriosis share and navigate. My story is not the centre of this research, but it does inform my perspective. My dissertation has always been a product of relationality between myself and others, from the very first time I was dismissed by a doctor, to the day I looked up endometriosis online. I come into this work with an obvious bias towards this subject matter as well as shared experiences with my research participants, but that bias is an inherent part of the process, and it would be a mistake to pretend otherwise. My experiences with endometriosis provided me an entryway into the online communities that I would not have otherwise had. They gave my interviews an intimacy particular to the experiences my participants and I share and made room for difficult conversations to take place. My experiences opened me up to the existence of endometriosis itself and, even more importantly, the communities of people living with it and the everyday continuous work they do to shape everything that endometriosis is and will be. Where there is pain and disbelief, there is also resistance, sometimes in the smallest, most ordinary sense, and sometimes in much grander ways. These subsequent *networks of endometriosis*, in all their complexity and value, are what this dissertation aims to address.

A Brief History of Endometriosis

Endo What? Mediating Endometriosis Over 2000 Years

Endometriosis is a chronic inflammatory condition that is steeped in myth and mistreatment, despite affecting an estimated 1 in 10 women and undetermined numbers of transgender and non-binary people (and very rarely those assigned male at birth)[1] (Rogers et al. 2009; Shim, Laufer, and Grimstad 2020). Endometriosis is defined by tissue that is similar, but distinct from, the lining of the uterus growing throughout the body. This

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[1] Endometriosis is so mired in myth and misunderstanding that even tracking down the number of individuals it affects proves difficult. Many articles cite an estimated a number of “176 million individuals” but this is based on research from 2010 when the population was significantly smaller than it is now (Adamson, Kennedy, and Hummelshoj 2010). An updated estimate, based on the “1 in 10” theory and the 2021 world population, would mean approximately 200-300 million people live with endometriosis. I had difficulty tracing where the idea of “1 in 10 women” came from, despite its constant citation by endometriosis foundations and on social media. Considering the lack of knowledge about endometriosis, the long delay in diagnosis, and the number of people who likely go undiagnosed, I would suggest that the number of people living with endometriosis may be quite higher than these estimates, but what is apparent is an overall lack of concrete data.

distinction is important, as endometriosis is often misrepresented as a uterine disease. Endometriosis can cause (often debilitating) chronic pain, infertility, organ dysfunction, severe bowel symptoms, pain with sexual intercourse, fatigue, depression, limited mobility, and an overall decreased quality of life for patients[2] around the world (Culley et al. 2013; Facchin et al. 2015; Marinho et al. 2018; Warzecha et al. 2020; Wahl, Imtiaz, et al. 2021; Mousa et al. 2021). Endometriosis can also negatively affect relationships and self-identity (Moradi et al. 2014; Clark 2012). Research shows that those with endometriosis tend to be at a higher risk for comorbidities including hyperthyroidism, fibromyalgia, chronic fatigue syndrome, autoimmune diseases, allergies, and asthma (Sinaii et al. 2002). Living with endometriosis often leads to lessened productivity and economic and societal costs similar to other chronic conditions such as rheumatoid arthritis, type 2 diabetes, and Chron's disease (Simoens et al. 2012; Nnoaham et al. 2011; Levy et al. 2011). However, whereas diabetes (which affects only two times more people than endometriosis) received $1.1 billion in funding from the NIH in 2019, endometriosis only received $13 million, approximately 85 times less[3] (NIH Report n.d.). In fact, $13 million is a fairly high figure for endometriosis funding, as only one year earlier it received just $7 million from the NIH. In Canada, "endometriosis-related projects received only $7.3 million the past 20 years—just $7.30 per person estimated to be living with endometriosis in Canada today" (Wahl, Yong, et al. 2021).

There are several reasons as to why endometriosis is so underfunded and misunderstood including societal factors such as ableism, the taboo around menstruation, and stigma around chronic pain and chronic illness, as well as sexism.[4] Endometriosis has,

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[2] I try to use the phrase "people with endometriosis" as often as possible throughout this dissertation, however at times I rely on the term "patients" for simplicity or contextualization. My use of this word is not meant to reduce people to their illnesses, rather I am actually very interested in the irony of the term. People with endometriosis end up being extremely *patient* in order to receive care, whether they are waiting for a referral to go through or idling hours in a waiting room. Being forced into the role of a *patient* patient is a key struggle for people with endometriosis and can have lasting impacts, as I will explore.

[3] It could be argued that diabetes is much more severe than endometriosis because it can be terminal, but that also does not take into consideration the under-researched prevalence of suicide and death by complications in patients with endometriosis, something that I have witnessed countless times during my research period. Similarly, rheumatoid arthritis, which affects approximately 2.5 times less people than endometriosis, is funded about 7 times more by the NIH (NIH Report n.d.)

[4] The kinds of stigma (and their intensity) differ between different locations. In a study of women with Arab ancestry living in the United Arab Emirates, only 4% were willing to talk about dyspareunia (pain with sexual intercourse), a much lower percentage than Western countries (Mousa et al. 2021).

for as far back as we can trace, been mediated through cultures, social values, and media technologies. I use the term mediation throughout the dissertation to describe the ways that meanings and ideas are altered through communication processes. As I will explore later in this chapter, communication is always inherently mis-communicative. By considering the many ways that mediation and (mis)communication occur in endometriosis communication, we can begin to untangle *why* the disease is defined and treated the way it is. Endometriosis has a long history of being mediated and represented in ways that often obfuscate and neglect it entirely. Endometriosis communication has never been, and never will be, perfect, but there is certainly room for improvement.

For example, many endometriosis advocates question how differently endometriosis would be treated if it affected cisgender men as extensively as it does those of other genders.[5] In the comic "Joe with Endo," author and endometriosis advocate Mary Lou Ballweg and artist Meri Lau explore what it would look like if men were treated the way so many cisgender women with endometriosis are.[6] When Joe says he is in too much pain to have sex, his doctor with 20 years' experience tells him that getting married will help and to take birth control until his fiancé is settled in her job (Endometriosis Association n.d.). While this example may seem ludicrous, many of those living with endometriosis are treated exactly this way, particularly when they highlight pain as their primary symptom. Endometriosis is far more likely to be treated (and treated faster) when patients come in with concerns about fertility rather than pain (Shohat 1992; Arruda et al. 2003; Freedman 2016). Endometriosis care is tied into the histories of mistreatment around chronic pain conditions, particularly in the case of people of colour or gender-marginalized individuals (De Ruddere and Craig 2016; Dusenbery 2017). Although I will refer to chronic pain research throughout this dissertation, it is also important to remember that pain is not the only symptom of endometriosis.

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[5] In one example of sexism in endometriosis representation, Ella Shohat explores how representations of laser surgery for endometriosis have depicted the technology as masculine, heroic, and penetrative, while endometriosis patients are feminized, fragmented, and sometimes even sexualized in contrast. Her work explores how people with endometriosis have reinterpreted and reappropriated these medical images to instead become a form of empowerment (Shohat 1992).

[6] Non-binary, genderqueer, and trans individuals with endometriosis also experience gender-based discrimination from doctors, however "Joe with Endo", like many projects in endometriosis advocacy, focuses primarily on the experiences of cisgender women.

One of the confounding things about endometriosis is that the severity of symptoms does not necessarily correlate with the extensiveness of the disease, so some people with endometriosis can have severe pain and very little disease, while others have no pain and extensive lesions. These discrepancies can also lead to medical dismissal, where patients are dismissed despite their reduced quality of life because their disease does not *look* severe (Whelan 2007). This exacerbates the already difficult time people with endometriosis have appearing sick when their disease is almost only ever visible internally to an expert eye. Like many invisible, hidden, or non-apparent[7] disabilities, people living with the disease often experience dismissal for not "looking" sick and stigma for requiring accommodations, such as disability parking or mobility aids (M. L. Hirsch 2018; Brydges 2021).

Endometriosis is mediated through doctors as well as through the medical-industrial complex and social concepts of ablebodiness more generally. Across medical research, advocacy groups, and books, endometriosis is commonly described as "enigmatic" or "puzzling," but a large part of this mystique is due to outdated myths, stereotypes, and theories about the condition that still pervade clinical practice despite having been disproven, many of which are tied to gender stereotypes (Nezhat, Nezhat, and Nezhat 2012; D. B. Redwine 2012; C. E. Jones 2015). As retired endometriosis surgeon Dr. David Redwine explores in his book *Googling Endometriosis* (2012), many of the early diagnoses of pelvic pain-based "hysteria" were likely endometriosis. Those living with the condition today are, as he writes, "trapped by errant words from the past" stretching to as far back as 1825 BCE (Redwine 2012, 43).[8] In as early as 400 BCE, doctors were already blaming women for their symptoms (citing "causes" such as poor morals or too much sexual intercourse) in the face of lacking knowledge around treatment. In fact, by tracing the history of endometriosis, Dr. Redwine also traces the history of patient-blaming. In each historical example of pelvic pain he considers, the patient is always to blame when a

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[7] The use of "hidden" and "non-apparent" reflects a move in disability studies away from the word "invisible," a metaphor which evokes the able-bodied act of seeing as something solely ocular (Sandahl 2003).

[8] Dr. Redwine argues that the reason these "errant words" were sustained for so long within medicine is because "the written word commanded far too much respect because words on a page were permanent and not readily challenged" (43). Although this is likely true to a degree, it doesn't consider the power relations and systems that were invested in keeping those ideas alive, such as the patriarchy.

treatment is not successful. Over time, this dismissal becomes more and more systemic. For example, Redwine explores how the abdomen used to be known as the hypochondrium and patients who had unexplained pain located anywhere below the ribs were often thought to have the condition "hypochondriasis." Much like "hysteria," hypochondriasis had innocent origins and described something physical, but grew into a way of dismissing patients, particularly women, with unexplainable conditions.

Many of the treatments that were practiced over the next 2000-3000 years (venesection, electrotherapy, sterilization, bondage, cervical and intravaginal leechings, etc.) succeeded in stopping patient's complaints, but likely due to the unpleasantness of the treatment, rather than its success.[9] One doctor claimed that blistering patients' skin with Spanish flies (leaving second degree burns) was a successful treatment because patients stopped returning for appointments. (We can only imagine why!) Unfortunately, even this example carries some truth today. Although the treatments have changed, many people with endometriosis stop returning to doctors who are unable to provide adequate relief for their symptoms, meaning those doctors do not often learn that their treatments were unsuccessful. As Redwine identifies throughout his book, "*Googling Endometriosis* shows that certain actions have been displayed by physicians for centuries when dealing with female pelvic pain of any origin. These include blaming the patient and her psychology or dissolute lifestyle as well as trivializing pain which cannot be easily categorized or understood" (D. B. Redwine 2012, 250).

This patient-blaming has continued well beyond the 19th-century, but that is not the only myth pervading endometriosis treatment today. This prejudice ties into a much longer history of sexism and implicit bias in medicine. In her book *Doing Harm: The Truth About How Bad Medicine and Lazy Science Leave Women Dismissed, Misdiagnosed, and Sick,* Maya Dusenbery identifies how many of the diseases that are considered 'mysterious' or go overlooked, disproportionally affect people assigned female at birth:

> Women make up about two thirds of people with Alzheimer's disease, which experts now consider the third leading cause of death (after heart disease and cancer), though it receives only a fraction of the research dollars. They're at least twice as likely to have chronic pain conditions that affect 100 million

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[9] Not all the treatments were as horrific. Some were more absurd by today's standards, such as fumigating patients and their genitals with incense, meats, or other strong smells.

> American adults but that are woefully undertreated and under-researched. Then there are conditions like fibromyalgia, chronic fatigue syndrome, chronic Lyme disease, and multiple chemical sensitivities that are 70 to 80 percent female dominated and so poorly understood they have yet to be fully accepted as real diseases by the whole of the profession. (Dusenbery 2017)

She identifies how women and people of colour are both more likely to get mistreated as patients and less likely to be funded and published as practitioners (Chapman, Kaatz, and Carnes 2013; Newman-Toker et al. 2014; Dusenbery 2017). She also identifies another old bias at work in western medicine, which is "medicine's tendency to treat women's illness as perfectly normal" (Dusenbery 2017). It is an all too common trend in endometriosis treatment to not only blame patients for their symptoms, but also normalize their extreme symptoms (M. Ballweg 1997; Nezhat, Nezhat, and Nezhat 2012). This is what leads endometriosis to often being understood as nothing more than "bad period cramps,"[10] despite the fact that the pain can spread to an individual's entire body and that those "bad cramps" have sometimes been described as more painful than childbirth (Shohat 1992; Ballard, Lowton, and Wright 2006; Dusenbery 2017; M. L. Ballweg 2017). The idea of "normalcy" of health in general is largely subjective and often relies on the assumption that "normalcy" is value-neutral when it in fact ideologically organizes people and reinforces certain structures of knowledge (Canguilhem 1991). Mediation helps define what is considered "normal" and, in doing so, also defines what is considered *ab*normal, which then informs how disability and illness are ideologically understood. As mentioned above, there is a long history of stigma around chronic illness and chronic pain, particularly when it comes to marginalized patients, who are more likely to be dismissed as drug-seeking or hysterical (Werner, Isaksen, and Malterud 2004; Thernstrom 2010; Hoffman et al. 2016; Singhal, Tien, and Hsia 2016).[11] In the case of both gendered conditions and chronic pain, responsibility for the illness and its improvement is often placed on the patient, particularly when an illness is not curable and thereby extends beyond western healthcare's capacity for care (Thernstrom 2010; Marchant 2016; Clare 2017).

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[10] The normalization of "bad period cramps" (dysmenorrhea) has been widely criticized by endometriosis advocates for furthering the mistreatment and misdiagnosis of patients (Ballard, Lowton, and Wright 2006; M. L. Ballweg 2017).

[11] The histories of chronic pain care are explored more in Chapter four.

In the 20th-century, particularly 1948-1990, endometriosis was characterized in medical textbooks as a "career woman's" disease that occurred when (predominantly white) women chose to wait to have children (Shohat 1992; Sanmiguel 2000; Carpan 2003; C. E. Jones 2015). In other words, when women went outside the "normal" expectations that they should become wives and mothers. This idea linked endometriosis to "women's 'selfish' desires for higher education and paid employment" and grew out of "postwar cultural anxieties concerning the family and women's role in the paid labor force" as well as racist and classist fears around fertility in marginalized communities (Sanmiguel 2000, 60). These ideas were predominantly spread by women's magazines during the postwar era but perpetuated into the 1960s-1980s where they gained some wider representation. Throughout much of the 20th-century, people with endometriosis were depicted as burdens on both their families and society at large. Although the feminist health movement had some impact on women's magazines in the 1980s and early 1990s, their focus turned only towards patient self-education and did not address the larger systemic issues at play.[12] The continued myth of the "career woman's" disease led to the perception that endometriosis was an illness that only affected middle-to-upper-class white women, despite its prevalence in other communities. This was in part due to the fact that "career women" were the only ones able to afford and advocate for their care at the time (Sanmiguel 2000; Dusenbery 2017).

This rigid idea of what an endometriosis patient looks like has continued into the present moment and contributes to the deprioritization of care for transgender men, non-binary and genderfluid people, and, in rare cases, cisgender men, as well as people of colour with endometriosis (Jabr and Mani 2014; Cook and Hopton 2017). Although there is no research suggesting that endometriosis is more prevalent in white communities, Black, Hispanic, and Asian individuals are less likely to be diagnosed than their white counterparts (Sanmiguel 2000; Bougie et al. 2019). Further, despite the fact that gynecology was developed through experimentation on Black slaves (Owens 2017),[13]

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[12] The emphasis from women's magazines during the 1980s and early 1990s was still often that motherhood was the "best choice" women could make for themselves (Sanmiguel 2000).

[13] As Dierdre Cooper Owens describes in her book *Medical Bondage: race, gender and the origins of American gynecology*, gynecology was not only built on (often painful) experimentations on enslaved women, particularly Black women, but these enslaved women also became skilled labourers, learning to clean and

research into endometriosis in communities of colour is limited. Black people with endometriosis still regularly experience dismissal and racial bias, and are expected to act stronger in the face of pain, while simultaneously being less likely to receive pain medication or have their pain believed (Meghani, Byun, and Gallagher 2012; E. A. Stewart et al. 2013; Hoffman et al. 2016; Singhal, Tien, and Hsia 2016; Allen et al. 2019). A study of survey data between 1999-2006 showed that Black and Hispanic women tend to be diagnosed at an older age than non-Hispanic white women, implying greater difficulty accessing diagnosis (Li et al. 2021). As much as endometriosis is a gendered disease, it is also racialized, and classed, and unfortunately these misconceptions continue to be perpetuated today.

Another misconception of endometriosis is that it is purely a reproductive illness, even though it has been identified in stillborn babies (Signorile et al. 2009), foetuses (Schuster and Mackeen 2015), teenagers (Sarıdoğan 2015), and post-menopausal women (D. Redwine 2003; Ozyurek, Yoldemir, and Kalkan 2018). It has been found in all 11 body systems: cardiovascular/circulatory; cutaneous (integumentary/skin); digestive; urinary/excretory; lymphatic; respiratory/pulmonary; reproductive; muscular; skeletal; neurological; and endocrine (Foster et al. 1981; Jubanyik and Comite 1997; Roesch-Dietlen et al. 2011; Yazdanian et al. 2014; Loh, Lew, and Sim 2017; Lomoro et al. 2019; Sarmast, Takriti, and Sepehrmanesh 2019; Meggyesy et al. 2020). Although "extra pelvic" endometriosis (where tissue located outside the pelvis) is considered rare, some endometriosis advocates and patients suggest that it may just be under-researched (Bingham n.d.). In the survey data I collected of 287 people living with endometriosis, 14.3% (n41) mentioned "chest pain/cough/breathlessness" as some of the main symptoms they sought out support for on social media. It is possible that those with more severe endometriosis symptoms may be more likely to turn to social media, however more research is required to determine that.

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dress wounds, restrain patients, and observe surgery. While James Marion Sims became 'the father of gynecology,' these labouring 'mothers of gynecology' were forgotten. For Sims, gynecology was about providing women the means to "fulfill their social obligation of motherhood" and nothing more (Sanmiguel 2000, 85)

Thanks especially to patient lobbying and advocacy, research around endometriosis *has* progressed over time, but much of it has yet to be consistently integrated into clinical practice and public knowledge (Shah et al. 2010; Wahl, Yong, et al. 2021). Education around endometriosis is severely lacking, in both sexual health education and medical school (Holowka 2018; Zale et al. 2020; Roullier et al. 2021). It is telling that the main documentary on endometriosis is titled "EndoWhat?" and that the 2021 14th World Congress on Endometriosis was named "Cracking the Enigma." Although the causes and treatments of endometriosis are still uncertain, there are treatment and management options available, and this continued representation of endometriosis as an unsolvable puzzle often justifies the deprioritization of patient care (Shohat 1992). It is common for individuals living with endometriosis to experience dismissal and mistreatment of their symptoms meaning that they often experience delays in diagnosis and treatment. In fact, the worldwide average time from onset of symptoms to diagnosis is approximately 7.5 years for people with endometriosis (Hadfield et al. 1996; Arruda et al. 2003; Huntington and Gilmour 2005; Ballard, Lowton, and Wright 2006; Nnoaham et al. 2011; E. Denny 2011; Bullo 2018). In my own survey data, the average timeline between symptoms and diagnosis was identified as 10 years, possibly suggesting that people with endometriosis may be more likely to turn to social media the more delays and dismissal they experience. Further research is needed to determine whether this is the case.

People with endometriosis are also often initially misdiagnosed with other 'enigmatic' conditions, such as irritable bowel syndrome (IBS) and fibromyalgia (D. B. Redwine 2012), although sometimes these are also comorbidities with endometriosis. When properly diagnosed, people with endometriosis are regularly offered ineffective treatments, such as being told pregnancy will cure them or undergoing ineffective surgeries, including unnecessary hysterectomies or oophorectomies. People with endometriosis are also often put on hormonal birth controls or GnRH antagonists/agnosists which simulate menopause before being surgically diagnosed with endometriosis or surgically treated. For some people, this manages their symptoms, but for others this leads to negative side effects and more time for the disease to progress (Johnson et al. 2013; Brown and Farquhar 2015; Zale et al. 2020; Burla et al. 2021).[14] For endometriosis patients, this ongoing medical neglect can cause reduced self-esteem, avoidance of medical professionals, and/or hesitancy to raise concerns about treatment (Elaine Denny and Mann 2007; E. Denny 2011). Many endometriosis patients also end up experiencing a distrust or negative perception of doctors and medical practitioners in general (Ballard, Lowton, and Wright 2006; Markovic, Manderson, and Warren 2008; Ng et al. 2020).

Endometriosis expert Dr. Edgardo Rolla explains in his overview of endometriosis classification, pathogenesis, diagnosis, and treatment that "[a]fter reading hundreds of publications on endometriosis, [he] realized that [he] began to understand this complex disease only when… shar[ing] meetings and workshops with patients. No book, no online publication, no medical meeting can explain the intriguing pathways of endometriosis alone. Those who have it can tell a lot about it" (Rolla 2019). This idea of prioritizing patients' experiences and collaborating in their care is not a new concept and has been written about by researchers in patient-centred care, narrative medicine, disability studies, and the health humanities, all of which privilege the individual needs of patients by keeping them informed, engaged, and empowered (Kleinman 1988; Charon 2016; Gagliardi et al. 2019). Rolla's comment highlights the importance of including patient experiences as data in endometriosis research to more effectively communicating what endometriosis is. This is something I practice within this dissertation as well.

There is more to the mediation of endometriosis and its medical mistreatment than just sexism, stigmatization, and bias in healthcare. A large part of endometriosis' continued neglect seems to be the result of media representations, public discourse, and other forms of knowledge production which have "long inscribed endometriosis as deviance and punishment" (Kleinman 1988; Shohat 1992; Sanmiguel 2000, 66; De Ruddere and Craig 2016; Dusenbery 2017). As Lisa Michelle Sanmiguel argues in her 2000 dissertation *From "Career Woman's" Disease to an "Epidemic Ignored": Endometriosis in Popular Culture Since*

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[14] These side effects (bone density loss, hot flashes, mental health impacts) are often described in research as "minor," but there are also lawsuits against Abbvie, the pharmaceutical company that produces Lupron and Orilissa, two controversial and commonly prescribed medications for endometriosis. ("Lawsuits" n.d.; D. B. Redwine 2009).

1945, endometriosis must be understood "historically in relation to a complex web of interests, practices, and policies that have shaped knowledge about the disease" (Sanmiguel 2000, 2). Sanmiguel traces the representations of endometriosis in American biomedical, mass media, and advocacy texts since 1948, when she claims it first appeared in popular literature. Her extensive research on this period (1948 - 2000) shows that "endo[metriosis] is continually produced and negotiated through discourse" (Sanmiguel 2000, 15). Her work begins by tracing how popular media perpetuated the idea of endometriosis as a "career woman's" disease and how that later developed into the 1990s fear that endometriosis was caused by chronic exposure to environmental toxins.[15] Her dissertation outlines how these cultural discourses shaped patients' role in endometriosis and how responsibility for the illness was continually placed on patients, whether it was because they were not getting pregnant soon enough, they were exposing themselves to too many chemicals, or they weren't working hard enough to educate themselves about their own healthcare.[16]

Sanmiguel's dissertation also examines how the lived experiences of individuals with endometriosis often resisted predominant media narratives. As she writes, "[m]ass media and medical discourses have failed to provide a sense of how women with endo cope with the disease, how they manage symptoms in relation to their day-to-day activities" (Sanmiguel 2000, 337). She uses interviews with people who have endometriosis to show how their own conceptions of the disease often resist these dominant narratives and complicate "the relationship between the discursive body and the material body" (Sanmiguel 2000, 338). Her dissertation concludes at the turn of the century, and gestures towards a future where endometriosis advocacy might focus less on individual experiences and instead work towards collective change.[17] My dissertation continues and expands upon her work, considering the contemporary moment (approximately 2015-2022) where social media has brought the lived experiences and coping strategies of people with endometriosis into the foreground. Lived experiences have now, in many ways, become the

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[15] Sanmiguel explores how, suddenly, endometriosis went from something that only appeared in "career women" to an epidemic that could affect *any* woman (Sanmiguel 2000).

[16] The last of these (patient self-education) will be addressed more in my chapter on labour and knowledge.

[17] In chapter four, I explore the ways in which individualism in advocacy has and hasn't changed on social media.

centre of mass media and sometimes this work can be very individualistic. My research, however, also extends beyond just representation and lived experiences to consider the individual and collective *practices* of people living with endometriosis. Although these often include representation, they also involve community-building, knowledge-production meaning-making, activism, and advocacy.

My dissertation also expands upon Sanmiguel's brief mention of "the embodied experience of endo" by using affect theory and disability studies to consider how endometriosis comes to be lived and experienced both individually and collectively in a variety of complex ways (Sanmiguel 2000). One of the massive gaps that Sanmiguel addresses is the lack of representation of the structural factors that construct endometriosis and its treatment. This fraught relationship between the individual and the societal/structural is one of the predominant tensions on social media today, where people's individual and collective practices reflect, address, and also reproduce long-standing histories and complexities in endometriosis care. With social media, we see endometriosis being mediated in both old and new ways.

Endometriosis and Social Media

The internet is an ever-growing resource for health information (Baumann, Czerwinski, and Reifegerste 2017; Bujnowska-Fedak, Waligóra, and Mastalerz-Migas 2019). A collection of data from the Health Information National Trends Survey (HINTS) between 2008-2017 showed that the internet was the most frequently used source of health information in the United States, growing from 61.2% in 2008 to 74.4% in 2017 (Finney Rutten et al. 2019). In 2018, "What is endometriosis?" was the third most trending health-related question on Google (Welch 2018) and each month of 2017, there were more than 400,000 Google searches of endometriosis in the United States alone (M. Hirsch et al. 2017; Howard 2018). In his book *Coping with Illness Digitally*, Stephen Rains explains this phenomenon by describing how the internet offers a wide array of activities to address the many complexities of illness, especially chronic illness. These include: making and reinforcing connections; soliciting and providing social support; sharing illness experiences; seeking health information; and/or changing patient-provider relationships (in the case that the digital tool affords these possibilities) (Rains 2018). He also identifies that internet use for health information is more common with those who are younger, more educated, and female, as well as those with stigmatized illnesses (such as mental health illnesses or sexually transmitted diseases). Although Rains does not discuss online endometriosis spaces in his book, the demographics of many living with the condition do cross over with his research on who is most likely to use the internet for health-related reasons and could explain why gender- and economically- diverse individuals with endometriosis tend to be less represented in online spaces. An article on "the therapeutic affordances of online support group use in women with endometriosis" also identifies many of the same practices as Rains in people with endometriosis, specifically: connection, exploration, narration, and self-presentation (Shoebotham and Coulson 2016). Interestingly, in a study on pain communication on Instagram, Anna Sendra and Jordi Farré identified endometriosis and fibromyalgia as the most commonly mentioned causes of chronic pain (Sendra and Farré 2020).

Although there is limited research on online endometriosis spaces compared to many other long-term conditions, what exists suggests that it tends to be a mostly valuable and positive source for those living with the condition (Shadbolt, Parker, and Orthia 2013; Shoebotham and Coulson 2016; Sbaffi and King 2020). That said, there are also negative aspects, including concerns over information accuracy, conflicts between people, data and privacy breaches, and the possibility of worsened depression or hopelessness (Neal and McKenzie 2011; Shoebotham and Coulson 2016; Sbaffi and King 2020). Although research into the legitimacy and accessibility of endometriosis information online reveals that much of it is unregulated, incomplete, inaccessible, or prone to misinterpretation[18] (M. Hirsch et al. 2017; King 2019; Sbaffi and King 2020), existing research also shows that, despite these disadvantages, many people with endometriosis still rely on the internet, particularly on social media, to fill the gaps in their medical care (Shoebotham and Coulson 2016; Sbaffi and King 2020). In Kathleen King's 2019 dissertation, she explores how individuals with endometriosis tend to trust online endometriosis information (particularly when it is from

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[18] It seems important to note here that this problem is not only associated with the internet. Doctors' information on endometriosis can often also be incomplete, inaccessible, and prone to misinterpretation. As I will explore more in this dissertation, many of my interviewees went to doctors who gave them misinformation about the disease.

endometriosis organizations), but find the internet even more useful when it comes to *sharing* health experiences (King 2019). Further, in their published 2020 article, Laura Sbaffi and King argue that many people with endometriosis turn specifically to "online peer-to-peer information exchange" because "[t]his online rapport is crucial to obtain the acknowledgement and validation that is missing in other aspects of their lives, where the condition is often dismissed, minimized or ignored all together" (2020, 387). According to my interviews and data collection, endometriosis really began to take off on social media around 2012-2013 with Facebook and, more recently, Instagram (Cohn 2020; Petersen 2020a). Because of the isolation and stigmatization commonly experienced by those living with endometriosis, contact with other patients is highly valued and social media is often one of the easiest (or only) ways to find these kinds of connections (Whelan 2007; Shoebotham and Coulson 2016; Sbaffi and King 2020).

Where existing research considers some of the reasons *why* patients turn to social media spaces, my research is more interested in exploring *how* these spaces are used and what we can learn from those who are engaging with them. Emma Whelan explores some of these same questions in her 2007 article "'No one agrees except for those of us who have it': endometriosis patients as an epistemological community" based on focus groups with individuals part of an in-person endometriosis support group as well as an endometriosis email list. Although the study is now almost 15 years old, much of what Whelan observed remains true in online endometriosis social media spaces today. She identifies how these communities operate on a series of shared practices and principles that create their own communal knowledge. In the case of the endometriosis communities she examines, this takes the form of sharing experiences and knowledge in order to receive support and/or advocate for care. Whelan identifies how many of the individuals in these groups both *relied* on medical knowledge to validate their lived experiences to others, while also *questioned* medical knowledge in cases where it did not reflect those lived experiences. The people she worked with privileged the experiential knowledge of other endometriosis patients over all else and would often use that to understand and interpret their own experiences, but they rarely valued the experiential knowledge of medical practitioners in the same way. As the title shows—"no one agrees except for those of us who have it"—the patients seemed to hold and share an implicit belief that those without endometriosis can never have a true understanding of it (much like the earlier quote from Dr. Rolla suggested).

Whelan's article shows both the value of lived experience for individuals with endometriosis, but also just how fraught and uncertain that experience can be, particularly when patients have been routinely dismissed or ignored. The key takeaway from this study, I argue, is the apparent necessity for those living with endometriosis to interpret their own bodily knowledge and experience *relationally* and *socially* (whether through medical research or in conversation with other endometriosis patients). This is precisely where online illness communities come into play, as they offer a space of continual interpretation, relationality, and mediation in which to understand the self—*a network of endometriosis*. Much like Whelan's participants suggest, this mediation can often become a form of *resistance*. At times this resistance is more explicit, taking the form of lobbying or advocacy, but more often it is ordinary and habitual. As Whelan writes, "particularly via the internet, the line between political resistance and epistemological action blurs" (Whelan 2007, 977). The lines between a person's distinct experiences with endometriosis and how they come to conceptualize the disease communally/socially are also blurry. Recent research has shown that "the social experience of endometriosis plays a vital role in [gaining] access to appropriate care" (Krsmanovic and Dean 2021). This is why an updated look at endometriosis from a communication studies perspective is needed. Researching the intersections of social media and endometriosis shows not only how certain ideas come to take form and stick in the public consciousness, but also illuminates the areas in which endometriosis care is lacking and how those might be improved. By examining the practices of people with endometriosis, I am interested in examining the ways that endometriosis gets mediated: between our bodies and our minds; ourselves and others; our experiences and online representations; our online representations and clinical definitions; and beyond.

This research addresses the following research questions: how and why do people with endometriosis use social media; what draws them to these spaces and what pushes them away; and how do these practices both respond to histories of endometriosis as well as shape the future of the disease?

Theorizing Endometriosis Online

Endometriosis, I argue, is a sticky disease. I mean this both literally, in the way it can physically glue organs together in the body, as well as metaphorically, in how its representation and cultural meanings tend to stick to bodies and social networks, trapping so many patients in outdated treatments and myths from the past. Pulling from Sara Ahmed's theorization of "sticky" affect, my research traces how certain feelings and political affinities about endometriosis get lodged in our bodies and our cultures, how "[w]e move, stick and slide with them," and what those circulating affects *do* (Ahmed 2013, 14). Both endometriosis and social media are sticky in their own ways, but in tandem they draw people together under a blanket of shared experiences (and shared adherences) into both community and conflict. I use stickiness as a way of understanding these connections and disconnections, weaving together my multiple fields of inquiry—life writing, disability theory, and social media studies—under the overarching theoretical framework of affect theory. Affect encompasses, as Carrie Rentschler writes, "the *felt* aspects of everyday life, social change, and durable structures of power" (Rentschler 2017). I frame my research using affect theory to address both the personal experiences of those living with endometriosis, as well as how those experiences are mediated through networks of communication and solidified into systems and meanings. These systems of meaning (created through *networks of endometriosis*) can look like many different things but, as Whelan observed in her own study of endometriosis communities, knowledge-production, resistance, and mediation are all important aspects of endometriosis communities, and these are some of the entanglements I too explore.

This dissertation is necessarily interdisciplinary. Just as proper endometriosis treatment relies on a multidisciplinary team that can address each affected area of the body, research into endometriosis' relationship to social media requires not only media studies, but also feminist disability studies, affect theory, and life writing studies. This multidisciplinary approach offers a complex but thorough framework through which to consider the wide range of practices enacted in online endometriosis spaces while also attending to the histories associated with those engagements. In order to thoroughly analyze the different types of practices taking place in these communities, we first need to frame the contexts in which they are emerging and what theoretical frameworks are guiding this intervention.

Mediating Endometriosis Online

This project is situated within communication studies and media theory. At the heart of this research is the act of communication, of trying to transmit information, connect with others, and express oneself. These acts of communication are a means to survive and a lifeline for many people with endometriosis. Regardless, communication is always also an act of translation and interpretation, whether we're communicating our thoughts to one another, or communicating pain signals to our nervous systems. As media studies scholars have long explored, communication always moves through a medium (intermediary) and that medium is always an imperfect messenger. Messages are transmitted (encoded) through signs and symbols and interpreted (decoded) into meanings that may or may not match the original intent (Hall 1973). Communication is inherently imprecise and there is always room for miscommunication. This is, as John Durham Peters puts it "the dualism of communication—at once bridge and chasm" (Durham Peters 1999). The social practice of communication is always being mediated, through technologies and their protocols (Gitelman 2006, 7). The flaws of communication do not make it any less important of an endeavour, but they do complicate the dream of perfect understanding that the word "communication" often evokes. In this particular project, I will explore how social media operates as a sometimes-necessary, but inherently flawed, communication tool for people with endometriosis.

Endometriosis is mediated in many ways: through the eyes of doctors, through pills and hot packs, TENS units and surgeries, through magazines and television, through societies and communities. The media we use informs (or becomes) our messages (McLuhan 1994). What we communicate is both semiotic *and* material. It shapes our bodies, our feelings, and our systems of meaning (Gitelman 2006; Williams 2015). In this research, I explore how social media has brought new dimensions to endometriosis—particularly around patient-led advocacy and awareness raising—but also how it has become another mediating factor in many people's experiences and understanding of the disease. Social media platforms and algorithms depend on conflict and the circulation of emotion, and these material realities of the medium have become a part of the experience of endometriosis itself. Social media is contradictory: it helps us share (mis)information, (mis)understand one another, and (de)construct communities.

In *Speaking into the Air*, John Durham Peters uses the plural *communications* to refer to, as Williams writes, “the institutions and forms in which ideas, information, and attitudes are transmitted and received” (Williams 1962, 9). Similarly, in this dissertation, we will see many *endometriosises* emerge through these many communications. These many endometrioses make up what I refer to as *networks of endometriosis*—a complex web of conflicting and simultaneous ideas, practices, and experiences all encapsulated under the single word “endometriosis.” This concept of multiple endometriosises emerges from the work of Annemarie Mol, who writes in her book *The Body Multiple* that ontologies “inform and are informed by our bodies, the organization of our healthcare systems, the rhythms and pains of our diseases, and the shape of our technologies. All of these, all at once, all intertwined, all in tension” (Mol 2002, 7). As we dig deeper into these networks of endometriosis (a concept I will explore in more detail below), the disease will seem to become messier and more complex. But it is within this mess, these conflicts and gaps in understanding, that the full expansiveness of endometriosis can be explored. As John Durham Peters writes, acts of communication are not utopian methods of understanding one another. Rather, “the dream of communication stops short of all the hard stuff” (Durham Peters 1999). But the hard stuff is where things become the most interesting; it’s where connection happens, where differences are recognized and celebrated, and where future work can begin. This dissertation is centred around miscommunications and the hard stuff, around mess and trouble.

The future of endometriosis care depends on giving voice to the lived experiences of people who live with the disease. Alongside this, it is necessary to understand how “even the lived experience of one’s own body is mediated” (Mol 2002, 26). One of the complicating factors within endometriosis research and care is that the experience of endometriosis is mediated differently by different individuals’ bodies and nervous systems. Some people never feel pain, others experience no end to pain. If mediation is at the core of even our own bodies, what hope do we have of untangling endometriosis, of untangling ourselves? Perhaps this is what makes social media so interesting. As we lean deeper and deeper into mediated, networked spaces, we are confronted with this messiness in our everyday practices. The goal then, is to not untangle, not to search for the pure core of endometriosis, but to rather consider *how* our experiences are mediated, *what* that mediation tells us, and how *mediation itself* is a critical part of what makes up the lived experience of the disease—to see endometriosis in all its complexities and contradictions. Perhaps we cannot fully treat our bodies without understanding the networks we are entangled in and shaped by.

Networks of Endometriosis

Throughout this dissertation, I use the phrase "networks of endometriosis" as a way of conceptualizing the complicated and messy map of relations between actors—both human and nonhuman, both social and material—that structure the meaning of endometriosis. This network includes both things and people as well as concepts: doctors, patients, medications, hysteria, hot packs, even our very own organs. The network is comprised of the links between these objects and concepts— "a topography that organizes everyday experience in terms of sociality and relationality" (Levina 2017). It is through these relations, objects, and practices that endometriosis is enacted and comes to be understood (Mol 2002). The term network reflects the "always-mediated" nature of the world and offers us a way to map out the (mis)communications and relations that create endometriosis, as well as better understand how power moves between these connections to shape our bodies and beliefs (Levina 2017; Latour 2005).

My framing of "networks of endometriosis" draws on the work of posthumanist scholars such as Karen Barad and Judith Butler as well as the concept of "affective networks" (Butler 2005; Barad 2007; Papacharissi 2011; Levina 2017). Drawing on the work of Bruno Latour, Actor Network Theory, and Donna Haraway, Barad and Butler explore the relations and entanglements between both human and non-human actors (objects, concepts, people), and how we can better understand our world by examining these relations and what they *do* (Latour 2005; Barad 2007; Butler 2004). The concept of "affective networks" similarly explores the ethical and affective influences of these relations—how *doing* and *being in relation* construct what comes to matter and what guides our beliefs— as well as our vulnerability to one another (McCosker 2012; Papacharissi 2015). The concept of the network helps us understand life in a relational, mediated world that is always in the process of becoming. It helps us trace *how* things come to be, how meaning and power are created and reinforced. Being networked is inevitable, but the network can also be played with because it is constructed through our *relational* and *networked* practices. For example, within this vulnerable relationality, networks of care and support can emerge, such as those seen in many endometriosis and disability communities (Butler 2004; Lakshmi Piepzna-Samarasinha 2018; Malatino 2020).[19]

In their book *Care Work*, Piepzna-Samarasinha discusses how online spaces can be helpful for coordinating care while also acknowledging that these spaces are not accessible for everyone. Although social media *can* be a useful space for those with endometriosis, it is not accessible to all people with the disease and there are likely vast majorities of people across the world who do not even know that they have endometriosis and may never be able to access that knowledge or care. This dissertation focuses on the ways social media has been used by some people with endometriosis, but social media is by no means a viable solution or option for all people who live with this disease. Even within social media spaces, power is distributed unevenly, and certain people are afforded more options than others. For example, while my research features people from around the world, the interviewees are predominantly from North America and certain perspectives from within North America, such as those of Indigenous people, are noticeably absent. There are many communities worldwide with limited or no access to social media and technology for whom these online endometriosis spaces are completely inaccessible. Relatedly, access to healthcare varies widely across the world, meaning that a large population of people with endometriosis, particularly those who live in more remote communities, likely do not even know they have the disease.

We can see the distribution of power in networks and *networking* play out in healthcare and social media in this quote from Hil Malatino's book *Trans Care*:

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[19] The practice of wearing a mask to protect others from illness is a good example of practicing networked care.

> The better networked you are, the more social media capital you have, the more successful your bid for funding will be. This means that crowdfunding favors folks with the time, the extroverted capacity for engagement, and an extant and well-received 'brand.' In other words, it makes health care access in the context of compounded inequalities tantamount to a popularity context. (Malatino 2020)

Within these networks, certain meanings and concepts take hold and *stick* (Ahmed 2013). Certain emotions, concepts, and beliefs drive the network and how it operates. I like to think of stickiness as where the network gets concentrated, where the most communication flows through. This is not immaterial, we can see the effects of this stickiness, even in our own bodies and nervous systems.

For example, in pelvic physiotherapy, I have learned how to massage my adhesions, to lean into my myofascial tissue and breathe through the pain signals my body wants to send. Years of being in pain has made my nervous system more attuned to pain, meaning my pelvis is in a constant state of tension, ready for pain at any moment, and often reacting to triggers in exaggerated ways. This pain was a part of me for so long, it shaped the way I saw the world. As I lean into the tender spots, breathe through the scar tissue, I feel it begin to give way. Sometimes I can feel it gently ripping, the stickiness releasing, as I rewrite what pain means within my body going forward. I think of the stickiness of networks as a lot like this scar tissue. By looking at the sticky points in these networks we consider what is driving our networks and what is being solidified as knowledge. Stickiness, like my own myofascial pain, emerges out of repeated practices, impressions, and repetitions, an "accumulation of affective value" (Ahmed 2013). In this dissertation, I begin to identify (and massage) the tender points of endometriosis networks to better understand what is driving the conceptualization(s) of endometriosis today.

In a moment, I will move temporarily away from networks to explore the other theories and fields that guide this research, the first being life writing studies. Although the move to discussing individual lives and the self may seem to be in juxtaposition to this discussion of networks, the two are intrinsically linked. The networked self, the networked identity, is constituted through its relations to others, meaning it is always in a state of creation and self-definition (Papacharissi 2011; Levina 2017). We always exist in relation to others, to concepts, to objects, and these relations make up our networks. Through writing and articulating the self, we put ourselves in conversation with these networks, particularly when what we share is uploaded to a social media network like Instagram or Facebook. It is this active role in networks, in creating and defining their sticky points, that makes social media such an interesting tool, particularly for a disease like endometriosis, whose patients have long been silenced and excluded from the conversation.

Life Writing and Automedia

Scrolling through the hashtag "#endometriosis" on Instagram reveals a number of recurring trends and sticky practices: yoga pictures, shots of food, selfies that show pain, selfies that mask pain, hospital selfies, pregnancy tests, bellies, baby photos, illustrations, inspiring quotations, pictures of scars, surgical videos, product advertisements, and more. Although at first glance these Instagram posts appear to be predominantly focused on visual representation, many feature long texts in the captions of the post that add to or elaborate on the image above.[20] Scrolling through endometriosis Facebook groups reveals similar trends, although the focus on written text is more obvious in these spaces. Across both platforms, most posts are focused on knowledge or self-improvement, some on asking for support, a few on selling a product or lifestyle, but many are representational, oriented around trying to find some way of visualizing the effects of endometriosis through words and images. This focus on representation is why I turn to life writing studies as an important framework for researching endometriosis and social media. The field brings with it a history of representing illness and endometriosis in pre-internet media as well as opens a pathway into thinking about the mediation of both the self and the other online.

Life writing encompasses a wide range of genres including, but not limited to, auto/biography, memoir, diaries, letters, testimonies, blogs, and emails. These genres, which tend to intersect and overlap with one another, are best articulated in Sidonie Smith and Julia Watson's foundational text, *Reading Autobiography: A Guide to Interpreting Life*

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[20] In mid-2022, Instagram (owned by Meta) changed the platform so that it more closely resembles TikTok and is far more focused on short video content. Although more video features (including Reels) were introduced during my research period, my research focuses largely on an era where Instagram was focused on still images and captions. It is a sign of how fast-moving and adaptable social media is that my research was already referring to past practices even before it is finished.

Narratives. Smith and Watson problematize the term autobiography, adding a forward slash between "auto" and "bio" so as to articulate the complex subjectivities between writing the self and the other (Smith and Watson, 2010). *Auto/biography,* however, is a specific term which tends to refer more to literary forms of life writing and self-writing, whereas *auto-ethnography* refers to a more academic form of life writing and combines the practices of self-reflection with the anthropological practice of ethnography. *Pathography* and *auto-pathography* are other life writing genres that come up particularly in relation to illness life writing, pathography representing subjects as *patients*, whereas *auto-pathography* carries the potential for the patient to reclaim their own experiences through the act of telling (Couser 2009, 75). The term "life writing" remains the broadest, encompassing all these genres.

The intersections of chronic illness and life writing have been explored by many scholars across several fields. G. Thomas Couser's (2009) extensive work on disability and illness in contemporary life writing has provided a key background for considering the ways in which life writing can be used by patients to claim autonomy of their bodies and treatment. Medical anthropologist Arthur Kleinman and health humanities scholar Rita Charon both consider how bringing patient narratives into clinical practice can improve care and disrupt some of the stigmas and biases present in medical care (Kleinman 1988; Charon 2016). Further, many texts that explore disability or illness use life-writing or auto-ethnography to incorporate the author's lived experiences into the study as a form of ethical and intimate engagement with the research (Garland-Thomson 2005; Cvetkovich 2012; Patsavas 2014; Price 2015; Clare 2017; Dokumaci 2023). There are also many non-academic texts by disabled writers that give voice to the variety of experiences encompassed within the concept of 'disability' (Mairs 1997; Mantel 2004; Lorde and Smith 2020). Although sometimes hidden under different names, life writing has continually been employed within disability studies, the health humanities, patient-centred care, art/narrative therapy, medical anthropology, and other fields to highlight the importance of patients' lived experiences in clinical practice and medical advancement. As comparative literature scholar Julia Epstein puts it, "[s]tories also draw lines and limits around the human body with their narrative authority and with their beginnings, middles, and ends" (1994, 186). Life writing's intersections with medicine and illness/disability often involve considering storytelling and discourse more generally, such as how systems of meaning come to shape clinical practices, diagnoses, and bodies.

The literature on social media and life writing is growing but is still in its early stages. The most notable development in this area is Julie Rak's use of Smith and Watson's term "automedia," which Rak defines as "an enactment of a life story in a new media environment" (Rak 2015, 155). In the *M/C Journal* special issue on Automediality, Ümit Kennedy and Emma Maguire articulate automedia as a "theoretical framework or approach to studying not only new media life stories, but auto/biographical practices as they are enacted in a range of media forms, analogue and digital alike" (Kennedy and Maguire 2018). Maguire similarly positions "autobiographical practices as media work that involves complex interplay between users, producers, and consumers," putting the long-standing discussions of representation in literary theory into more explicit conversation with the concept of mediation in media theory (Maguire 2018, 3). As Rak writes, automedia is not just a "product (media about a maker)," but also a "process (the process of mediating the self, or auto)" that goes into that product (Poletti and Rak 2014, 161). An automedia framework therefore would involve analyzing the "*process* of being, doing, creating, and distributing the self, in relationship with media and their affordances, limitations and participants" (Kennedy and Maguire 2018, emphasis my own). Like in auto/biography studies, the automedial self is understood as always unfixed and in the process of becoming. Automedia is therefore a useful term for bridging some of the boundaries between life writing studies and media studies and makes room for the complex sociality and interrelations between the self and other that take place in these digital spaces. As Anna Poletti writes:

> We are never totally inscribed in a single media, and this is precisely because each form of media inscribes us differently. The difference is the result of the specific affordances and ideologies that each media form materializes, and how these intersect with the forms of power, knowledge, and ethics that inform what we value about a life, and how. (Poletti 2020, 170)

When I refer to *networks of endometriosis*, I am including all these intersections that each social media platform brings with it. The way that endometriosis comes to be understood, even outside of social media, is more and more informed by what people with endometriosis are doing and practicing on social media as time goes on.

Emma Maguire's use of the phrase "automedial strategies" further situates automedia as something that is practiced (Maguire 2018, 3). Automedia is a process, a process that references a long history of marginalized self-inscriptions, as has especially been explored by girlhood and feminist scholars. Women and girls' life writing and social media practices have long histories of being dismissed. As Maguire writes:

> When girls' texts are framed as identity work, media-making, self-expression, or artefacts of 'girl culture,' what becomes obscured is the important work of mediation that is central to girls' self-representations. (Maguire 2018, 12)

Bringing auto/biographical studies into media studies situates the media work of girls or other marginalized figures (in the case of my research, the social media practices of those living with endometriosis) within a long history of marginalized life writing practices. It historicizes this work, while media studies situates life writing as an ongoing process that is "increasingly relational, mediated and inherently dialogic, self-conscious of the impact of audience and reflects the dominant discourses of the societies in which it functions" (Friedman and Schultermandl 2018, 145).

That said, the concept of automedia is quite new and my research is an experiment in doing this kind of analysis. The concept offers me a way to refer to the multiple forms of self-mediation that I will be talking about, including life writing, self-imaging, and more. At times, I have found it more grammatically useful to say "digital/online life writing" in place of "automedia," particularly when I am drawing on older auto/biographical research, but even in these instances I am still in conversation with this idea of automedia. The practices I consider involve life writing, but can also extend to photo-sharing, drawing, or other modes of digital expression that are best understood within automedia theory. My dissertation aims to further tease out the intricacies of what automedia can be.

Feminist Social Media Studies and Affect Theory

My theoretical approach to this project is further defined by the rise of academic research considering the everyday, habitual, and repetitive practices of social media use (Papacharissi 2011; Keller 2014; Dobson 2015; Chun 2016). Many of the contemporary social media scholars draw on use affect theory as a way of understanding these everyday practices qualitatively. Affect theory considers how people come together, how emotions circulate through digital spaces, and what those relationships and practices produce (Papacharissi 2011; Rentschler 2017). Much like Whelan's observations of endometriosis communities, feminist social media studies and affect theory often situate everyday and ordinary practices as knowledge-producing and potentially resistant. Affect scholars Kathleen Stewart and Margaret Wetherell both theorize "ordinary affect" as the everyday ways in which "people engage with the momentous and the global political" (K. Stewart 2007; Wetherell 2012, 7). These repetitive and habitual acts such as posting on social media, as Chun writes, "[are] not simply exhaustion: not simply repetition of the same that uses up its object or subject. [Rather, they can create] constant ethical encounters between the self and other" (Chun 2016, 91). Within digital girlhood studies, for example, social media is explored as "often one of the only places in which [young girls] can engage in [feminist] practices," due to their not being able to 'take to the streets' or limited access to feminist discourse within their own communities (Keller 2014; Dobson 2015).[21] People with endometriosis who use social media often find themselves dismissed not only for their symptoms, but also for their social media practices, as well as for gender, race, or other intersecting identities. Their turn to digital platforms is often a double (or triple)-edged sword.

The everyday practices of disabled and chronically ill people have not been studied much within social media studies and girlhood studies (Hill 2017), however there is a fair bit of writing on this topic within disability studies (Hedva 2016; Lakshmi Piepzna-Samarasinha 2018; Dokumaci 2018; 2023). These practices of everyday life writing on social media (automedia) are not new and can be situated within histories of women's 16th- and 17th- century letter writing and 20th-century publishing practices (Dowd and Eckerle 2007; Cofield and Robinson 2016; Humphreys 2018). Life writing scholar Leigh Gilmore describes social media as a "testimonial network" in which stories of the self are circulated and gather meaning" (Gilmore 2017, 3). Even without mentioning affect theory,

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[21] Susan Wendell has critiqued feminist activism for not accounting for the disabled body (Wendell 2996). Girlhood studies also often neglects to bring disabled people into the discussion of girlhood.

her work evokes similar concepts, showing that many of these fields are in conversation with one another, even when it is not done explicitly.

Affect theory also provides a tool for conceptualizing what it means to live with chronic pain, which so many people with endometriosis do. Neuroscientific research shows that the sensation of pain can be experienced differently depending on how it is processed or understood psychologically (Melzack 2001). The way pain comes to be *felt* in bodies is not just about physical damage or degeneration but is also dependent on the kinds of stories and meanings that circulate about that pain. This does not mean the pain is any less real or treatable, but it does offer a road into understanding how nuanced the experience of pain and sickness can be, and why mediating the self and relating to others can be so critical. Both Anthony McCosker (2012) and Jean E. Jackson (2011) use affect theory to tie understandings of pain as a *sensation* together with pain as an *emotion* by bridging the gap between the humanities' and medical science's understandings of pain. Similarly, Lisa Folkmarson Käll's book *Dimensions of Pain* (2012) uses affect theory to explore how pain is constructed through a number of social, political, cultural, historical, and affective processes. Often drawing on the work of affect theory scholar Sara Ahmed (Ahmed 2013), these scholars use affect theory as a way to understand the contingency and relationality of pain, as it is felt both individually and socially. Although the literature mentioned focuses primarily on pain, it also extends to sickness more broadly. There has not yet been much written on the intersections of chronic illness and social media from an affect-based media studies perspective but, as I will show, endometriosis communities offer a great window into these overlapping areas.

Feminist Disability Studies

These complexities of how the body, mind, pain, sickness, and affect interrelate have long been important aspects of feminist disability studies, a field which also emphasizes the stories and lived experiences of disabled, sick, and crip people (Wendell 2996; Garland-Thomson 2005; Hedva 2016; Puar 2017; Lakshmi Piepzna-Samarasinha 2018). Feminist disability studies navigates how disability is both socially constructed while *also* being embodied and felt. Disability scholars such as Alison Kafer (2013), Jasbir Puar (2017), and

Margaret Price (2015) consider the difficult material realities of living in a sick body, while also positioning the "sick," "crip," or "disabled" identity as unfixed and in flux. Others consider how disability can become an act of meaning-making itself or a way of creating new kinds of realities (Dolmage 2014; Dokumaci 2023). Like the previously mentioned fields, feminist disability studies also expores ordinary forms of resistance, sometimes framing simply the act of just existing in a sick body as a form of resistance in a productivity-oriented, abled, neoliberal world (Hedva 2016; Lakshmi Piepzna-Samarasinha 2018; Dokumaci 2023). As Jasbir Puar explores, disability and impairment can also be used by the state to prevent or target resistance (Puar 2017).

As will be explored more throughout this dissertation, those living with endometriosis have a complicated relationship to the idea of disability. For some, the term does not feel useful, while others may identify as disabled but are not always able to qualify for government disability support. These kinds of challenges and uncertainties are what disability studies is often so good at addressing however, as Cara E. Jones writes, endometriosis has been largely absent from feminist disability studies (C. E. Jones 2016). Although the lines between endometriosis and disability are sometimes tenuous, disability studies provides many years of theory in which to frame the embodied and constructed experiences that so many folks living with endometriosis also negotiate.

Perhaps most applicable to endometriosis is the work of disability scholars Susan Wendell (2001), Tobin Siebers (2013), Alyson Patsavas (2014), and Margaret Price (2015), and Arseli Dokumaci (2023) who consider the place of chronic pain within disability studies. For example, Patsavas' "cripistemology of pain" explores the "process of knowledge production that situates pain within discursive systems of power and privilege" (Patsavas 2014, 205). She acknowledges the importance of the lived experiences of those living with chronic pain, while also considering how that pain is never just individual, but always constructed "within a system of connectivity" (Patsavas 2014, 214). As disability studies has illustrated, disabled people are often expected to manage their disabilities individually, despite disability itself being always constructed by and/or dependent on others. As Pastavas writes:

> We are implicated in a system of power that places the doctor in a position of evaluating me and providing me (one part of) the relief I need to survive. I

> bring with me an individual history of doctors dismissing my experience of pain and a collective history of women in pain being locked up and/or thrown out of offices for 'hysterical behaviour,' just as the doctor brings with him a history of seeing thousands of other patients expressing pain and a collective history of a medical system that trains doctors to view pain and people in pain as suspect. Recognizing our connectivity allows us to respect the weight of these histories while simultaneously establishing a space to talk about pain without losing its materiality, without automatically reiterating the link between disability and pain, and without losing sign of the social and cultural conditions that contribute to how we *feel* pain. (Patsavas 2014, 215)

Patsavas' "cripistemology of Pain" brings both the literal and figurative connective tissue of pain into view. These "systems of connectivity" she describes are something that I argue is apparent in unique ways on social media, where all these histories intersect.

I return here to the idea of *networks of endometriosis,* that is, the way endometriosis comes to be represented, to be felt, to stick, and to matter both individually and socially. After years of engaging in online endometriosis spaces, it has become only more difficult to disentangle myself from these networks of endometriosis. But perhaps I can't be disentangled, perhaps I shouldn't be. The concept of entanglements and *my* entanglements are precisely what makes this study what it is: a patient-led project focused on the entanglements of patients within networks of endometriosis; a project centred around examining what people with endometriosis are saying and trying to make those voices, those concepts, *stick*.

Auto-Affective Media Practices

In order to consider the complex ways in which people living with endometriosis engage online, I have developed a concept I call "auto-affective media practices" which I will use to break down my analysis and chapters. This concept is built upon several intersecting theories, all of which emerge from feminist cultural studies and poststructuralist theories. Following in the footsteps of the qualitative endometriosis studies that have come before me, my research considers the interrelations of discourse and subjectivity in constructing *what endometriosis is*. Many of the feminist theorists I pull from ground their research on the work of Michel Foucault and his writing on knowledge, subjectivity, and power. In *Technologies of the Self,* Foucault (1988) breaks down four major types of technologies:

> (1) technologies of production, which permit us to produce, transform or manipulate things; (2) technologies of sign systems, which permit us to use signs, meanings, symbols, or signification; (3) technologies of power, which determine the conduct of individuals and submit them to certain ends or domination, an objectivizing of the subject; (4) technologies of the self, which permit individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfect, or immortality. (Foucault 1988).

These technologies often work in relation to one another, shaping both individual and social lives, and aid Foucault in his conceptualization of domination and power as well as the processes of resistance. Although I use the word "practices" in this dissertation, my conceptualization of this term draws on Foucault's technologies, particularly his "technologies of the self" and "technologies of production" as well as the work of feminist scholars since Foucault who have used his theories to articulate every day and habitual forms of resistance in relational spaces (Butler 2004; 2005; Chun 2016).

Foucault's technologies set up a framework for understanding the relations between the self, the other, power, signification, and discourse. For Foucault, discourse is a "group of relations" or rules that structure systems of knowledge (Foucault 1972, 49). Although some of the theorists I draw upon use "discourse" to refer to narrative and linguistic representations, I argue that a broader definition is required to effectively talk about embodiment and the lived experiences of those living with endometriosis. Therefore, I also bring in the work of feminist theorist Karen Barad whose conception of discourse is useful in this case. As she writes:

> Discourse is not a synonym for language. Discourse does not refer to linguistic or signifying systems, grammars, speech acts, or conversations. To think of discourse as mere spoken or written words forming descriptive statements is to enact the mistake of representationalist thinking. Discourse is not what is said; it is that which constrains and enables what can be said. (Barad 2003, 819)

For the purpose of this dissertation, my definition of discourse therefore includes multiple systems of knowing and a wide array of practices beyond just linguistic representation.

Auto-affective media practices provides me a way to conceive of endometriosis discourses and how they are shaped by the work of my research participants and those living with endometriosis more broadly. To quote from Deborah Lupton in her book *Medicine as Culture*, endometriosis is "constituted in and through discourses and social practices that have complex histories" (Lupton 2012).

The term *auto-affective media practices* emerges out of a wide range of fields, beginning again with life writing studies and automedia theory. Much like Foucault, life writing studies has long situated identity as unfixed and continually in the process of development ("identity-as-practice") (Poletti and Rak 2014). Therefore, life writing is not just about representation, but ways of thinking, knowing, and processing both the self and the social world. Although self-representation and language (blogs, Instagram posts, narration, selfies, and so on) are quite prominent in online endometriosis spaces, so too is a broader understanding of the self as a part of a network and social world—"a bricolage or set of disparate fragments" in a broader discourse (Poletti and Rak 2014, 78). Automedia involves "processes of being, doing, creating, and distributing the self, in relationship with media and their affordances, limitations and participants" (Kennedy and Maguire 2018). These practices of representation, being, making, and mediating are all a part of the online endometriosis spaces I write about as well as a key component of my conception of *auto-affective media practices.*

Coming from more of a media studies background, Lee Humphreys coins the term "media accounting" in her book *The Qualified Self* (2018) to describe "the media practices that allow us to document our lives and the world around us, which can then be presented back to ourselves or others" (Humphreys 2018, 9). Like automedia, the concept of m*edia accounting* considers not only how media traces and self-representations allow for self-exploration (both individually and socially), but also how they are circulated and mediated in broader systems. Drawing on a history of women's writing in letters and diaries, Humphreys explores how self-writing has long been used to not only understand the self, but also navigate, understand, and even *shape* the world around us. As she writes,

> For hundreds of years we have used media to talk about ourselves and the world around us. We do this to connect with others, to fulfill social roles and responsibilities, to help us hold on to and commemorate the people and things that are important to us, and to better understand our relational place

> in the world. Mobile and social media help us to this today as our qualified selves are shaped and reshaped through our media traces and our sharing of them. In a very ordinary way, we have found great meaning and connection, in using media to share our everyday activities and experiences. (Humphreys 2018, 28)

Humphreys' *media accounting* captures many of the practices we see happening in online endometriosis communities. This includes connection and meaning-making through every day and ordinary practices of circulation and mediation. It also includes a sense of *accountability* and what it means to possibly take control of a story, put it into conversation with similar stories, and render a system or one another accountable. In the case of endometriosis social media spaces, we will see accountability and, later, response-ability emerge as recurring themes (see Chapter 5: Conclusion).

What is missing from Humphreys' concept of *media accounting* is the everyday affects that drive social media. In both media and life writing studies, the "ordinary" and the "everyday" are used to describe how the habitual practices people participate in can shape meaning and create ethical encounters between people (Wetherell 2012; Gilmore 2012; Ahmed 2013; Chun 2016). Although affect is often talked about in ways that situate it as a practice (such as what affect and the circulation of affects *does*) (Gregg and Seigworth 2010; Ahmed 2013) the clearest definition of "affective practices" appears in Margaret Wetherell's book *Affect and Emotion: A New Social Science Understanding* (Wetherell 2012). Wetherell's "affective practices" or "affective discursive practices" consider the embodied meaning-making practices of people in order to consider how "power works through affect, and affect emerges in power" (Wetherell 2012, 16). She clarifies the more elusive conceptualizations of affect by bringing the body into consideration. She ties affect theory in with neuroscientific research so as to consider the intersections between mind and body or, as disability and trauma scholars term it, the "bodymind"(Price 2015). As she writes, "[b]odies and sense-making are like two sides of the same sheet of paper. So let's study the whole sheets of paper—the affective-discursive practices and affect orders of social life—and take the interwoven phenomena as our units of analysis" (Wetherell 2012, 53). Although she does not draw a connection to disability studies in her text, her move away from the vague circulation of emotions to *embodied* affects connects to the conversations happening within that field.

I finalize my conceptualization of *auto-affective media practices* by tying in the work of disability and media scholar Arseli Dokumaci and her concept of "activist affordances" which she describes as the way disabled people go about "*making up* and *making real* worlds that we were not readily given by *making do with* what we have" (Dokumaci 2023; 2018). These can be understood as a "set of everyday survival techniques that disabled people create within the very constraints and normative environments that are imposed on them" (Dokumaci 2023). As we will see in this dissertation, social media is often used as a survival strategy by people with endometriosis. In these online endometriosis spaces, we see examples of individuals not only making space for their bodies in a world that does not accommodate them, but also toying with the affordances of social media platforms to reshape the representations and discourses that structure their disease. Although the idea of *activism* did not always resonate with my participants, this idea of everyday forms of resistance within media studies, disability studies, affect theory, and life writing is still useful throughout this project. For some of my participants, their practices are simply survival techniques, while for others they are an intentional mode of resistance and advocacy. Most often, it is a combination of both, as I will explore. Regardless, these practices are always relational, meaning that they are always, even in small ways, actively structuring the networks of endometriosis.

My concept of *auto-affective media practices*[22] provides me with a broad and interdisciplinary framework through which to understand the activities of my research participants, including but not limited to practices of meaning-making, community-building, self-representation, knowledge production, accountability, activism, resistance, and advocacy. It is through these practices that the networks endometriosis are mediated and continuously reshaped from a patient-centred approach.

Methodologies

Digital Ethnographic Methods

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[22] For the sake of simplicity, I will often simply use the term "practices" or "social media practices" throughout the dissertation, however I am always referring to *auto-affective media practices,* which are inherently relational.

In order to consider *these auto-affective media practices* in all their complexities, I employed a wide range of digital ethnographic methods. Following in the footsteps of contemporary feminist social media scholars, I used small data methodologies for my research, including qualitative thematic analysis and digital ethnography. Whereas big data analysis often uses algorithms or software to "capture social media data, scrape them, archive them, visualize them, and make sense of them," small, thick, or lively data capture more intimate or qualitative data, such as emotions, affect and/or daily interactions (Luka and Millette 2018). In their article, *(Re)Framing Big Data: Activating Situated Knowledges and a Feminist Ethics of Care in Social Media Research*, Marie Elizabeth Luka and Mélanie Millette (2018) argue that all data, whether small or big, should be analyzed with a consideration for the people behind that data. With my participants who primarily use Facebook, many of their posts are made in private groups and so interviewing them was the only consensual way to talk about their contributions, even if it meant a certain degree of selection bias (Fiesler and Proferes 2018). While the Instagram posts of my research participants are available for data scraping and quantitative analysis, conducting that research on them without their consent is ethically dubious, particularly as many of them have turned to Instagram as a platform where they can talk about their experiences with marginalization, informed consent, and power imbalances within medicine and be heard. That quantitative data would also, I argue, not reveal the most interesting parts of my particular study, as it would give little insight into *why* and *how* my participants interact with social media.[23]

Many of the articles that have been written on the intersections of endometriosis and social media (or even more broadly chronic illness and social media) come at the topic from a quantitative perspective. However, there is a lot that can be discerned from looking at these spaces qualitatively, such as the lived experiences of individuals, the reasons behind their participation, and the systems of meaning they produce. Further, there is a lot

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[23] There has been a good deal of writing on the consent and ethics in online research and there are a variety of methods than can be used (Fuchs 2018; Fiesler and Proferes 2018; franzke et al. 2020). Different topics (such as online extremism) can require different approaches. My methodological approach is based on what worked best for my participants and my approach as a patient-researcher at the time of this work. I am particularly interested in my participants having informed consent around the use of their public content, because of the lack of informed consent in so much of endometriosis care.

that can go missing in big data analysis, such as the smaller details of private or intimate communities. Although looking through the hashtag #endometriosis, for example, may show an overall representation of what is most commonly posted, it does not attend to realities of participating in these communities, the conversations happening between posts, and the work simultaneously taking place offline. Similarly, the use of a platform can change depending on the communities one is observing. For example, in Linnea Laestadius' (2018) article in SAGE Handbook of Social Media Research Methods, she describes Instagram as a platform which is more image-based than text-based. Although this is an accurate analysis of the app as a whole, it does not account for the significance that text can take on Instagram, especially in a context like the one I am studying, where captions and comments are often key components of #endometriosis posts and where much of the connection, self-representation, and conversation takes place.

My study of the public Instagram hashtag #endometriosis and the public-facing Facebook groups included a bit of qualitative thematic analysis to identify what trends existed in these spaces, who to conduct interviews with, and how to structure this dissertation. I immersed myself in these online endometriosis communities throughout my PhD (particularly from January 2019-January 2021) and recorded the themes I saw emerging. The questions I considered were as followed:

1. What visual, textual, and thematic trends exist across these posts?
    a. What are the outliers?
2. What do these users seem to be using these hashtags or pages for?
3. What practices are being used?

These questions led to my conceptualization of *auto-affective media practices* and shape how I structure my chapter breakdown. Although the majority of my analysis focuses on the perspectives and intentions of my participants' practices, I do at times draw on this qualitative thematic analysis to articulate how different posts and trends circulate throughout networks beyond the intentions of their creator(s).

I used the qualitative thematic analysis to code themes in Notion about my own observations and the social media posts of my interviewees, but these were then compared to the codes from my interviewees and survey respondents. This approached allowed me to explore Luka and Milette's proposal that social media scholars should "activat[e] research *with* others rather than conducting it *upon* [them]" (Luka and Millette 2018). When coding the interview and survey results in Dedoose, I focused less on identifying my own themes and predominantly used the participants' own words as codes, meaning that their own answers shaped the research.[24] This meant that I was comparing my own personal reflections and thematic analysis alongside the words and themes identified by my participants when going through my results. I elaborate more on these methods in the chapter breakdown and Appendix 1: Table of Themes. This concept of activating with others in research is not only important within feminist social media research (Luka and Millette 2018; Mendes, Ringrose, and Keller 2019), but is also a key part of patient-centred care, the health humanities, many disability communities, and most endometriosis advocacy groups (Kleinman 1988; Faulkner and Thomas 2002; Titchkosky 2007; Price and Kerschbaum 2016; Gagliardi et al. 2019). Although it was outside the scope of my research project to ask my participants to formulate and write this dissertation with me, their stories do inform and guide every aspect of the work. In fact, my participants sometimes had more experience in research co-creation than I did. Many of them have spent their lifetimes promoting work made from within the endometriosis community, as well as finding ways to accessibly feed that information back to patients. Their networks provided me with a space to not only to share my survey but share my research back to participants when it is complete.[25]

The consistent theme in all these research models (patient-centred care, social media research, disability justice) is the importance of offering individuals an opportunity to express themselves in their own words and create room for empowerment, agency, and/or community. This dissertation is in many ways far less about social media than it is

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[24] Notion is a productivity and note-taking app that I used to organize my research notes, the social media posts I wrote about, as well as my other observations. Notion allows user to create their own "tags" to code content. Dedoose is an app designed for analyzing qualitative and mixed methods research which I used to code my interviews and survey responses.

[25] This dissertation only practices some aspects of community-based research (Access Alliance Multicultural Health and Community Services 2011). Ideally, I would have created a focus group of people with endometriosis to analyze the interview and survey results with me, or even contribute to the writing. I have learned a lot during this dissertation and through my recent work in community organizing. I hope to build upon this research project in the future by conducting more community-based research within endometriosis communities and documenting the community responses to this dissertation as well as the article I published based on this work (Holowka 2022).

the people and communities behind the posts and accounts. Because informed consent was a continual theme that came up in my interviews and research (and is something that has historically been woefully absent from endometriosis research and care) it was important to me that I make informed consent central to my methodologies. Therefore, beyond going through the University Research Ethics Board and receiving the participants' consent before the interviews and survey, I also made sure that to check with my interviewees before finalizing my dissertation to get their consent both on how they are referred to throughout the dissertation and the use of their images. They were also given a copy of the almost-finalized dissertation draft to read so that they could provide feedback if they wished.

Recruitment and Participants

The practicalities of my ethnographic methodology were fairly straightforward, consisting of a series of interviews and surveys with people who have endometriosis and use social media. I focused on the platforms Facebook and Instagram as they seem to be the primary places in which endometriosis discourse takes place (Sbaffi and King 2020). My project was approved by the Research Ethics Board at Concordia University, meaning that all survey and interview respondents consented to be included in this research and I followed specific protocols that included the following: I reached out to ten Facebook groups (including both information-based and support-based groups) and received responses from five. I chose these groups based on popularity, the recommendations from other survey respondents and interviewees, as well as the groups' focuses (for example "Endo Knows No Gend-o" focuses on trans, non-binary, and gender non-conforming people with endometriosis). I then recruited participants by sharing my survey about endometriosis-related social media practices across these five endometriosis Facebook groups, with permissions from the group administrators. I used gender-neutral language in the recruitment material, but did not specifically include calls for diversity. The instances where I did not receive responses were predominantly due to the moderators of certain groups being inactive.[26] I then conducted one-on-one interviews with several of these administrators, 12 individuals with endometriosis-related Instagram pages, as well as any people from the survey who had anomalous results, primarily two individuals who answered that they did not find social media beneficial or positive in relation to their endometriosis. Although I tried to reach more individuals who did not find social media use beneficial, this was difficult because my primary form of recruitment was through social media. I amended my research ethics to try and reach these individuals through the snowball method, but it did not work in this instance. To find Instagram users, I checked the hashtag "#endometriosis" every day on Instagram for two months and followed any related endometriosis pages that the app or other users recommended to me. Some of the other participants were recruited using the snowball method and recommendations from the survey respondents.[27] The interviewees are made up of many of the key informants within endometriosis advocacy and social media spaces, but they also include two individuals who found social media to be difficult and/or unhelpful, as well as those whose experiences varied from the majority of survey responses.

In total, I contacted sixty-two people for interviews and interviewed twenty-three. The interview participants ranged in age from late 20s to late 70s. Nineteen identified as women and three as non-binary or genderfluid. Eighteen of them lived in North America, with the others coming from Israel, South Africa, England, and Ireland. All participants spoke English as at least one of their languages and seven of the twenty-three participants were visible minorities. To qualify for the interview and survey, all participants had to be over 18 and identify as living with endometriosis, although I did not require surgical confirmation. No demographic data was collected from the survey participants.

The survey received 287 responses, although more could likely have been collected with further time and promotion as well as the networks I now have in the

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[26] Some Facebook groups, especially large support groups, are no longer moderated and are a bit like the wild west of endometriosis support. These were often the groups that my survey respondents described leaving or avoiding due to misinformation or conflict.

[27] The limits of the snowball method are that it can lead to selection bias and a lack of generalisability and representativeness (C. Parker, Scott, and Geddes 2019). In the case of this research, and perhaps social media research in general, it also means that the research may end up representing one specific "echo chamber" or community within a broader online community. In the case of my research, the snowball method was used sparingly, but it is possible that the Instagram algorithms also directed my research towards particular online communities based on what was trending.

community. My main site of recruitment was Facebook groups, which all but one of the participants identified as using (99.7%). The other popular platforms they used were Instagram (43.6%), Reddit (16.7%), Twitter (7%), and Tik Tok (3.1%). The survey took approximately 20 minutes to complete and included both multiple choice and short answer questions. Not all the survey questions were mandatory, so some of the results are based on slightly less responses, as will be seen in the figures. I conducted 22 interviews with patients ranging from 30-60 minutes over zoom, using semi-structured, open-ended questions (see Appendix 1: Table of **Themes**

The following table represents all 101 of the themes and topics coded throughout the various parts of my research. The first column "Health and Research Journal" refers to the observations I recorded during my research phase and is what eventually became the auto-ethnographic sections of this dissertation. I coded these thematically so that I could incorporate them into the dissertation later. The "Social Media Posts" column reflects the themes I coded based on various Instagram and Facebook posts I saved throughout the research period from my interviewees. The "interviews" section refers to the interviews I conducted and the "Survey results" section represents all the *qualitative* answers to the survey results. The quantitative data from the survey has been reflected elsewhere throughout the dissertation. I used all these codes in conjunction with the qualitative data from the survey to identify the main themes of the dissertation as well as to structure the chapters.

These themes and ideas were coded using Dedoose and Notion using *in vivo* and values coding. For the interviews and surveys, in most cases the respondents' own language was used where applicable but, as seen below, some of the codes are used as placeholders to connect back to readings and observations I had made (such as "auto-ethnography/life-writing"). The twenty most commonly mentioned codes are: advocacy (beyond self); community (as a descriptor); connection; dismissal (medical); emotion/affect; excision surgery; experiential knowledge and shared experiences; fertility and infertility; hysteria (feeling crazy); information-sharing; isolation (feeling less alone); knowledge; misinformation (from doctors *or* online groups); pain; research (patients as researchers); self-advocacy; self-education (online); support (receiving or giving); surgery (general); and "toxicity" (conflict, negativity). These concepts shaped the structure of the dissertation and helped determine which posts, quotations, and personal observations were included, as I tried to represent the concerns that were most present for my participants, as well as areas that are more often overlooked, such as race, gender, and finances (money/cost).

Coded Themes	**Health & Research Journal**	**Social Media Posts**	**Interviews**	**Survey Results**	**Total Count**
Accessibility of social media			4	7	**11**
Advocacy (beyond self)			52	11	**63**
Alternative medicine	1			7	**8**
Artistic representations of endometriosis	4		5		**9**
Attachment (to disease)			3		**3**
Authenticity			5		**5**
Auto-ethnography/life-writing	7				**7**
Awareness-raising			2	15	**17**
"Big pharma" and pharmaceutical companies	5	8	5	1	**19**
Body image	1			2	**3**
Cancer (comparing to endo)			2	5	**7**
Cannabis use				17	**17**
Capitalism	5				**5**
Caregiving			11		**11**
Community (as a descriptor)	1	3	49	23	**76**
Confidence				17	**17**
Connection			54	71	**125**
Control (loss of)				3	**3**
Cooperation & collaboration	1	2		2	**5**
Covid-19	9			2	**11**
Delay			10		**10**
Depression (because of or separate from endo)			11	15	**26**
Disability	1		6	8	**15**
Dismissal (medical)			30	64	**94**
Doctor experiences (in detail)			33		**33**
Doctor unreliability	12			33	**45**
Emotion/affect	2	2	44	33	**81**
Empowerment			14	11	**25**

Endo belly (symptom)	2		1	8	**11**
Excision surgery	3			87	**90**
Experiential knowledge & shared experiences		2	36	99	**137**
Family (mentions of)	4		5	37	**46**
Fatigue (symptom)	3			17	**20**
Feminism(s)	1	4			**5**
Fertility (infertility)	4		10	50	**64**
Food/diet	2			31	**33**
Gender	4	2	14	20	**40**
Grief		3		2	**5**
Healthcare (commentary on)		1	19	7	**27**
Hopeful (due to social media use)				17	**17**
Hopelessness and despair (due to social media or endometriosis)			10	8	**18**
Hysterectomy/oophorectomy			7	21	**28**
Hysteria (feeling “crazy”)	10	4	36	37	**87**
Identity (in relation to disease)	2	2	16	4	**24**
Information-sharing			32	76	**108**
Inspiration	1			3	**4**
Isolation (from the disease)			11	8	**19**
Isolation (feeling *less* alone)				101	**101**
Knowledge		10	56	36	**102**
Labour	2	4	35	1	**42**
Lupron	1		2	13	**16**
Meaning making			11		**11**
Medical advice online	3		14	5	**22**
Medications, pharmaceuticals	5	6		35	**46**
Mental health	4	2		20	**26**
Misinformation (from doctors *or* online groups)	9		20	40	**69**
Mistreatment (medical)			18	15	**33**
Moderation (of online spaces)	5	1	14	1	**21**
Money/cost	6	6	19	4	**35**
Naming (validation in the name)			10	1	**11**
“Normal”				55	**55**
Not on social media			14		**14**
Orilissa	2			4	**6**

Overwhelmed (by aspects of social media spaces)				35	**35**
Pain	6	5	25	184	**220**
Patient-informed care			9		**9**
Politics	2	5			**7**
Positives of chronic illness			5		**5**
Practices	2		15		**17**
Prevention (helping others)			15	11	**26**
Queer			5	9	**14**
Race	3		4	1	**8**
Reels (Instagram)		2			**2**
Representation		4	21		**25**
Research (patients as researchers)	8		16	56	**80**
Resources & tips			15	35	**50**
Self-advocacy	4		9	48	**61**
Self-education (online)	6	5	26	131	**168**
Selfie	3				**3**
Sexual intercourse (intimacy)	2	1		11	**14**
Sexism (direct mentions of)	1		7	7	**15**
Shadowban		2			**2**
Shared symptoms				32	**32**
Stealing content		1	2		**3**
Storytelling and sharing	5	5	10	20	**40**
Suicide	2			5	**7**
Support (receiving/giving)		2	32	129	**163**
Surgery (general)	6	4	3	51	**64**
Surgical images or “gross” imagery	5			1	**6**
Systemic issues		2		20	**22**
Therapy (psychology)			8		**8**
Thoracic endometriosis	2			8	**10**
“Toxicity” (conflict, negativity)	3	10	54	52	**119**
Transphobia	1	1		9	**11**
Trauma	5		4	1	**10**
Travel (for care/surgery)	2			10	**12**
Trigger warning use	1	1		3	**5**
Understanding (of self or of disease)			4	34	**38**
Validation			18	31	**49**
Work and career				3	**3**
World / change-making			14		**14**

Appendix 2: Interview Questions). One interview lasted over two hours. The questions used for the interview and survey were similar, although the interview left room for more elaboration and included 16 additional questions about Facebook group administration and Instagram for those it pertained to (see Appendix 1: Table of **Themes**

The following table represents all 101 of the themes and topics coded throughout the various parts of my research. The first column "Health and Research Journal" refers to the observations I recorded during my research phase and is what eventually became the auto-ethnographic sections of this dissertation. I coded these thematically so that I could incorporate them into the dissertation later. The "Social Media Posts" column reflects the themes I coded based on various Instagram and Facebook posts I saved throughout the research period from my interviewees. The "interviews" section refers to the interviews I conducted and the "Survey results" section represents all the *qualitative* answers to the survey results. The quantitative data from the survey has been reflected elsewhere throughout the dissertation. I used all these codes in conjunction with the qualitative data from the survey to identify the main themes of the dissertation as well as to structure the chapters.

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Understanding (of self or of disease)			4	34	**38**
Validation			18	31	**49**
Work and career				3	**3**
World / change-making			14		**14**

Appendix 2: Interview Questions and Appendix 3: Survey Questions). The primary focus of the interview and survey were the participants' experiences with endometriosis symptoms, diagnosis, and treatment, what the disease means to them, and why and how they use social media. I also interviewed one endometriosis specialist but include those quotations sparingly, as I was not able to build an adequate sample size representing endometriosis doctors' experiences with social media use.

Overall, people were very enthusiastic to support the project and I was never short on interview opportunities. I made a lot of room for rescheduling interviews in case my participants had flare ups or urgent doctors' appointments, which several of them used. The biggest challenge was finding people with endometriosis who *did not* use social media in any way, particularly because my main source of recruitment was done online. I revised my ethics submission so that I could ask my participants for recommendations of people they might know who live with endometriosis and don't use social media, but still had few results, as the people who had no social media involvement expressed less interest in being researched. Although there is still a fair bit of representation in this dissertation on the negative sides to social media use and opinions from those who use social media very sparingly, all my participants had at least some engagement with social media and that should be considered throughout. This research is a representation of people with endometriosis who use social media but cannot and should not be generalized to the broader population of those living with this disease. Further, the results of my research often represented people with a high degree of media literacy and ability to discern misinformation and does not represent a full picture of all people with endometriosis. Although some of the survey respondents included misinformation, most were extremely knowledgeable about the disease and spoke about discerning between information and misinformation. This is possibly due to the limitations of the snowball method and the recruitment through Facebook groups, both of which can lead a lack of generalizability and diversity (C. Parker, Scott, and Geddes 2019). This research is an important representation of a specific group of people with endometriosis but is not generalizable to all people with endometriosis.

Bias as a Patient-Researcher

Throughout every part of this project, I have been explicit about my bias as a patient-researcher. I was upfront about my own history with endometriosis when engaged with participants. I explained my positionality and my personal investment in this research in both my calls for participation as well as before my interviews. In many ways, this approach made it easier to find participants as I was seen as ‘part of the community’ and trusted as a researcher (at least to a degree). In many of my interviews, people would say things such as “you know how it is” or “I don’t have to explain” which seemed to make it easier for them to summarize their experiences and move onto more difficult topics of conversations. I chose to be upfront about my endometriosis in part because, as Luka and Millette explore, no research is immune from bias, whether relying on big or small data or situating itself in medical literature or the social humanities. The necessary part of working with bias is to bring it into consideration with the research so as to map out the power relations and social complexities that are inherent to the project. Although medical professionals’ and pharmaceutical-funded publications on endometriosis have often been privileged over patients’ advocacy because of their presumed neutrality or rigour, bias is still as much a part of that work (Lenzer 2013). It is possible that, because my interviewees assumed I “know how it is” to have endometriosis that certain things may have gone unsaid. It is also possible that this familiarity created more comfort for them to say things they feel unable to in other situations. To address these contradictions, I bring my bias to the table in this dissertation by using an auto-ethnographic methodology.

This auto-ethnographic methodology is my way of grappling with my positionality as both an insider and outsider to these social media spaces and patient communities. During my research period, I acted mainly as an observer and researcher within these communities but, as I moved into writing the dissertation, I became more involved as an endometriosis advocate and endometriosis content creator on social media myself. I used social media to share my research more accessibly within the community and, in doing so, became much more of an insider within these spaces. Although there was a shift in my actions, for me this positionality as an insider within these communities has always been present as I have never been able to divorce my own experiences with this disease entirely from the stories of my survey and interview participants. I would not have conducted this research in this way if it were not for my role as a person with endometriosis and I do not believe research from outside of the patient experience can account for all the nuances that living with this disease introduces, particularly in endometriosis care where dismissal and mistreatment have been engrained into the very fabric of the disease.

Beyond my bias (and perspective) as a patient-researcher, I also bring my own systemic biases to the table as a white, Canadian, university-educated person with endometriosis. Although I began identifying as non-binary during the process of writing and researching this dissertation, I also know that I am cis-passing and do not mind presenting as a woman in many situations, including doctors' offices. I also often choose to hide my queerness and polyamory in doctors' appointments which is both a privilege and a burden. Endometriosis care is, on the whole, lacking for all except very few, and the barriers to care are only magnified for the most underrepresented groups of people living with this disease, many who may not even know they have it and/or have never heard of it. I have tried to address some of these absences by including the voices of racially diverse, queer, and otherwise underrepresented people with endometriosis, however there are many groups missing from this conversation, particularly Indigenous people with endometriosis, who are often discounted in endometriosis care and advocacy, as well as in healthcare worldwide.

December 8, 2021: I'm a part of this research

I just found out that some of the papers my gynecologist published were funded by Abbvie, the pharmaceutical company that produces Orilissa. I wonder what it meant when she said she could harass the company to send more free samples? She made it sound like she had a certain kind of sway with them. I find myself reflecting on how she keeps referring to the experience of one of her patients to encourage me to take Orilissa – "She has mental health issues like you, and she's doing great. It changed her life." It's interesting that she is using patient experiences here, to justify her prescription. If I used patient experience, even my own experience, to justify my refusal, would it carry the same weight?

The truth is that I don't trust the lived experience she is bringing to the table, just as the participants in Whelan's study didn't trust their doctors, even if I know those one or two successful patients probably do exist (Whelan 2007)*. This doctor lost my trust a long time ago, through previous dismissals. But I also honestly wish I could be that patient and take a magic pill that would help. How suspicious should I be of Dr. X's advice, this drug company? Orilissa is the only option she gives me, so even if I am wary of suicidality and bone density loss, I wonder when I'll just have to give in.*

All this to say: I'm a part of this research. *I've been reading* <u>Googling Endometriosis</u> *today and there's a line in there about how many people with endo experience flu-like symptoms with their periods* (D. B. Redwine 2012)*. I have felt this for so long. I am feeling it right now. I know it's real. But I remember the distinct moment I mentioned it to Dr. X and she said, "that's not caused by endo, that must be something else."*[28] *It's no longer just what I'm reading online. It's what the research says. And yet I don't feel comfortable coming to my doctor and saying, "I have been researching this extensively and you're wrong." Why not? That's a deeper question.*

When I post on Instagram about a small thing where my doctor didn't send my prescriptions through the pharmacy everyone reacts with great sympathy, and I realize that I never talk about this stuff. "This stuff," I say, referring to the awful mistreatments that come with being chronically ill. "This stuff" happens all the time. "This stuff" is so normal for me. I want to bring awareness to it, but I'm also uncomfortable posting about it all the time. I'll be ridiculed for making too much of it. People will get tired of hearing it. People will think I'm malingering. I'll be documented as crazy (again).

Recognizing my own fears only makes me even more amazed by the social media content so many of my interviewees manage to create. Despite—or because of—this dismissal. Where do they get the strength?

Auto-ethnography & Life Writing as Methodology

Following in the footsteps of feminist theorists such as Ruth Behar (1996) and Ann Cvetkovich (1996), I take up life writing and auto-ethnography as the final part of my

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[28] Spoiler alert: the flu-like symptoms disappeared after proper endometriosis excision surgery.

methodology. Like Behar and Cvetkovich, I use self-reflection as a way of accounting for my own subjectivity in this research. Because of my personal relationship to this subject matter, and my own experiences with chronic pain and social media, I believe that it would be unethical to pretend that I am not implicated in this work. My primary goal is to highlight the voices of others while also bearing witness to my own subjectivity and relationality throughout the process. As Behar writes, engaging in this kind of "vulnerable writing" allows the researcher to be upfront about her implication in what she is studying and to ethically engage with these subjectivities and biases. In doing so, she resists an objective claim to knowledge, instead opening a space for the critical analysis of how *knowledge is constructed*. Following the lines of scholars such as Faye Harrison, I use auto-ethnography as not only a method, but as a way of accounting for the hierarchy and power-relations so entangled in the concept of—and networks of—endometriosis (Harrison 1995). I address my subjectivity and positionality head on by including fragments of my research/health journal throughout this dissertation. In doing so, I attend to my bias as well as practice life writing in similar ways to my participants—not only as a way of *knowing*, but also of *thinking* and *processing*.

I do not think it is a coincidence that so many texts on disability, sickness, madness, and endometriosis include the lived experiences of the researchers (Sanmiguel 2000; Cvetkovich 2012; Patsavas 2014; Price 2015; Fritsch 2016; Clare 2017; Dokumaci 2023). Rather, these first-person perspectives are critical citations in areas of research that have too often written over these lived experiences with other forms of knowledge (scientific, medical, political, and so on). As Patsavas writes, "experience is often the most accessible resource disabled people can leverage when it comes to knowledge production" (Patsavas 2014, 206). Vulnerable writing does not mean that "anything personal goes," but rather that the vulnerable—or personal—might at times be critical in informing the research (Behar 1996, 14). The fragments I have included in this dissertation are intentional and specific and are often used to address and negotiate the messier aspects of this research project, where academic writing cannot capture the full picture, or where the work conflicted with my own lived experiences and practices of self-care as someone with endometriosis. I have included these excerpts in areas of the dissertation where things become particularly sticky or messy, or where my own subjectivity and story became a part of the analysis. They situate me within the networks of endometriosis that I write about, while also (in small ways) shaping those networks with my own experience and research. Some of these sections are edited slightly for grammar or clarity, but they are overall accurate depictions of my sentiments at the time they were written. Writing in pain is not always sensical and, although that can be an interesting representation of pain, it often obfuscated my intentions for including the journal excerpts. Perhaps this is due to a lifetime spent trying to be believed and needing to prove myself as reliable. In many ways, the writing of this very dissertation is itself an act of survival and proof.

I referred earlier to my auto-ethnographic excerpts as originating in my "research/health" journal, which I recognize may sound odd. My auto-ethnographic process began as something closer to memo-ing, where I would record my reflections on my thematic social media analysis or make notes of what I was seeing in online endometriosis spaces. In their guide on community-based research, Toronto-based organization Access Alliance describe how memo-ing as a "process of recording observations and thoughts about the data" which can "include impressions, personal reflections, or questions" (Access Alliance Multicultural Health and Community Services 2011). They also argue that memo-ing can be a "rigorous method of naming and accounting for subjective reactions to data" (Access Alliance Multicultural Health and Community Services 2011). For this project, my observations quickly became tied up in my own health journey and began to include details such as my pain levels and how they were preventing me from being able to work. It became clear quite early on that there was no real way to separate my experiences with endometriosis from the research work I was doing in any clear way. Because of this, the auto-ethnographic excerpts that will appear throughout this dissertation will themselves be messy, sometimes more theoretical and observational, and other times quite raw and personal. As a patient-researcher, I believe that all these interventions are not only important ethically but are also necessary in highlighting the importance of lived experience for those with endometriosis.

Although auto-ethnography and memo-ing are established practices in advocacy- and disability-based research, I do also add my own life-writing-influenced narrative touch here. The resulting style may sometimes seem to shift between genres (academic writing and memoir) whereas other times they merge and cross over. This is in part because of my own difficulty situating myself between community-based and academic research, two areas that sometimes speak so clearly to one another and at other times are frustratingly at odds. I do not have answers to this conflict yet, as it is something I hope to explore after I finish this dissertation, focus my energy on my community-based work, and begin adapting this dissertation into something more broadly publishable. For the sake of this dissertation and my writing style, I have used this auto-ethnographic methodology to bring these conflicts somewhat into play. Not to resolve them, but to "stay with the trouble" and explore (Haraway 2016).

Throughout my PhD I also engaged in my own auto-affective media practices on social media. The auto-ethnographic work included in this dissertation extends beyond these pages and into my own life, my own practices, as the sections from my research/health journal explore. My goal has always been to make this research accessible for people with endometriosis, meaning going beyond open-access research publications to share my knowledge through videos and social media content. Although I am never outside of the networks of endometriosis, I have taken a very active role in these networks at times throughout this dissertation, particularly through social media, and have played a small role in shaping the conversation in these spaces. My auto-ethnographic methodology ties into my claims that endometriosis is always networked and mediated, through social media, relationships, cultures, and objects. Social media is not the only messy aspect of this research. Medicine in general is messy business (Mol 2002). Endometriosis in general is messy business and my journey through this research has also been a mess. I began my PhD with one endometriosis surgery and am ending it not long after another. My own relationship to social media has shifted countless times throughout this process, at times helping me stay alive and at other times very literally contributing to the death of those closest to me. Similarly, my relationship to endometriosis, to healthcare, to my own doctors, has been a mess. As someone who has, even throughout this dissertation, depended upon endometriosis social media spaces to maintain my health, I cannot fully disentangle myself from the mess of endometriosis networks, I can only do my best to account for that mess and make room for it within this research.

Messiness

I am not the only scholar who has talked about endometriosis as messy. As Kate Seear writes in her book *The Makings of a Modern Epidemic: Endometriosis, Gender and Politics*, "endometriosis is a disease exemplified by an unusually high degree of uncertainty, mess, and contestation, so that even if it were *preferable* to produce a list of basic 'facts' about the disease, or a neat overview, it would not necessarily be *possible* to do so" (Seear 2014).[29] When people turn to social media to try and understand their endometriosis, things become only messier. Although there are wonderful things that occur within these spaces—that I intend to highlight throughout this dissertation—online endometriosis communities are *far from ideal*. In fact, one of the most significant takeaways from this research is just how inadequate endometriosis care must be that such provisional, experimental, and messy online spaces can become *so* critical to people's wellbeing. The work that those living with endometriosis perform on these platforms is enormous and requires attention. That is why I have structured my chapters around their auto-affective media practices and what those practices accomplish. These practices define the messy networks of endometriosis, they do the networking (the bringing together), and shape what endometriosis (in all its variations) comes to be.

Chapter Breakdown

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[29] Seear elaborated on the topic of mess more recently in her 2021 presentation "Pinning Endometriosis Down: The Need for Ontopolitically-Oriented Research" for the Endo Social Research Network (Seear 2021).

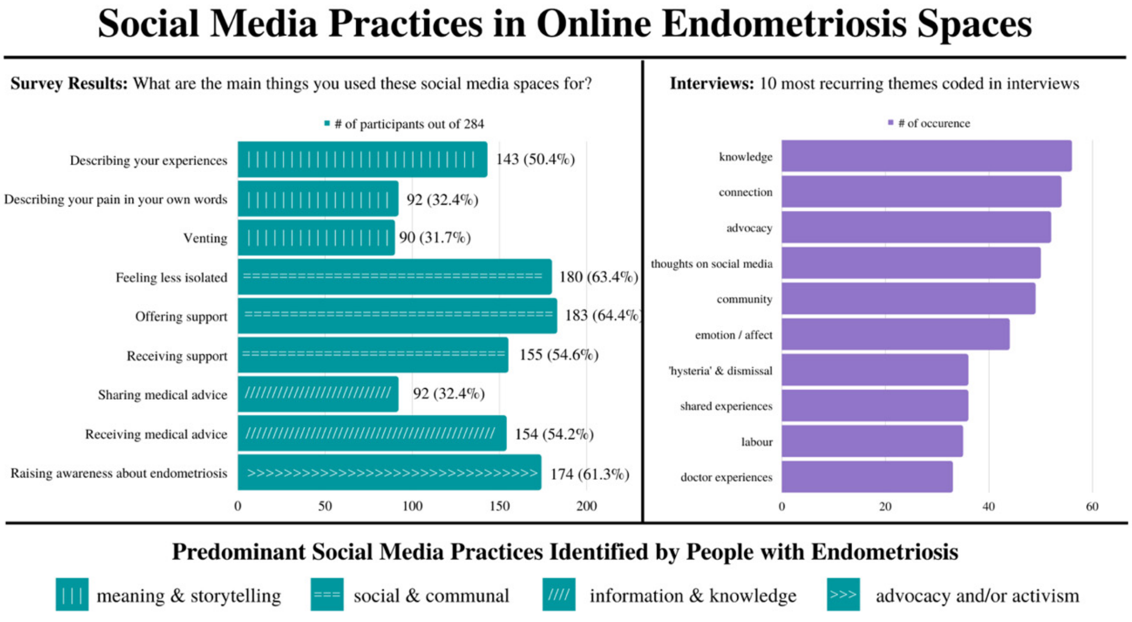

Figure 1: The most common social media practices in online endometriosis spaces, based in thematic coding and survey results. This image was originally published in Frontiers *(Holowka 2022).*

The structure of my dissertation was also based on the results from my surveys and interviews. Both the survey and interview results were coded and analyzed thematically using Dedoose and Notion. Themes were coded using *in vivo* coding and values coding, meaning that participants' words were for the most part used to determine the code names, with some liberties. For example, in the case of code "hysteria," I used this term to demarcate moments where people describe being made to feel "crazy." I used "doctor experiences" to refer to any instance where participants describe their medical experiences in detail so I could go back and read them later. In total, there were 64 codes from the interviews and a total of 101 codes across my research/health journal, qualitative thematic analysis of social media post, interviews, and qualitative survey results. For a full picture and breakdown of all 101 codes, see Appendix 1: Table of Themes. The most common interview codes were: knowledge; connection; advocacy; reflections on social media; community; emotion; experiences and shared experiences; histories of hysteria and dismissal; labour; and doctor experiences (see Figure 1). These results were then compared to the multiple-choice results for the survey question "What are the main things you use these social media spaces for?" Based on these results, I identified four main types of practices: meaning and storytelling practices; social and communal practices;

information and knowledge practices; and advocacy and/or activist practices (see Figure 1).

Participants could select multiple options and almost all of them chose at least two. They could also add their own options which 35 (12.3%) of them did. Most of the added options focused on information and knowledge practices, such as "I just read, read, read!", "finding accurate and up-to-date information about endometriosis", or "tracking my experiences to see early on if my future children were [to] have any issues". A few of the responses added options specifically about seeking or sharing information regarding doctors or surgeon recommendations. Some users specified that they do not post themselves, but mostly just engage with what other people write, which was also reflected in another question where 25.8% of participants said they never post and 19.8% said they post once a week or very rarely. A couple of the additional options also focused on advocacy and/or awareness raising, particularly for "queer and gender diverse people with endo" or to address "insurance discrimination."

My chapter breakdown is structured around these practices, as identified by participants. The other themes and ideas that I coded are represented within these chapters through quotations from the interviews and surveys, or through my own observations and analysis. Chapter two looks at the information-sharing and knowledge-creation social media practices of those with endometriosis. It highlights the enormous workload that endometriosis patients (need to) do and emphasizes how important it is that this labour is recognized within research. Those with endometriosis are often active participants in reshaping their disease and this chapter considers what this knowledge-creation looks like in terms of social media. Chapter three considers the social and communal practices of those with endometriosis. Drawing on affect theory, disability studies, narrative medicine, and feminist theory, this chapter explores the shared experiences, identifications, and feelings of people with endometriosis and how community and relationality play out both online and in our bodyminds. Chapter four looks at the meaning-making and world-building practices identified by the survey participants, such as storytelling, representation, and advocacy. This chapter puts research on pain communication and life writing/automedia in conversation with participants' Instagram posts to explore how posting on social media can pave the way to new futures for endometriosis, whether in the individual bodymind or on a larger institutional scale. In my conclusion, I reflect on the previous chapters and my own journey with this research, as someone who has been deeply embedded in these online communities and my own body, as well as a researcher who has seen a continual rise in dismissal of social media use, particularly when it pertains to the social media practices of chronically ill, mad, and disabled people.

Chapter 2: Networks of Knowledge

It's hard work to be in nook and it's not for everyone.
(Petersen 2020a)

Introduction

This chapter looks at the information and knowledge practices that were identified in the survey and interview results of this research. Comparing these results to the social media posts made by participants shows the revolutionary value that online self-education, knowledge-creation, and information-sharing has had for many people living with endometriosis. However, labour and the "hard work" of being an endometriosis patient becomes one of the primary focuses of this chapter. Despite the positive influences of online self-education and self-empowerment, endometriosis knowledge creation and information-sharing are difficult work, and it is a kind of work that has been historically devalued. These nuanced histories of dismissal are explored in conversation with the complicated notion of endometriosis knowledge using examples from the interviews and analyses of participants' social media posts. As explored in the introduction, endometriosis is a poorly understood and messy disease. This chapter further explores that messiness by showing how endometriosis knowledge is not fixed and that, particularly with the rise of endometriosis social media spaces, there are in fact many conflicting kinds of endometriosis knowledge being produced both on and off social media.

Media Practices: Information, Knowledge, and Labour

> *"Without [social media], I would be largely ignorant and unable to navigate my treatment options. Because of what I've learned on social media, I feel empowered, educated, and able to make my own decisions. The resources available to me have enabled me to take control of my diagnosis and find ways to live better, healthier, and with less pain."*
> – Anonymous survey respondent

This quotation comes from one of the 275 responses to my survey question "What does 'endometriosis' mean to you? Has this changed over time?" Like many of the responses, this anonymous participant describes the ongoing labour involved in living with endometriosis and the knowledge produced along the way. The theme of labour was recurrent throughout the survey and interview results. One interesting outlier to this question was someone who said they used these spaces to promote their GoFundMe. Posts about medical crowdsourcing were something that came up occasionally while I was observing online endometriosis spaces. Usually, these fundraisers were created by a patient or the family of a patient to raise money for surgery. They tended to be in support of people who were living in countries without public healthcare, but occasionally regarded those who were seeking treatment in another country due to lack of access or long wait times in their own nation.[30] Covering medical expenses using crowdfunding websites has become common enough that the GoFundMe website has a page dedicated to "Tips for fundraising for medical expenses."

Medical crowdfunding has been used to not only fund individuals' health needs but also medical research and treatment development, which only further suggests the turn towards the individualization of healthcare, particularly in the United States, Canada, and parts of Europe (Ren, Raghupathi, and Raghupathi 2020). As Lauren S. Berlin and Nora J. Kenworthy have observed, medical crowdfunding "distract[s] from crises of healthcare funding and gaping holes in the social safety net by encouraging hyper-individualized accounts of suffering on media platforms where precarity is portrayed as the result of inadequate self-marketing" (Berliner and Kenworthy 2017). Although medical crowdfunding can give successful campaigners the ability to avoid debt, it simultaneously puts the responsibility of illness back into the hands of the patient, which for people with endometriosis is already so often the case. As discussed in the first chapter, patient-blaming around endometriosis has a long history within medical care. Further, some people are more likely to succeed at crowdfunding than others. As Hil Malatino writes, "very few trans crowdfunding projects meet—or come close to—their goal" (Malatino 2020). Successful crowdfunding requires a strong social network and plenty of social media capital, which requires time and energy to curate.

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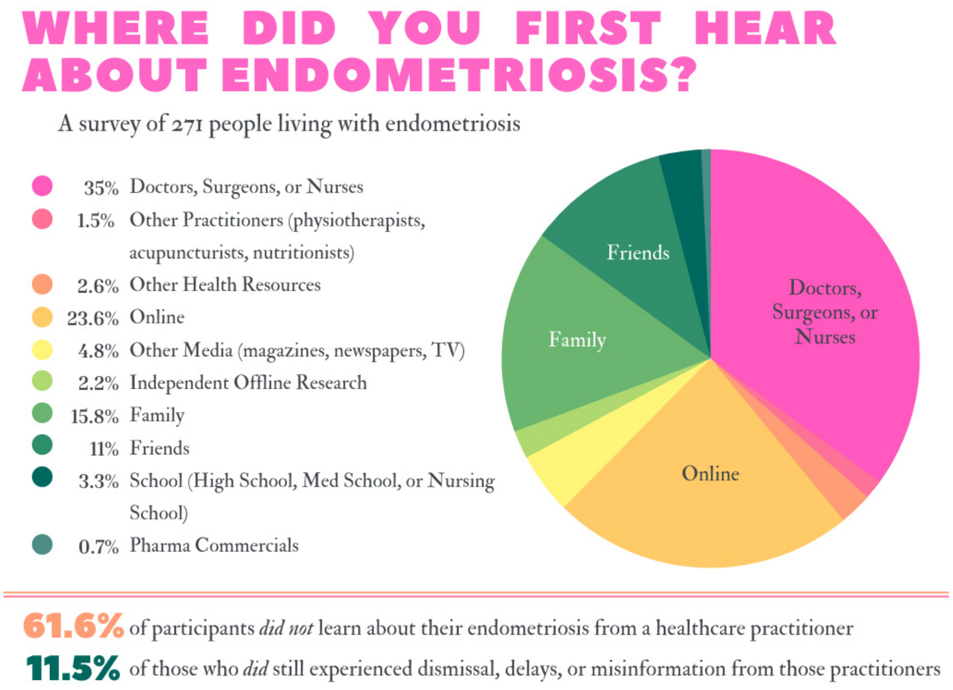
[30] Traveling out of country is a decision many Canadians face due to the lack of specialized surgeons in the country and long wait times (myself included). These limitations have only increased during the COVID-19 pandemic, which led to the start of the "Out of Country Endometriosis Excision Surgery Fund" ("OOC Excision Fund" n.d.). This fund is open to anyone in the world and was started by Christina Paruag, a Canadian who used GoFundMe to pay for an out-of-country excision surgery during the pandemic. She had already waited 4 years for surgery at the time and her kidneys were at risk of failing. When I first wrote this footnote, I never thought I would go out of country for care. Now, as I edit it, I'm three months out from my own out-of-country surgery.



61.6% of participants *did not* learn about their endometriosis from a healthcare practitioner

11.5% of those who *did* still experienced dismissal, delays, or misinformation from those practitioners

Figure 2: Pie chart of where survey respondents identified first hearing about endometriosis.

My survey results revealed a massive communication and information gap between doctors and patients regarding endometriosis. When asked if social media played a role in their process of seeking a diagnosis or learning about endometriosis, 81.6% of respondents said yes, while 3.8% said that social media wasn't around when they were looking for information. 61.6% of respondents learned about their endometriosis from somewhere other than a health practitioner, although some of the online sources people consulted may have been health resources (see Figure 2). 11.5% of those who *did* hear about it from their doctor specifically added (without being asked) that they still experienced dismissal, delays, or misinformation. These results are, of course, influenced by the fact that all the participants were found online. However, the results were still surprising in revealing just how many people found social media beneficial in some way. For example, when asked if their social media use taught them anything new about endometriosis that they did not hear about elsewhere, 92% of respondents said yes (see Figure 3).

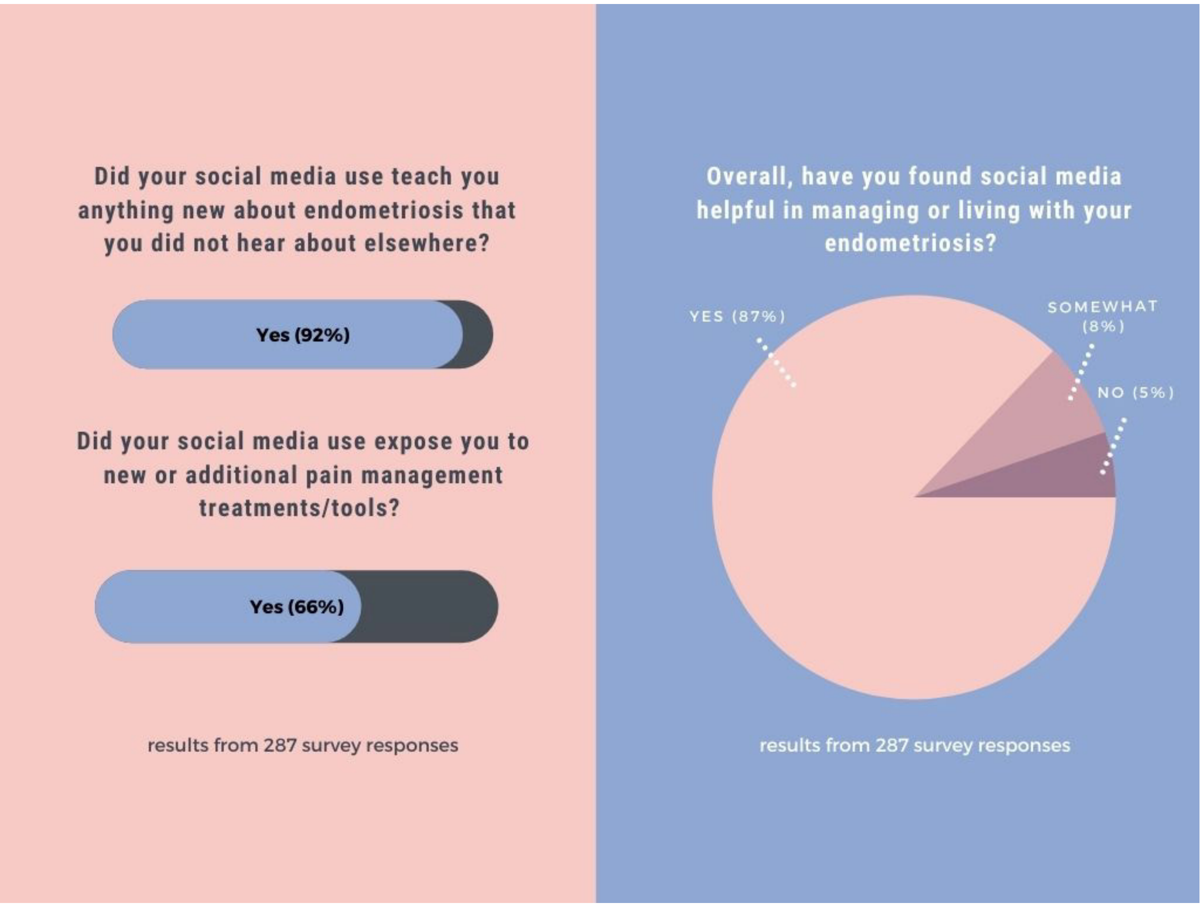


Figure 3: Representation of social media's influence on knowledge and disease management for survey respondents.

What many of these results point to is the labour involved in being an endometriosis patient, particularly, an endometriosis patient online, where knowledge and sometimes even treatment becomes the responsibility of the individual, as I will explore in this chapter. As several scholars have explored, being a woman in healthcare alone requires a lot of work. Although endometriosis affects more than just cisgender woman, the disease is often characterized as a "women's disease." As discussed in the first chapter, the gendering of endometriosis not only makes it less likely to be researched and properly treated, but also means that trans men, non-binary individuals, and genderqueer people with endometriosis often experience further discrimination or misgendering when seeking care[31] (Bauer et al. 2009; Snelgrove et al. 2012; Safer et al. 2016; Stovicek 2018).

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[31] Academic research into endometriosis care for transgender, non-binary, and genderqueer individuals is thoroughly lacking.

In her book *Doing Harm*, Maya Dusenbery identifies two mutually reinforcing problems in the prejudiced treatment of women—"the knowledge gap and the trust gap." She writes:

> Are women's complaints so often dismissed because doctors simply don't know enough about women's bodies, their symptoms, and the diseases that disproportionately affect them? Or are women's complaints so often dismissed because doctors hold an unconscious stereotype that women are unreliable reporters of their symptoms? Is it a lack of knowledge or a lack of trust? It seems to be both. (Dusenbery 2017)

It is telling that Dusenbery's book on the mistreatment of gendered illnesses ends with a discussion of the internet's affordances for dismissed patients. In a section titled "women are a source of knowledge" she describes how well-informed many of her interviewees are about their conditions and available treatments, but that this also signifies how "we are asking individual women to compensate for the medical system's failures." As she writes, "[w]hile some patients may *want* to be partners in their medical care, and the internet has certainly made it easier for some patients to educate themselves, not all women have the vast resources required to become 'empowered patients.' And doing so should not be mandatory" (Dusenbery 2017). Although Dusenbery focuses on women, the knowledge and trust gap she identifies plays out similarly in endometriosis care for trans, non-binary, and genderqueer patients. As this chapter will explore, people with endometriosis often find themselves working very hard to produce knowledge around their condition, whether for just themselves or for others. Although social media has opened up many new opportunities for information-sharing (Kirschning and von Kardorff 2008; Rains 2018; Lupton and Maslen 2019), it has also created new forms of labour for those living with endometriosis, whether they are looking for personal medical guidance or engaged in lifelong advocacy and awareness-raising.

"It's hard work behaving as a credible patient"

In their 2003 article "It's hard work behaving as a credible patient: encounters between women with chronic pain and their doctors," Anne Werner and Kirsti Malterud describe the work patients conduct to be believed, understood, and taken seriously when consulting a doctor. In the face of repeated dismissal, belittlement, and mistreatment, many women find themselves working hard to avoid being seen as "whiners or complainers." The work patients have to do, as Werner and Malterud show, involves maintaining "a subtle balance not to appear too strong or too weak, too healthy or too sick, too smart or too disarranged" (Werner and Malterud 2003, 1409). Those who appear "too young" or "too strong" risk being seen as too healthy or functional to be sick, whereas those who appear "weak" or "disarranged" are more likely to be dismissed as being mentally unwell or quarrelsome. Further, research has shown that when doctors dislike their patients, they are less likely to take their pain seriously (De Ruddere et al. 2011). These observations are also reflected in other studies on those living with chronic pain, gendered illnesses, and endometriosis specifically (Ballard, Lowton, and Wright 2006; Thernstrom 2010; E. Denny 2011; Dusenbery 2017).

During our interview, Wendy Bingham, founder of the non-profit Extrapelvic Not Rare and Doctor of Physical Therapy, Dr describes the mental toll that dismissal took on her:

> I'm a medical practitioner for God's sakes and I [felt like I] was run over by a truck. I couldn't speak up for myself. When I got really really sick I could not speak up and I was scared to death. I could not handle that anymore and I look at women that don't have that background. […] I would get so excited before my appointment and then it [would be] a failure. You get to the point where it's like, why even go? Because they're going to make you feel ten times worse [and it takes so much] energy to get there, especially on a day where you really don't feel good […] And they don't see that. All they see is you. They may see you walk into the office, they don't see you otherwise. (Bingham 2021)

Like Werner and Malterud's article, Wendy's story illustrates the amount of invisible labour that goes into being a patient, particularly a disabled patient, advocating for care and how much importance a single doctor's appointment can carry. Wendy adds that she sees social media providing people with endometriosis tips on how to approach their doctors more successfully. In her own experience, Wendy says she "did not get any care until we were in the social media world."

Dismissal is also commonly experienced by trans men and non-binary people living with endometriosis. Although under-researched, medical discrimination against genderqueer people is pervasive and training to reduce stigma remains limited (Kenagy

2005). In a 2015 study, 80% of gynecologists in the United States were shown to never have received training on the care of transgender patients (Unger 2015). Transmasculine patients are less likely to be tested for endometriosis, partly due to a normalization of their pain as well as the conception that endometriosis is a "female" disease (Shim, Laufer, and Grimstad 2020). One of my interviewees, Les Henderson who founded Endo Queer and identifies as a masculine-of-center lesbian woman, describes her experiences seeking gynecological care during our interview:

> There was just so much disparity. I went to the ob-gyn many years ago and this was just for a simple pap smear and she told me—you know I've loved women pretty much for a very long time [laughs], so I've always been confident enough to know my sexuality—but she says to me, unless you switch teams, meaning unless I switch over to men, I don't even have to come in because I wasn't getting vaginally penetrated, or at least not vaginally penetrated by a 'real' penis. So I was just like, wow, I hope she's not saying this to other lesbians coming in here, or are you saying that virgins who aren't having hetero sex don't need to come here? That was so dangerous and I'm glad I didn't believe her. (Henderson 2020)

As research has shown, chronically ill people, particularly those who are women, trans, or genderqueer, often end up having to negotiate a careful balance between being assertive and convincing, while also not coming across as too emotional or aggressive (Werner and Malterud 2003; Dusenbery 2017). This forced modulation or medicalization of affect and emotion is something that disability scholars have critiqued as a form of enacting control over marginalized people (Kafer 2013; Puar 2017; Clare 2017). Many people with endometriosis or other gendered illnesses describe that they have more success getting through to doctors when they bring a man to their appointment or display 'masculine' traits (Pelletier et al. 2014; Dusenbery 2017).

Further, as discussed in the first chapter, the long-standing myth that endometriosis only affects middle-to-upper-class, white, cisgender women means that anyone who doesn't fit this description is more likely to experience dismissal. Les describes this intersectionality through their own experiences:

> If it's hard for women like you, then okay, I'm black, that's one factor, then I'm masculine-of-centre lesbian, working class. You know I dealt with this with having no insurance, with having Medicaid, and private insurance, and there's a staunch difference. (Henderson 2020)

Each of these intersections leads to more work that people living with endometriosis must do to get care, alongside other things such as seeing multiple doctors, advocating for treatment, tracking symptoms, living and working through fatigue and pain, coping with grief, finding money or navigating the insurance system, and more. Annika M. Konrad's concept of "access fatigue" describes the effort and energy that disabled people are required to perform, often independently, in order to simply get access (such as describing their disability or their needs) and that these efforts are "intertwined with axes of oppression and privilege" (Konrad 2021, 181). Following Konrad, I argue that naming and identifying the labour that people living with endometriosis perform solely to survive can reveal the areas in which endometriosis care is not only lacking, but *further disabling* those living with this disease. It is a common belief in endometriosis advocacy communities that earlier diagnosis and improved access to excision surgery could greatly reduce the likelihood of endometriosis becoming a long-term disability.[32]

It's Hard Work Being an Endometriosis Patient

For many people with endometriosis, the first and sometimes most difficult step is just being believed (Cox et al. 2003). A recurring theme throughout my interviews and surveying was how long it can take someone with endometriosis to find a doctor who will believe their symptoms and this is likely a major factor in why the delay in diagnosis for endometriosis averages around 7.5 years worldwide (Hadfield et al. 1996; Arruda et al. 2003; Ballard, Lowton, and Wright 2006; Nnoaham et al. 2011; E. Denny 2011). One of my participants Casey Berna, a social worker and endometriosis and fertility advocate, told me how she had to lie in order to access treatment for her struggles with endometriosis-induced infertility:

> I went to my gynaecologist who told me I was too young to be dealing with infertility, that painful periods were normal, that maybe I was just too stressed or just too obsessed with having a baby and I said, "you know I'm going to need a referral" and I lied to her and said that I had been trying for a year because I read up that if you were my age, at 26, unless you were trying

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[32] There are ongoing efforts to make endometriosis more easily diagnosable through blood tests, ultrasound, and other techniques. This is also something that is controversial in some endometriosis advocacy spaces, not because earlier diagnosis is undesirable, but because these efforts tend to lead to the decreased access to excision surgery to remove existing endometriosis, something that is already extremely difficult to access.

> for a year they wouldn't refer you. So I lied. And I insisted upon a referral. (Berna 2020)

Casey had been living with GI symptoms caused by intestinal endometriosis for years that doctors had dismissed as a "nervous stomach".[33] She had seen numerous specialists for her infertility and other symptoms but, even when her endometriosis was eventually diagnosed, it wasn't properly treated. She describes the toll that this medical dismissal took on her during one occasion:

> I broke down [in the doctor's office]. Like, I'm a social worker, I'm solid. I did crisis counseling post 9/11 on survivors. I am a hearty person and I just started hysterically crying so that one of the other doctors took me in a room because I was making a scene—like hysterical—in the main room. (Berna 2020)

Casey's use of the word "hysterical" here is significant, as her hysterical crying is not something that originated within herself or her "wandering womb" (as myths around hysteria would suggest), but rather was a direct result of mistreatment.

Female hysteria? Why yes, being misdiagnosed time after time does make me hysterical.

@THE ENDO MONOLOGUES

theendomonologues Consider me hysterical all the time.

[Please credit if reposted.]

#endometriosis #adenomyosis #obgyn #chronicillness #spoonie #chronicallyill #chronicpain #menstruation #fertility #infertility #fertilityhealth #menopause #ttc #polycysticovarysyndrome #pcos #ovariancyst #ovariancancer #reproductivehealth #sexualhealth #menstrualhealth #pmdd #periodhealth #pelvichealth #perimenopause #theendomonologues #invisiblepain #butyoudontlooksick #invisibleillness #invisibledisability

Liked by **cbdnaturae** and **734 others**

FEBRUARY 20

Figure 4: February 20, 2021 post by @TheEndoMonologues

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[33] This description alone evokes historical diagnoses of hysteria and other "nervous conditions" that were regularly given to explain women's pain or displeasure (Guidone 2020a; Mollow 2014).

This subversion of hysteria is reflected in a post by another one of my participants, LP. Writing under the username @TheEndoMonologues (a play on *The Vagina Monologues*), LP's posts include diary entries from her uterus and images featuring sarcastic and witty commentary on life with endometriosis. In one of her posts, an image with text reads: "Female hysteria? Why yes, being misdiagnosed time after time does make me hysterical" (see Figure 4). As with Casey's story, LP's post redirects hysteria back towards the medical system itself. Both of these participants show how it is often the act of being dismissed as hysterical *itself* that causes the so-called 'hysteria' of having an emotional response to mistreatment (Guidone 2020a; Werner, Isaksen, and Malterud 2004; Mollow 2014).

Endometriosis patients are already more likely to have their symptoms dismissed as anxiety or other mental health disorders (M. Ballweg 1997; Cox et al. 2003). This is problematic on multiple levels. For one, mental health is too often used to dismiss patients for reacting in reasonable ways to their continual medical neglect, as both LP and Casey experienced (as well as almost all my other interviewees) (Young, Fisher, and Kirkman 2019). Further, diagnoses such as depression and anxiety are common comorbidities in people living with endometriosis, meaning any reasonable treatment plan should include care for these conditions, not dismissal (Estes et al. 2020). In a BBC study of more than 13,500 people living with endometriosis, half said that they had suicidal thoughts (Bevan 2019). Not enough research has been done to determine whether anxiety and depression exist in relation to the endometriosis itself (possibly due to hormones, inflammation, or prolonged pain) or as an outcome of the disabling medical system. As many endometriosis researchers have explored, the spectre of hysteria, although long-disproved, lives on in contemporary endometriosis treatment (D. B. Redwine 2012; Seear 2014; C. E. Jones 2015; Guidone 2020a). As Gabrielle Jackson writes in her book *Pain and Prejudice*, "deep in the collective knowledge of women is that doctors have the power to label them as 'crazy' or to dismiss them entirely, notions that scare many sufferers out of seeking treatment" (G. Jackson 2019; Young, Fisher, and Kirkman 2019). The same can be said for people with endometriosis of all genders.

In a fascinating recent article called "Do Mad People Get Endo or Does Endo Make You Mad?: Clinicians' Discursive Constructions of Women with Endometriosis," the authors explore how entrenched the hysteria discourse is for many clinicians. The title quotation, "do mad people get endo or does endo make you mad? It's probably a bit of both." comes from one of the article's interviewed clinicians. The article breaks down how clinicians view "good patients" as those who accept their judgement, while "difficult patients" are those who "mak[e] endometriosis the centre of their biographical narrative even though the clinician did not perceive the women's disease to be 'severe enough' to warrant this, and [use] endometriosis as an excuse for their own inadequacies" (Young, Fisher, and Kirkman 2019, 351).[34] The article furthers existing evidence that those with endometriosis who react negatively to their disease are quickly viewed by clinicians as hyperbolic or hysterical, rather than appropriately distressed. It also reveals that clinicians are not necessarily implementing patient/person-centred care practices (such as shared decision making in chronic care) if they believe that patients who disagree with their recommendations are "difficult" (Zoffmann, Harder, and Kirkevold 2008).

Kate Boyce, co-owner of the misinformation-dispelling blog and Instagram account @EndoGirlsBlog, tells me about her own fraught journey with birth control, mental health, and dismissal during our interview:

> I'm 18 at this point and finally trying birth control and it's not working. It makes me insane. Nobody believed me that it made me crazy. "Oh, birth control doesn't cause that." And meanwhile I'm like, *okay*? I'm in a relationship with someone who's telling me I'm crazy, my friends are like, "what's wrong with you?" So then I started drinking and—I'm a recovering alcoholic—I drank my way through my pain. And I have a hard time because I see all these endometriosis patients suffering and trying to manage their pain and I get asked, "what did you do?" And I'm like, "I drank." And it worked. But I can't tell you to do that. And I did, I just blacked out drunk. And people say, "[alcohol] makes me flare" and I say, "that's why I was an alcoholic." I drank 24/7. I stayed drunk or at least tipsy to dull that pain. So that's how I managed through my late teens until [I was] about 24 or 25. (Boyce 2020)

Kate's story reflects the experiences of many people living with endometriosis who are offered hormonal treatments for their symptoms but find themselves unable to tolerate

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[34] One of the interviewed clinicians uses the phrase "endometriotic cripple" to refer to "difficult patients" (Young, Fisher, and Kirkman 2019). His use of the derogatory term does not validate the disabling aspects of endometriosis, but rather implies that the patient is disabling themselves through their attachment to endometriosis. This is, unfortunately, a commonly held narrative, and one that I return to in chapter four and the conclusion.

them. Although some people do benefit from these medications, others find themselves unable to take them due to negative side effects which often include mental health symptoms such as depression, irritation, or even suicidality (Skovlund et al. 2016; Rafique and DeCherney 2017; Grandi et al. 2019).[35] When patients push back against this treatment, they are often labeled as difficult, even though these side effects are well-documented (D. Redwine 2003; Johnson et al. 2013; Brown and Farquhar 2015; Skovlund et al. 2016). More research on the effectiveness of hormonal contraceptives, progestins, and Gonadotorpin-releasing hormone (GnRH) agonists and antagonists has yet to be done, however reports of negatives side effects are common in online endometriosis spaces, possibly because people who experience side effects are more likely to go online looking for alternatives. As Kate Seear writes in her book on endometriosis, one of her interviewees "vividly detailed how, after commencing treatment, she became so depressed that she fantasised about slamming her head through plate glass so as to end her mental anguish" (Seear 2014, 127). Whereas an emotional response to mistreatment results in the patient being dismissed as 'too emotional,' when it comes to treatment, patients' emotions *themselves* are often dismissed (Cox et al. 2003). Either way, the responsibility is once again placed on the patient instead of on the western medical system which so often neglects to treat the body and mind in tandem.

Kate's story also reflects the many people with endometriosis who develop maladaptive coping strategies, usually alongside adaptive ones (Zarbo et al. 2018). As both Seear and Sanmiguel's social scientific approaches to endometriosis identify, people living with the disease are asked to self-regulate an unreasonable amount of their lives to avoid their symptoms—symptoms that sometimes cannot be self-controlled regardless of efforts. They are expected to hide their symptoms and told to regulate their emotions, control their diet, reduce stress, exercise, and even avoid all toxins (Sanmiguel 2000; Werner and Malterud 2003; Seear 2014; Dusenbery 2017). As Seear writes, people with endometriosis are sometimes even told to avoid these "risks" if they want to prevent endometriosis in

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[35] The side effects of treating endometriosis symptoms with medication can impact more than just mental health, however I focus on mental health here to illustrate a particular kind of medical bias that is tied to the history of hysteria. Although hormonal treatments and medications are helpful for some people with endometriosis, the negative mental side effects of birth controls and GnRH antagonists/agonists were a recurring theme in my interviews and surveying, as well as (to be completely frank) my own life.

their children and families, placing not only the responsibility of their own illness in their hands, but also of their descendants (Seear 2014). Both Seear and Sanmiguel critique the ways in which the blame for and responsibility of endometriosis is so often put onto patients. Although their analyses end in the early 21st century, in many ways their observations remain true today where the individualized focus on self-empowerment perpetuated on social media can end up disguising the bigger systemic failures in endometriosis care, as I explore in the following examples.

Sometimes this displacement of responsibility seems to emerge out of bias or misinformation. As endometriosis Instagrammer and patient advocate Madelyn Morneault explains in a blog post, one of her physicians blamed her endometriosis on her touching her own body:

> [The doctor] continued his interrogation and asked how I noticed the bulge [on my cervix] (note: he is acknowledging that my cervix is bulging even though he previously declared it "normal"). I began explaining that when I couldn't physically fit the suppository into my vagina due to the swollen bulge and a couple of small nodule-like lumps, I inserted my fingers without the suppository; flustered that there was something blocking my vaginal canal. I told him how I grabbed a mirror and began to feel around just to see if I could examine it. As soon as I said that it was as if I handed him a golden ticket; a justification for all my pain that he couldn't explain. An avenue in which it was all my fault:
>
> *Oh you really shouldn't be giving yourself exams.* ***You can't do that, it can cause problems.*** *You know, this can happen with a lot of girls, they start looking around and they notice things that they haven't before and get scared. That can also cause irritation and swelling so I recommend you don't continue…* (Morneault 2020, emphasis as written)

In her blog post on this incident (which she also brought up in our interview), Madelyn describes how the doctor then went on to question her mental health and suggest that her dropped cervix and endometriosis-inflamed vaginal canal were somehow both "all in her head" and caused by her exploration of her own body.

Other forms of patient-blaming are more subtle and systemic. Buzzfeed deputy directory Lara Parker describes in her book *Vagina Problems: Endometriosis, Painful Sex, and Other Taboo Topics* how exhausting and mentally detrimental it was for her to constantly monitor her own behaviours to reduce pain and how that spiralled into unhealthy self-blame:

> If I enjoyed a cookie at an office get-together with coworkers, I would spend hours afterward staring at my list and telling myself that it had to be my fault that I was in pain […] This self-blame became toxic […] and what was becoming increasingly clear above all else was that I could do absolutely everything right—I could avoid soy, never touch almond milk, not eat an ounce of sugar or ever let caffeine touch my lips, walk slowly and in the right shoes while doing my stretches afterward—and I would still be in pain. (L. Parker 2020)

Although things such as anti-inflammatory diets, exercise, and self-monitoring can be beneficial to those living with endometriosis, they are also not always achievable and involve access to a lot of resources such as nutritionists, (pelvic) physiotherapists, mental health supports, money, education, and more.

For another example, consider this passage from Jessica Drummond's book *Outsmart Endometriosis: Relieve Your Symptoms and Get Your Career Back on Track:*

> To work at your highest level as a person with a chronic illness, you have to think of yourself as a 1950s white male executive. […] Imagine you're a Mad Men-esque marketing executive. […] Perhaps you can delegate *all* housework, cooking, and shopping for the next two years or so as you heal. Perhaps you can hire an intern or work assistant to help you do background research and event planning, or schedule all of your appointments. You're likely doing something in your life that doesn't one hundred percent have to be done by you. If there is anything you can delegate, this is the time to take it off your plate. I know it's not easy […] This phase is not forever, but it's generally between six and twenty-four months, and can be a bit longer depending on if and when you have surgery. (Drummond 2021)

Although the suggestion to delegate and reach out for help is an important one, the implication that anyone can imagine themselves to be a 1950s white male executive and thereby have the same resources and privileges is a bit far-fetched and out of touch with the lived realities of most people with endometriosis.

Sometimes the shift towards placing responsibility in patients' hands comes from a place of genuine encouragement towards self-education and self-empowerment for patients. However, as the example from Parker shows, the line between what one person considers empowering and another finds dismissive can be very slim and subjective. This common focus on self-management and empowerment in endometriosis care is something that both Kate Seear and Lisa Michelle Sanmiguel identify and criticize in their feminist studies on endometriosis (Sanmiguel 2000; Seear 2014). Sanmiguel describes how many of the endometriosis treatment centres available in the 1990s/2000s claimed that "improvement from endometriosis [can] only come from women's dedication and full participation in health care," but questions whether everyone with endometriosis is able to perform that kind of commitment and what it means if they can't (Sanmiguel 2000, 312). Despite these critiques, 21st-century endometriosis management still tends to rely on the individual's own self-education and advocacy, particularly as western healthcare systems become more and more individualized. By placing the responsibility of self-education on the individual, the broader systemic failures of the medical system are easier to disguise. Despite being helpful in some cases, self-education and self-empowerment are both "technologies of power" that keep individuals focused on individuality instead of systemic change (Foucault 1988). Although some advocacy groups focus on bigger systemic changes such as improved endometriosis education in medical schools, generally patient self-education remains one of the main (or only) tools in which to manage or live with endometriosis for the time being. Self-education and self-empowerment are also some of the main focuses in online endometriosis spaces. Empowerment requires access, knowledge, and time that not every person shares. Self-education can also feel less empowering when it is done out of necessity and a lack of other options or access, as was also shown in an ethnographic study of women living with Multiple Sclerosis (Sosnowy 2014). However, what is interesting about online endometriosis spaces is that they can also allow for some of this labour to be shared and distributed.

Although empowerment remains a complex aspect of the patient experience, it did come up as a recurring theme in my both my survey and interviews, often in correlation with self-education and information-sharing. Stella Bullo observes that disempowerment tends to come from a "perceived lack of agency over achieving diagnosis and knowledge of the condition in order to understand and learn coping strategies" (Bullo 2018). Patients who experience regular dismissal have been shown to turn to internet-based self-education as a way of "proving" their illness to their doctors (Dumit 2006). Because of this, many of my interviewees explained how they often felt more informed than their doctors about endometriosis. Parker mentions this in her book as well:

> I am not a doctor. I am not a researcher. I did not go to grad school. I barely graduated from college. I struggle to comprehend basic medical studies. I

> mispronounced the word ‘anatomy’ until last year. But I am confident in saying that I know more about the pelvic floor—and how to treat pelvic pain—than 90 percent of the doctors I have seen in my lifetime. And I’ve seen a lot of doctors. (L. Parker 2020)

Although self-education and self-empowerment can be taxing and fraught, they are also two of the most common strategies for receiving care for endometriosis and chronic illnesses more generally.

Further, empowerment is one of the key factors in patient-centred care and the improvement of chronic illness care. Online endometriosis communities can help patients access certain aspects of patient empowerment, including: control, power, participation, support, knowledge and understanding, and psychological coping (Bennett, Bergin, and Wells 2020). Other aspects, such as shared decision-making, collaboration with service providers, and changes to the healthcare system are factors that social media can sometimes offer tips and tools for, but are more often beyond the scope of online participation (Greene, Tuzzio, and Cherkin 2012; Bennett, Bergin, and Wells 2020). In other words, social media can help with facilitating patient-centred care from a patient empowerment perspective, but not always in ways that change the patient-practitioner dynamic, as I will explore more in chapter four.

Self-empowerment and self-education are often tied in with taking care of oneself and trying to create better access to care in the future. In this way, social media practices can themselves be acts of self-care (sometimes even with therapeutic benefits) (Shoebotham and Coulson 2016).[36] Self-care can be a critical part of managing endometriosis, but it also has limitations that require more community-oriented and clinical forms of care (Lakshmi Piepzna-Samarasinha 2018; Leonardi et al. 2020). Much like self-empowerment and self-education, self-care can also operate as a technology of power and a tool of capitalism that distracts from systemic failures and power imbalances, keeping individuals disabled and controllable (Foucault 1988; Puar 2017; Lakshmi Piepzna-Samarasinha 2018). In many endometriosis social media spaces, self-care is commodified as a product you can buy to ‘feel better.’ With that said, self-care can also be a form of ethical engagement with the other, where taking care of the self facilitates taking

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[36] See my colleague Fanny Gravel-Patry’s work for more on self-care and social media.

care of others (Foucault 1997; Lakshmi Piepzna-Samarasinha 2018). There are ongoing debates about the role social media plays in self-care and mental health, with valuable concerns on all sides (Gravel-Patry 2021; Spratt 2022). As I will explore more throughout this dissertation, endometriosis social media spaces *can* provide tools for taking care of one's own bodymind in ways that are comparable to both the physiotherapy and psychotherapy approaches used with those who have endometriosis and medical trauma, particularly through meaning-making practices. They can also create space for community care. The stronger people with endometriosis become physically and mentally, the more collective power they wield to create systemic change. I explore these topics more in chapters three and four.

November 23, 2020: The toll of self-advocacy and self-care

I'm just reflecting on the absolute lack of confidence and complete insecurity I have around facing doctors. And I'm realizing the full extent of my medical 'trauma'[37] *and how I've been doing appointments for endometriosis symptoms since the age of 10. To the gastroenterologist who didn't think of endo. To the gynecologists that didn't mention endo. It dates back to my youth, to being left in a doctor's office for hours and forgotten about. It was the first time I'd gone in without my mom and it was awful. I've been forgotten in a room at the hospital since. I didn't even make the connection between those traumas until now, writing this.*

Today I have therapy and I'm going to donate the entire session to preparing for my call with the Dr. X on Thursday. I also posted for advice on the Endométriose Québec group (partly because it's one of the only groups not associated with my research and thereby the only one I feel comfortable asking for advice in— I've sort of screwed myself there).[38] *Both R & L offer advice that I need to be assertive, insistent, even annoyingly so. I know they both are trying to help — are, in fact, helping — but even the thought of doing that self-advocacy*

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[37] I've left trauma in scare quotes, because that is how I wrote it, and I think that's telling.

[38] For further context, this group was excluded from my research because it is predominantly in French. Which meant that not only was I struggling to get care from my doctors in English, but I also had to use my wobbly French to try and ask questions about endometriosis until I grew my own English-based Instagram community I could rely on.

makes me ill. I plan to talk to the doctor with statements such as "everyone around me is telling me I'm not advocating for my symptoms enough" or "I know this might sound crazy, but..." The idea of going in and saying, "I've read this medical journal and can vouch for the credibility of my symptoms" seems impossible.

I worry that maybe I'm caught up in social media and I'm not being objective and critical enough about my symptoms. Maybe I'm making it up, conflating regular symptoms with something more serious? See, I'm convinced already that I'm crazy. I come into the doctor's office already ready to concede and it makes it so much easier for them to jump on board with it. Do they know how crazy we already feel? Do they understand just how engaged, how informed, how desperate we are? If not, how do we tell them?

The Case of Nancy's Nook

With the growing accessibility of the internet, social media and websites have become two very common places for folks with endometriosis to access information and education about their disease (Sbaffi and King 2020). I mentioned earlier how books on women's health often end by gesturing towards the educational affordances of social media, and the same is also true for many of the existing endometriosis books and articles (Sanmiguel 2000; Dusenbery 2017; Hustwaite 2021). As Sbaffi and King's survey of 895 endometriosis patients shows, Official Endometriosis Organization Websites and Facebook Groups (whether associated with endometriosis organizations or not) were the primary preferred sources of online endometriosis information, over medical websites and even medical journals (Sbaffi and King 2020). The most popular of these (and this is reflected by my own survey results) is a Facebook group called "Nancy's Nook Endometriosis Education."

Nancy's Nook Endometriosis Education, called "Nancy's Nook" for short, is one of the most popular social media resources used by people living with endometriosis (Sbaffi and King 2020). Out of the 98% of my participants who identified as belonging to endometriosis-related Facebook groups, 87% used Nancy's Nook, as did the majority of my interviewees. Nancy's Nook was started in November 2012 by Nancy Petersen, an endometriosis advocate and now-retired nurse. It originally grew out of a virtual patient group but, after becoming difficult to manage on a website, moved to Facebook. What started with just 200 members has continued to grow, passing well over 100,000 members during my research period.[39] These members include patients, caregivers, advocates, and even doctors and other clinicians. Nancy's Nook focuses on the importance of self-education and provides an enormous archive of files with information on everything endometriosis related. Because of its strict focus on information-sharing, Nancy's Nook has clear rules and guidelines for admission into the private group. At the top of their "About" page, they provide the following "Group Purpose and Terms of Service":

> Our purpose is to educate patients, practitioners, and their loved ones about endometriosis with evidence based information and resources. Our members include endometriosis patients as well as physicians, other healthcare practitioners, husbands, partners, parents, and friends. This is not a support group and we do not provide medical advice.
>
> Upon admission, please read the pinned post and links as well as files, which are essentially a resource library that will answer many of your questions.

People who are admitted into the group are asked not to post anything in the discussion page for at least one week, to encourage them to first go through the existing resources. Posts that are made on the discussion page are vetted by the admins before going up, to rule out misinformation or content that would be more appropriate for a support group.

These limits of use are frustrating to some people, especially those who have already come across many barriers to their care and are desperate for support and not willing or able to commit to self-education.[40] Every so often Nancy or another one of the admins will make a post reiterating the focus of the group and the rules of participation. These posts often emphasize the size of the group, how the admins are unable to answer every question, and why comments need to be closed to prevent misinformation. Beneath

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[39] As of January 2023, they have over 168,000 members, almost double the amount they had during the start of my research. Nancy tells me by email that many who come to the Nook are now being referred by their physicians.

[40] Although my research project did not focus on the social media platform Reddit, I did keep track of the two major endometriosis communities there: "/r/endo" and "/r/endometriosis". In these communities, there are semi-regular posts (at least one or two a month) expressing frustration around the limits of Nancy's Nook. This is perhaps also one of the reasons behind two much smaller Facebook groups: "The Truth about Nancy's Nook" and "THE TRUTH ABOUT 'The Truth About Nancy's Nook'." The former claims to raise awareness about the people who have been hurt by Nancy's Nook, while the latter claims to provide a safe space from the hate and death threats that appear in the former. For more on the complexity of online community spaces such as this, refer to my third chapter.

one of these posts, Nancy comments: "It is hard work to be in Nook and it's not for everyone." Although this post might come across as harsh to someone who is looking for support, the perspective within Nancy's Nook is that self-education takes a lot of work and not everyone with endometriosis is going to want to (or be able to) do it.

In talking to Nancy during our interview, she explains how her team is more than happy to refer people to support groups if that is what they are looking for. She recognizes that Nancy's Nook cannot meet everyone's needs:

> [The focus on self-education is] frustrating for some of the members, they don't want to have to do that. And yet with 106,000 members right now, [even] with not allowing free posting, we handle about 40,000 posts a month. If we were wide open it would be impossible. (Petersen 2020a)

Not only is it "hard work to be in Nook," it is also hard work to *run* the Nook. Nancy, who describes herself as "pushing 80 years old" says she puts 60-70 hours a week into moderating and running her Facebook group, even with other moderators and admins involved. In our interview, she expresses concern over what happens when she is no longer able to do this labour. Her and her team want to avoid putting that workload onto someone else, while also preserving the enormous archive of research that Nancy's Nook houses. On January 29, 2021 the team behind Nancy's Nook launched a website (NancysNookEndo.com) that will hopefully make the dissemination of this information more manageable going forward.

Although Nancy's Nook created a centralized and relatively accessible space for people living with endometriosis to access all the most recent research around their disease, as well as to be in conversation with expert doctors and clinicians, the fact that this level of education is even necessary reveals some of the massive problems that persist in endometriosis care. As Nancy tells me, the group cannot address all of these problems:

> [Our group members] can't all access expert surgeons and that's a real frustration for me, there aren't enough of them. And many of them don't get paid well enough for the job they do so they go out of network and they have to charge above of what insurance is willing to pay. […] we don't have anywhere near enough surgeons to deal with the 106,000 patients I have, let alone the 8 million in the United States who aren't getting what they need. (Petersen 2020a)

Nancy's Nook offers a partial solution to some of these challenges by creating a space where people living with endometriosis can learn about available treatments, endometriosis specialists, and how to advocate for their own care. But Nancy's Nook alone cannot address the bigger gaps in endometriosis education and care.

Further, for some people with endometriosis, the idea of needing to seek out information online to become an empowered patient is less appealing or viable. There is a large presence of people in online endometriosis spaces who do not like the Nook because they aren't able to access any specialized surgeons, aren't good candidates for surgery, do not have the time and resources to spend hours reading through all the material on the website, or simply don't like the structure of the group. While Nancy's Nook has been a life-changing group for some people, including many of my survey respondents, it is also volunteer-run and unregulated, meaning that there are limits to how much the space can offer.

It's Hard Work Being an *Informed* Endometriosis Patient

Nancy's Nook is just one example in a much larger picture of the available archive of endometriosis information on social media. April Christina, a blogger and New York City-based endometriosis and women's health advocate tells me during our interview that she believes:

> Social media has definitely created another form of research. People can go to WebMD and other stuff like that but I feel like that's more for the older generation. Even with TikTok […] there's so much education now, why would you not utilize these different social media platforms? (April Christina 2020)

The amount of information available online about endometriosis is overwhelming. All my participants who had been working in endometriosis advocacy before the rise of social media and Web 2.0 commented on how much easier it is to access information thanks to the immediacy of social media. That said, an enormous challenge to being an endometriosis patient online is navigating misinformation. While the immediacy of social media provides the opportunity to quickly challenge misinformation, it also allows for that misinformation to spread just as fast. Many of the participants I interviewed described spending a lot of their time and energy trying to dispel this misinformation. Even the act of simply trying to find out *what endometriosis is* (the accurate definition) can take an enormous amount of work.[41] Endometriosis is often mischaracterized as a uterine disease that only affects cisgender women and reproductive organs, as seen in the millions of representations of angry uterus drawings across social media. Further, endometriosis is often misrepresented as something that only affects white people, which is one of the reasons that April Christina started posting about it on Instagram: "Because I'm African American, I didn't find anyone that was my colour that was talking about [endometriosis]" (April Christina 2020). Representing endometriosis, as will be discussed more in chapter four, also requires a lot of work.

Grace, an endometriosis advocate from Canada, explains in her interview how managing misinformation as a Facebook group moderator is tricky because "what one person considers misinformation, another person considers accurate" (Grace 2020). Although a certain level of misinformation can be easily identified, some aspects of endometriosis care come down to the personal opinions or the needs of a patient and Grace thinks these differences are important. Even as a researcher who knew some of the more common myths around endometriosis, I still found it challenging at times to wade through the weeds of misinformation and conflicting information online. I also often found new information and research about endometriosis on social media that hadn't crossed my path in academic databases.[42] Heather Guidone, BCPA, the Surgical Program Director of the Center for Endometriosis Care in Atlanta, Georgia, and a lifelong advocate for the disease, laughs when I mention this during our interview: "You're still going to be learning about endo 50 years from now, I promise you" (Guidone 2020b).

While the rise in information on social media has helped to keep many people living with endometriosis informed, the fact that so much self-education even needs to happen online again points to the systemic problems in endometriosis care. Kate from @EndoGirlsBlog explains how people living with endometriosis have very few options *other than* self-education:

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[41] Even in the early days of my PhD, I would sometimes describe endometriosis inaccurately. Even the definition within medical journals is often wrong.

[42] Much of this project is indebted to the continued work that my participants and others do to share accurate information about endometriosis. There were so many times throughout my project that these social media posts provided me with the perfect pathway through the research I was doing and I'm incredibly lucky for all this work that has come before me and been made accessible.

> I don’t know a better educated community of patients, I really don’t. Because they *don’t have an option but to be*. No, I’m like, *these people are learning the science behind their disease*. They’re smart. (Boyce 2020, emphasis my own)

Another interviewee, Alex Kuller who started the trans-inclusive Facebook group Endo Knows No Gend-o echoed this sentiment in their interview:

> I think we've really had to become the experts and advocates for ourselves because truly no one else is going to do that research or connect those dots for us. (Kuller 2020)

Although this kind of self-education may be necessary, it’s also something that doctors can look down on. Julianna (Jules) Ozorio, who posts on Instagram under the username @endo.days.ontario, tells me:

> I did my own research and I know doctors hate when patients consult 'Dr. Google' but I wasn't getting any help anywhere but so I was just doing my best to put pieces together on my own. (Ozorio 2020)

Jules’ comment gestures again to the role that patients often have to play in doctors’ offices to get care. They need to be both incredibly informed, patient, and likeable, while also not letting on too much about how they got that information.

Heather, the endometriosis advocate mentioned earlier, agrees that patients do a lot of the “leg work” for their own care:

> Patients […] shoulder the burden for getting themselves to care, paying for that care, you know they really are responsible for all aspects of their care. So it doesn’t surprise me that they’re empowering themselves and that’s really gratifying. There’s nothing sadder than finding out “yeah I had symptoms when I was 12 and didn’t get surgery until I was 30 because I didn’t know.” (Guidone 2020b)

For Heather, like many of my interviewees, self-education provides empowerment in the face of so much mistreatment. Heather continues:

> I would say that the patients are really at the centre of this disease and it seems so often that it's everything about us without us, so I really try to encourage our patients, remind our patients, or people in the endo community, [that] an educated patient is an empowered patient. (Guidone 2020b)

As many of my interviewees mentioned, social media provides a way for people living with endometriosis to self-educate and empower themselves. For many, self-educating is the only option they have for getting answers or learning how to self-advocate for treatment. As one anonymous survey respondent writes:

> Due to the lack of education [given] to OB-GYNs, it is a patient's responsibility to educate themselves on this disease.

This way of thinking has the potential to leave behind patients who are not considered as "smart" by the community either because they lack the capacity and skills to read medical information, or do not have the media literacy and other tools to discern misinformation from information. There can be a certain kind of intellectual ableism within these communities, as well as a lack of awareness around the systemic issues preventing people from "educat[ing] themselves on this disease." Many people do not even know they have endometriosis and, even if they did, cannot be expected to travel across countries or vouch for themselves to get better care. Self-advocacy itself is a learned skill that takes time and resources to develop. I think back to Heather's statement about the lifelong process of learning about endometriosis. While this is nice to hear as a researcher, it is worrying as a patient. With that much of a knowledge gap, how is the average person with endometriosis supposed to get care?

September 18, 2020: Do I have to do a podcast to get care?

I have realized recently that writing my PhD about endometriosis has provided me with a chance to fully understand my disease in a way I wouldn't have been able to if I were writing my dissertation on another topic or working another job. Although there are many reasons behind this project, I have started to see how becoming more educated about endometriosis and immersing myself in the online community might also help me find a way to better care. While I still am struggling to get some of the care I need, this time spent informing myself has made an enormous difference. But this thought is a little horrifying: is that what it takes to get treatment?

During the interview phase of my research, the COVID-19 pandemic hit North America and I became sick with a cough, fever, and shortness of breath. It was early in the pandemic and tests were not available to people who didn't work in healthcare. I ended up turning to the internet (again) to get help with my symptoms. Although I thought being dismissed over endometriosis would have made me more prepared for dealing with doctors, the medical trauma of that mistreatment only made it harder to access care for my presumed-COVID-19 *symptoms. My GP dismissed my symptoms as "just endometriosis," while my endometriosis specialist said they were probably COVID-19. Neither offered a referral for care and the internet became, once again, my best option for resources. As Felicity Callard and Dr. Elisa Perego write, "long-haul covid" was defined and named by "patients finding one another on Twitter and other social media" such as Facebook, the "Body Politic" slack group and more (Callard and Perego 2021).*

During this time, I connected with a colleague who was experiencing long-haul covid symptoms and watched as she started sharing her experiences online. Her interviews, podcasting, and posts eventually led to her receiving care from one of the few doctors focusing on long-haul covid in Canada. That night, I texted a friend:

> *Do I have to do a podcast in order to get care? What levels of self-advocacy do I need to achieve? I'm already working on a dissertation about endo [...] It's exhausting!!!*

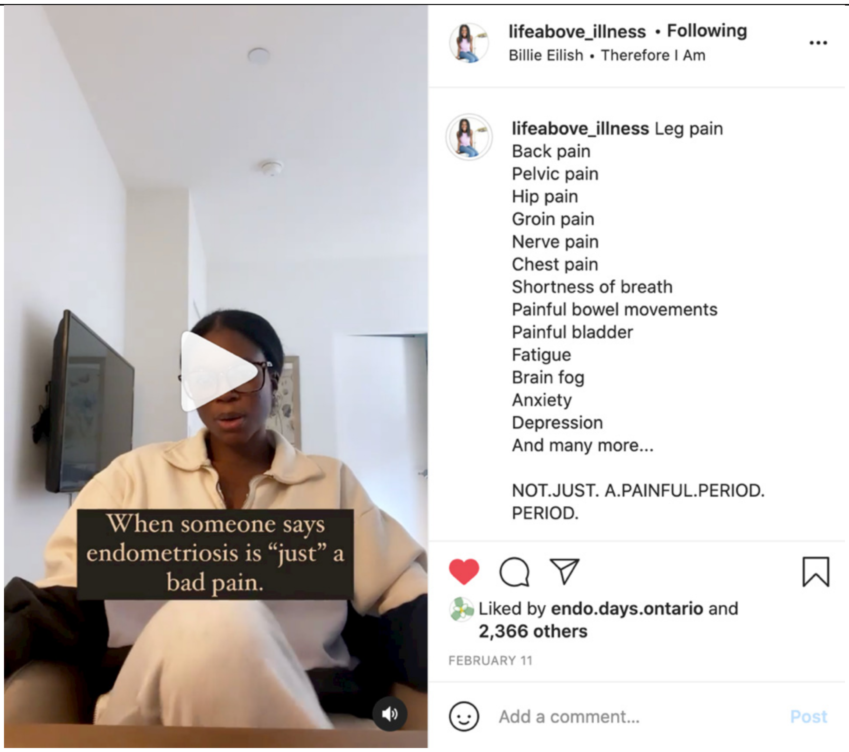
I have started to realize that I'm not sure I could ever do the kind of work my participants do to maintain an Instagram account or Facebook group about endometriosis, never mind COVID-19. Although I do share endometriosis information online, I often have to take breaks and step back from social media in order to rest and care for myself. When does being online become a problem and for how many people is just living with an illness alone already too much?

It's Hard Work Being an Endometriosis Patient *Online*

Not only is it hard work to be an endometriosis patient and, more than that, an *informed* or empowered endometriosis patient, it is especially hard work to be an endometriosis patient *online*. Navigating misinformation requires both health literacy ("the skills and competencies to find and evaluate health information") *and* media literacy (Baumann, Czerwinski, and Reifegerste 2017). Further, sharing information involves staying up to date with what is popular and trendy. Founder of the Endo Coalition and author of the chronic illness book *Part of You, Not all of You* (Rishe 2022), Jenneh Rishe tells me how she uses social media trends and her knowledge from her master's degree in education to make her Instagram posts both informative and digestible:

> [With] Nancy's Nook, everything is a lot of reading and research and all that. And that is really heavy. It's hard for a lot of people. And so it's been fun on Instagram now with reels and video and being able to speak to different people's learning styles. Some people just like to listen to me talk and some like infographics. [Some] people are visual and some are audible [learners] and it's really cool to be able to incorporate that into one space. (Rishe 2020)[43]

During my research period, Instagram developed a new portion of the app which allows users to upload short TikTok-style videos called "reels" to their page. Many of my participants, like Jenneh, began using reels (alongside posts, stories, and live videos) to share their endometriosis content. In one of Jenneh's reels, she lip-syncs along to a Billie Eilish song with the lyrics, "Stop. What the hell are you talking about?" while the text in front of her reads "When someone says endometriosis is 'just' a bad pain day." Her reel addresses the complexities of endometriosis pain, which she elaborates on in the caption with the phrase "NOT. JUST. A. PAINFUL. PERIOD" (see Figure 5).



When someone says endometriosis is "just" a bad pain.

lifeabove_illness • Following
Billie Eilish • Therefore I Am

lifeabove_illness Leg pain
Back pain
Pelvic pain
Hip pain
Groin pain
Nerve pain
Chest pain
Shortness of breath
Painful bowel movements
Painful bladder
Fatigue
Brain fog
Anxiety
Depression
And many more...

NOT.JUST. A.PAINFUL.PERIOD.
PERIOD.

Liked by endo.days.ontario and 2,366 others

FEBRUARY 11

Figure 5: February 11, 2021 Instagram reel from Jenneh (@lifeabove_illness)

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[43] Although the idea of different learning styles has been largely disproven, Jenneh's efforts still keep her content engaging, diverse, and accessible and this appeals to the Instagram algorithm (Kirschner 2017).

Kate from @EndoGirlsBlog also uses her media savvy to make medical information more available and accessible to people:

> Because right now, how it stands, the older advocates, they don't understand social media as well and they will […] put too much information and it's hard, people lose interest. You can't share something from PubMed, all of the text, no one's going to read that, they're just going to go on by. (Boyce 2020)

Kate describes how, when she began posting to Instagram, there were already several influencers talking about endometriosis in shareable and visually appealing ways, but with misinformation.

> There was a gap there, so I was like, I'm going to try to fill this, where the influencers have come in, and try to do it with proper information. […] This community is so educated in their disease that they don't deserve the dumbed down, watered down versions of all of this stuff they're getting from their doctors. So I'm going to take what I learned in school and break down this information into bits and pieces that are shareable, easily digestible, and really just spread it to give this community the credit they deserve […] I don't know a better educated community of patients. (Boyce 2020)

Of course, Kate's words lie in tension with the spread of misinformation on social media she herself identifies and tries to combat. Although there are certainly disagreements around what is and isn't considered misinformation online, Kate's words also suggest that many people with endometriosis are ready and willing to learn, given the proper resources. Part of what makes endometriosis spaces so susceptible to misinformation and such a target for scams is that they are full of people looking for information and answers in the face of lacking care. Kate suggests this gap can be filled by patient advocates, instead of by organizations trying to profit off of patients, who are some of the main sources of misinformation. Further, as a survey respondent going by Gabby says, "everything I learned about endometriosis I learned from endometriosis communities […] There's a lot of misinformation being spread, BY DOCTORS!" What constitutes accurate information varies, even between clinicians and researchers but, thanks to the resources advocates such as Kate provide, patients (and patient groups) are now playing a role in these scientific debates. This kind of patient advocacy has been shown to have radical potential, as seen in the case of breast cancer research where patient support groups became the site of political activism and created a complete shift in research funding and treatment (Osuch et al. 2012).

Founder of the Endometriosis Summit and pelvic physiotherapist Dr. Sallie Sarrel also describes using social media trends to combat the spread of misinformation. In our interview, she maps out all of the problematic content she has to compete against: pharmaceutical companies hiring influencers to promote their drugs, people trying to sell products for their multi-level-marketing scheme, others claiming they can cure endometriosis with herbs or thousand-dollar coaching plans. Despite these problems, she also admits "there would be no Endo Summit without the internet" (Sarrel 2020). She describes how posting on social media about their first Endo Summit conference led to it selling out in two days. Like Kate, she recognizes it as "a community that's starved for information" (Sarrel 2020).

Studies suggest that what Sallie and Kate have observed is true, and that people with endometriosis are keen to access more information about their disease using social media (Shadbolt, Parker, and Orthia 2013; Carneiro et al. 2020). In the article "Illnesses you have to fight to get: Facts as forces in uncertain, emergent illnesses" Joseph Dumit explains how patients "faced with restrictive bureaucratic fields [patients] collectively discover tactics that allow them, sometimes, to survive" (Dumit 2006).[44] Although these tactics (or practices) involve an enormous amount of labour, they also create important archives like Nancy's Nook or Instagram pages that provide people living with endometriosis with a wide array of resources. The knowledge produced in these spaces by patient advocates doesn't only include medical information, but also provides other useful practices for dealing with endometriosis, such as: how to effectively talk to doctors, how to prepare for surgery, tips for flare ups or dealing with the mental side of endometriosis, suggestions for artistic activities or selfie-challenges, and more.

Some of the knowledge produced specifically in Instagram communities focuses on how to successfully share information on the platform. Social media platforms are designed to be extractive and primarily benefit the wealthy stakeholders, meaning that people who want to use social media for unintended purposes often have to get creative (Dijck 2013). Throughout my research period, I witnessed many endometriosis accounts posting about

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[44] This also calls back to Arseli Dokumaci's work on "activist affordances" mentioned in chapter one (Dokumaci 2023).

the best way promote their content, encouraging followers to save and comment on posts as well as "like" them to boost their engagement. There were also a few instances where people in the Instagram endometriosis community were shadow banned, meaning that their content was no longer made publicly available on hashtags and that their account essentially functioned as if it were private. With shadow banning, users are not contacted by Instagram about a violation of the Terms of Service, they just notice their content is no longer being shared publicly without explanation. Madelyn, the participant mentioned earlier, had her account @miss.misdiagnosis shadow banned partway through my research period and had to encourage her followers to move to her new account @madymorneault. During Endometriosis Awareness Month in March of 2021, Endometriosis UK posted to Twitter saying that many of their supporters reported being blocked from posting with the hashtag #endometriosis on Instagram. In response to this, many popular endometriosis Instagrammers created secondary accounts in case they were shadow banned, including my participant LP from @TheEndoMonologues. To avoid these bans and promote their content, Instagram users have to learn a number of tactics to make the Instagram algorithm work in their favour and they often share these tactics to help one another.

Nomagugu Chantelle Nkosi, an Instagrammer from South Africa and endometriosis content-creator, describes how using Instagram involves playing the "game of Instagram and the algorithm of Instagram":

> Instagram's algorithm plays a part which you can't control […] For example, my post where I came out with my diagnosis, I didn't have my face in that, I just had my stomach and my hands because my hands have hospital bands. And that post got maybe—I'm by no means an influencer of any kind [laughs]—but that post maybe got 101 likes. And then in comparison, I posted something not too recent, not too long ago where I was in a yellow skirt [...] and a yellow top and I was holding a camera and it looked like I was in a forest where I took the picture. And that picture got over 300 likes. So you have to kind of play to that game if you want max engagement unfortunately. (Nkosi 2020)

Although none of my interviewees described themselves as 'influencers'—they all had other jobs and pretty conservative followings (under 10,000, except @theendo.co with over 20,000, @EndoGirlsBlog with 17,000 and, recently, Sallie's @EndometriosisSummit with 18,000[45])—they still ended up performing a kind of "aspirational labour" that Erin Brooke Duffy describes in her book *(Not) Getting Paid to Do What You Love*. Using her interviews with social media fashion bloggers and influencers as example, Duffy describes aspirational labour as "a mode of (mostly) uncompensated, independent work that is propelled by the much-venerated ideal of getting paid to do what you love" (Duffy 2017). Although my participants differ in that they are not often using their social media pages to try and get a job (although some of them get promotions, free products, sponsorships, writing opportunities, and/or speaking engagements), their labour is still aspirational in the sense that many of them are hoping to make a change in their own care, or endometriosis care more broadly.[46]

Chantelle's description of how she 'games' the algorithms also illustrates a "developmental aesthetic labour," a phrase Duffy coins to describe the technical skills and aesthetic techniques used by people on social media to represent a specific "brand" or image (Duffy and Wissinger 2017; Duguay 2019). Many of my interviewees have some kind of brand or aesthetic that they used to unify their content. For example, LP's page @TheEndoMonologues is usually themed around a colour and has a back-and-forth pattern of abstract images and illustrated text (see Figure 6). The Endo Co. chooses different themes every so often to display their content cohesively. These techniques in self-branding and successful posting practices illustrate even further everything that people with endometriosis often end up having to teach themselves if they want to contribute to and be a part of social media conversations and compete with the major organizations also making content. The labour they perform is not just about health information or patient advocacy, but also media literacy, branding, and the latest trends and aesthetics.

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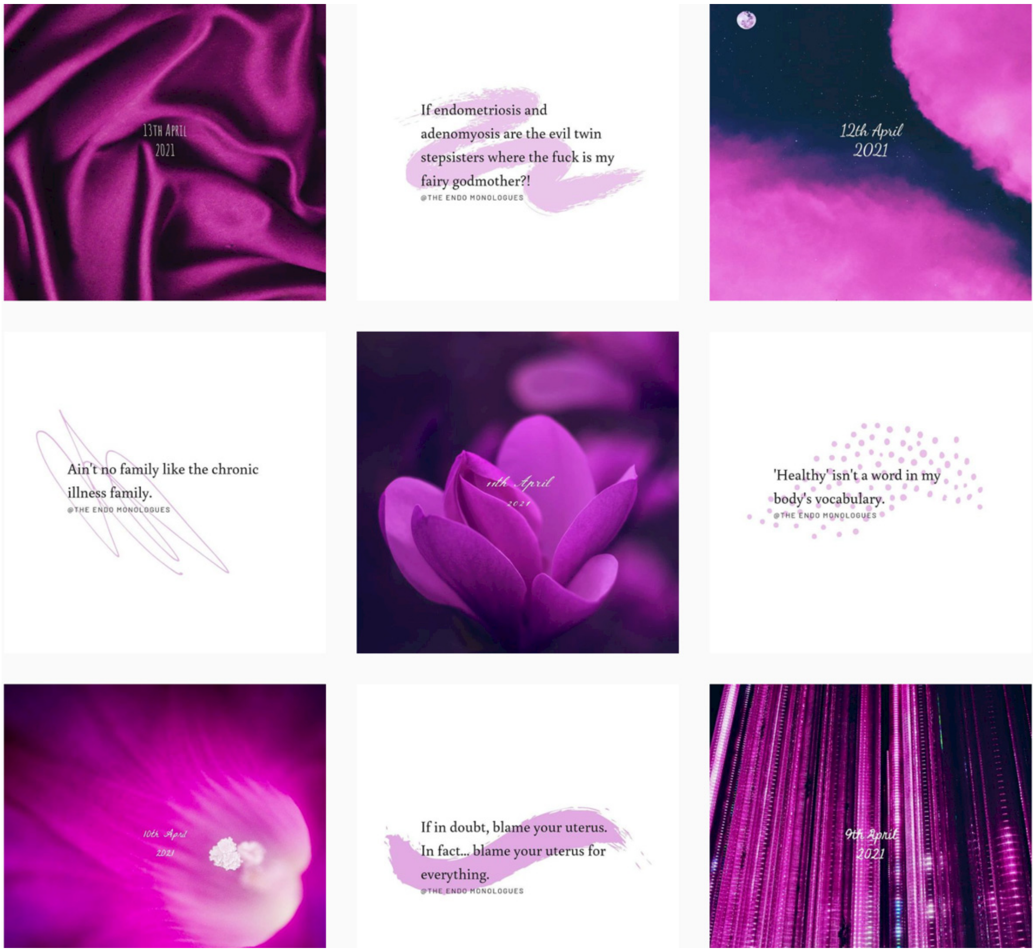
[45] As of August 2022. These numbers have grown considerably during my research period.

[46] PhD student Bridie Appleby-Gunnill has an interesting theory that folks with endometriosis often initially use social media for storytelling purposes but then (particularly on Instagram) get funnelled into the influencer pipeline. I am curious to see the results of her work, but the design of Instagram certainly does push people into developing a brand, growing their audience, and even taking sponsorships. These aspects of the platform inevitably shape the kind of content that gets produced, even by those who resist fully becoming "influencers."



If endometriosis and adenomyosis are the evil twin stepsisters where the fuck is my fairy godmother?!
@THE ENDO MONOLOGUES

Ain't no family like the chronic illness family.
@THE ENDO MONOLOGUES

'Healthy' isn't a word in my body's vocabulary.
@THE ENDO MONOLOGUES

If in doubt, blame your uterus. In fact... blame your uterus for everything.
@THE ENDO MONOLOGUES

Figure 6: Screenshot from April 19,2021 of @EndoMonologues's Instagram page

Although all my interviewees found value in the work they do—whether moderation, representation, information-sharing, or offering support— they also all admitted that it requires an enormous amount of work. Jules from @EndoDaysOntario admits that she feels a "a self-imposed pressure to provide useful things or post often enough that it's relevant" (Ozorio 2020). Sometimes this pressure leads to a burnout and, although all my interview participants have stayed active (to varying degrees) throughout my research period, there were times where they would step back for a couple of days or a week to take time for their health or mental wellbeing. Sometimes these breaks came as a response to interpersonal conflicts in the online community. Those who have active Instagram accounts or moderate Facebook groups often end up spending a lot of energy doing "affective labour" alongside their other work. Affective labour is work that involves managing the emotions of others, as often seen in domestic labour. It is often coded as feminine, rendered invisible, and goes unpaid, just like the significant organizing and community work that many of my participants perform and which I will discuss further in chapter three and four.

This affective labour translates to social media labour. As the scholar Lisa Nakamura writes, "[w]omen perform much of the 'free labor' of social media," much as they did in the household (Nakamura 2015). This emotional labour was apparent in many of my interviews. For example, Jenneh explains how she feels a responsibility to respond to everyone who private messages her on Instagram:

> I'm very passionate about helping as many people as I can […] like right now I have 150 [direct messages] just sitting there waiting to be answered. If you let me, I would just sit here all day and reply to people. I'm also someone who's not just good at being like "here's the information and here you go." I'll send you ten more back-and-forth follow up messages and I just can't help it because, when I was at my worst and when I was desperate, I would want an actual conversation from someone and that would have meant so much to me. I treat every message that way. (Rishe 2020)

Many of my participants have similar stories and their work goes largely unnoticed. For Alex Kuller, the moderator of the Facebook group Endo Knows No Gend-o, the emotional labour is an important part of their work:

> As a moderator, [I want] to make sure that there's room for people to share their hard feelings and to feel hopeless and desperate and frustrated, I think that's important that people can share those things and that we don't only keep it positive or don't shame people for having emotional experiences. (Kuller 2020)

Alex emphasizes that moderating Endo Knows No Gend-o has been an overall easy experience for them so far thanks to the small and supportive community, but for bigger groups and accounts this kind of work can quickly become unmanageable. Kathleen King, a fellow endometriosis and social media scholar and former chair of Endometriosis Association of Ireland, describes how exhausting the emotional labour of moderation can be:

> It does take a toll because you do end up absorbing […] everybody's personal story and you end up taking on their crusades as well. You feel you're on this journey with them in certain cases too. And often it's a very thankless job. (King 2020)

Similarly, Jenneh asks, "How do you scale-ably manage these platforms, wanting to always keep your very personal voice, but delegating the work to someone else?" (Rishe 2020).

This question gets at another form of emotional labour that my participants identified, one which Stefanie Duguay calls "intimate affective labour" in her article on microcelebrity labour in queer women's self-representation on Instagram and Vine. She defines "intimate affective labour" as "the affective labor expended in sharing and managing intimately personal details about oneself with others" (Duguay 2019, 5). What Jenneh identifies in her question is a certain kind of emotional authenticity or intimacy that is involved in managing her account. Talking publicly about the ins-and-outs of endometriosis already requires a certain degree of intimacy and transparency (things such as sharing information about one's menstrual cycle, bowel movements, frustrations, and more) but, because so many people's journeys with the disease involve dismissal, misdiagnosis, and mistreatment, many Instagram users and Facebook moderators have to perform a certain kind of intimate affective labour with their followers/members.

In her book *Care Work: Dreaming Disability Justice*, Leah Lakshmi Piepzna-Samarasinha describes how sick, crip, mad, and disabled people find ways to take care of themselves and one another through community "care work." Care work includes things such as cooking for one another during a difficult time or helping move someone into their bed or onto the toilet. Care Work is built around interdependence and communities of support, in the face of a world that devalues disabled people. Although endometriosis social media spaces sometimes seem to foster extreme independence (and self-empowerment), there is also a profound kind of care work that is enacted in these spaces, as seen by the ways in which so many of my interviewees hold space for one another or share information to save someone else the time they had to wait for answers. Although I will touch on these complexities more in chapter three, it is worth noting here the kind of effort emotional labour and care work requires, and that it often goes unrecognized, "denied and disavowed" (Malatino 2020).

This intimate affective work also means that many of the people who post on social media in this way are put into potentially very vulnerable situations. While talking to Madelyn, she describes the hardest Instagram post she ever had to make:

> I had to let everybody know that my partner was killed by a drunk driver because I posted about him a lot. (Morneault 2020b)

There is no hesitancy from Madelyn about maybe whether she truly "had to" make the post. The sharing is something that is important and necessary to her, and she tells me that posting publicly about her journey with this grief has actually been healing in some ways. However, this conversation comes up right after she finishes describing her experiences with exploitation on the platform:

> I get my pictures stolen and used without my permission a lot for different companies that are selling fibromyalgia-related apparel and accessories and products [...] There's actually quite a few pages that specifically take photos from other fibromyalgia warriors and chronic illness warriors and use it to sell their fibromyalgia t-shirts [...] I've had to report, I don't know, I stop counting, but that was definitely frustrating because it's like, okay you're just going to use me to promote your product without my consent but you get the money and also I don't even know if your intentions are good. (Morneault 2020b)

Madelyn explains that she's had stealing such as this happen mostly in the fibromyalgia or broader chronic illness Instagram communities, but that endometriosis brings its own scams and misinformation:

> On my endometriosis post, the scams that I always get are "go to this doctor who can cure your HIV, AIDS, and whatever else you may be feeling with these herbs." (Morneault 2020b)

Although the affective labour that people like Madelyn perform helps foster information sharing, community support, and awareness-raising, it is also unfortunately easily taken advantage of.

Further, a lot of companies use Instagram to promote their products. Many of them will use the same hashtags as the people looking for support, so they can directly target a vulnerable community. Period product companies will commonly give free samples away to people with endometriosis accounts for review and promotion, meaning that the company gets relatively cheap advertising thanks to the labour someone else has done to build their platform. Even the pharmaceutical companies behind some of the more common endometriosis medications have hired influencers to promote their treatments. One of my participants who had attended an event hosted by one of these pharmaceutical companies told me that the company admitted to also observing popular endometriosis hashtags and accounts to see what issues matter to patients so they could determine their future advertising strategies. In other words, the intimate, personal, but inevitably public, posts Instagram users make about endometriosis are being used without their knowledge or consent as data through which to survey and target them for advertising. In my survey, only 16% of participants identified concern with their data or privacy when posting about endometriosis online, while 7% said sometimes. One anonymous respondent specified that they were somewhat concerned about security, but that they were "past the point of worrying about it. The need to speak up is now greater than the risk I may occur [sic] identifying myself." This quotation again highlights the costs, labour, and vulnerability associated with doing online advocacy.

The rest of the respondents said they had no concerns (41.8%) or they had no concerns because they only posted in private groups (33.1%). Although private Facebook groups (especially those with strong admin teams) are safer from exploitation, they still are not immune. Kathleen who has worked with the Endometriosis Association of Ireland describes how the team's private Facebook group was subject to a data breach where people from other groups came in and took screenshots and other information. The team ended up creating an anonymous forum on their website instead. This allowed them to control misinformation and exploitation more easily, but also meant that less people had access. Grace, who works with a Canadian endometriosis organization, similarly described how one of the biggest jobs their Facebook admin team does is vetting the 100 or so requests to join the group each week:

> We have 3 questions that people answer to join our group […] We want to make sure people aren't trying to sell something in the group and if somebody joins and they sell essential oils or whatever, we don't want them trying to sell that in the group. And sometimes people will private message [other] people [in the group to sell them things] so we have to be very careful about intake […] so we sort of look at someone's profile and, if we notice that they're selling something, we have to have a conversation explaining our rules for it, making sure they understand. Sometimes even then they violate the rules but at least they've had it explained and they get kicked out. (Grace 2020)

While this kind of moderation work may help keep a group safe from misuse, it can also feel exclusionary to others, such as LP who describes Facebook groups as "elitist and [...] cliquey" (LP 2020).

This difference in perspective is partly due to what kind of experience a person is looking for (ie: support, information, etc.), and partly due to the point that Grace made about how the definition of misinformation varies between people ("what one person considers misinformation, another person considers accurate"). As LP explains:

> [Facebook is] a weird place to be because […] I would post asking for help and understanding and people would just [tell me to] look at this research and I was like, that's great, I've already done that, I'm looking for a kind of personal point of view on what it's like to have endometriosis. […] You would just see someone posting saying "my doctor's recommended this medication" and people would be like "no don't take that medication, it's going to do x, y, and z, and it's made me feel this way" and just, I couldn't deal with the fact that there would be individuals asking for help and advice and would be making medical decisions based on feedback that either was based in lies and misinformation or just one person's experience. […] I think Facebook is the worst one for that. I think it's very cliquey. (LP 2020)

For some of my interviewees, encouraging medical treatment would be seen as spreading misinformation. For others, discouraging medical treatment counts as misinformation. Although social media often gets blamed for "the spread of misinformation," these competing ideas are in large part due to the fact that these disagreements *also* exist within the medical community and published research itself. It is not surprising that patients get pulled into these conflicts, especially considering the knowledge and trust gaps inherent in the medical system. As Grace, who works in medicine herself, explains, "in endometriosis it just seems everybody is free to say, this is the right thing, that's the right thing, and the level of evidence is almost always very low. That's the problem, as far as all these treatments […] well, nobody really knows. There isn't enough evidence" (Grace 2020). Although Grace identifies an important discord around endometriosis information, all the patients advocates that I observed throughout my research were always clear to specify that every patient must make their own, informed decisions about what is right for them.

The Knowledge and Trust Gaps

As discussed at the start of this chapter, a large part of the discriminatory treatment towards marginalized people and/or marginalized illnesses is due to a lack of research and knowledge (Dusenbery 2017). Not only is endometriosis under-researched and underfunded, but as Shannon Cohn, the producer and director of the endometriosis documentaries *Endo What*? and *Below the Belt*, says in our interview, "endometriosis is usually in the US on a list of various health conditions covered in an hour [in medical school], so it's no wonder that doctors just don't know [how to treat it]" (Cohn 2020). Similarly, Jenneh, who went through nursing school, says she did not hear the word endometriosis until after 7 years of working as a nurse, despite all her symptoms and medical experience. Endometriosis guidelines are also lacking a proper systematic literature review and, without standardized guidelines, there are no set practices. Many medical publications still mischaracterize endometriosis as a gynaecological condition, despite its prevalence in other body systems (Yazdanian et al. 2014; Roesch-Dietlen et al. 2011; Foster et al. 1981; Lomoro et al. 2019; Sarmast, Takriti, and Sepehrmanesh 2019; Loh, Lew, and Sim 2017; Meggyesy et al. 2020). For example, although extra pelvic endometriosis (endometriosis that occurs outside the pelvis) is referred to as "rare," Dr. Wendy Bingham argues that there is not enough accurate research to truly claim such:

> We don't have a solid base for endo to begin with on statistics. We don't have good prevalence studies on the disease itself, let alone endometriosis on the organs outside reproduction. (Bingham 2021)

Many of my interviewees have been active participants in the process of trying to advocate for improved endometriosis research and guidelines for years, decades even, but they remain in that battle today. There are also doctors who do this work, such as Dr. Gabriel Mitroi, an endometriosis specialist working in Romania. In our interview, he explains that he and his team at the Bucharest Endometriosis Center "use Facebook mostly to raise awareness and to post informative and educational materials" to their followers (Mitroi 2020). He tells me that every single one of his international patients first learned about his practice through social media, so posting on social media also helps him acquire patients. Because of the deprioritization of excision surgery (and surgery in general) in Canada, as well as the dysfunction in the Canadian healthcare system (particularly after the pandemic) 30% of Dr. Mitroi's caseload comes from Canada (McSheffrey 2022). Many Canadians (such as myself) have travelled to other countries such as the United States to receive proper endometriosis care. More research is needed to see how many Canadians leave the country for care.[47] Although Canada's healthcare system is under a particular kind of pressure these days, similar challenges with endometriosis care exist in many other countries, including Australia and the United Kingdom.

The role of pharmaceutical companies also plays a significant role in Canada and other countries, where medicinal treatment is prioritized over surgical care in endometriosis guidelines. Pharmaceutical funding is a major contributor to the knowledge gap in endometriosis research. Pharmaceutical funding is behind most endometriosis conferences, organizations, guidelines, research projects, as well as many of the specialists. Even if all the individuals and organizations who receive pharmaceutical funding remain unbiased (which seems unlikely), the industry still carries enough power and financial influence to control the production of knowledge (Ford and Saibil 2010). The role of the pharmaceutical industry also contributes to the trust gap between patients and practitioners, particularly when it comes to the debate between treating endometriosis symptoms with medication or undergoing surgery. For patients, particularly marginalized patients, this trust gap is also due to a long history of both systemic and personal mistreatment, including the particular histories of hysteria, sexism, classism, and racism in pharmaceutical testing (Dusenbery 2017).

For doctors, the trust gap (the thing that keeps them from believing their patients) often seems to come down to implicit bias or prejudice against their patients, whether for reasons of identity or because of misconceptions about disability and chronic illness (Chapman, Kaatz, and Carnes 2013; Singhal, Tien, and Hsia 2016; Hoffman et al. 2016; Dusenbery 2017). Unfortunately, the trust gap and knowledge gap do reinforce each other. As Dusenbery writes in regards to women's healthcare,

> [W]omen seem to be caught in a self-fulfilling prophecy. On the collective level, since medicine has failed to explain many of our symptoms, women are, in reality, more likely to have 'medically unexplained symptoms'—whether those symptoms are side effects of drugs that haven't been tested in women, or atypical symptoms of diseases that have been largely studied in men, or symptoms of functional somatic syndromes that are more common among women and that medicine, assuming they must be psychogenic, has hardly researched at all. (Dusenbery 2017)

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[47] I hope to conduct this research in the future, if I am able.

Jules explains this eloquently in her own words during our interview:

> Because fertility was not my priority, I was dropped to the bottom of the list. I rage about this a lot: the lack of the knowledge in the medical community in general is just a blatant example of systemic misogyny but then, even within the world of endo treatment itself, there's another layer of misogyny because I was only deemed worthy to treat if it was to preserve fertility […] So throughout all of this, I am learning the hard way that I cannot rely on doctors, even specialists, for information. I was learning the most from other women who had been through it. (Ozorio 2020)e

Interviewee @tomis_endo similarly describes how in Israel endometriosis is also often only treated when fertility is concerned. As discussed above, sexism, is alive and well in endometriosis treatment and it makes navigating trust and misinformation around endometriosis particularly messy, as the examples in this chapter reveal.

Dr. Mitroi tells me that he believes practitioners should be more open to embracing social media as a method for reaching their patients:

> Doctors and people need to know that not all the information on social media is bad or incorrect. There are lots of people from various backgrounds that help to share information about illnesses and since social media is such a big part of our lives, [it] is at the same time the faste[st] way to reach a larger audience. So when a patient says I have read on Facebook, it does not mean that what s/he read is wrong, just cause it was on social media as opposed to a medical journal/site. It might be an article shared by a well-known doctor who uses Facebook to engage with patients. (Mitroi 2020)

Some studies on social media illness communities and health information encourage practitioners to take this step into social media to reach out to patients, however this comes with risks and also means asking practitioner to perform free labour themselves (Dizon et al. 2012; Househ 2013; Guidry and Benotsch 2019).

A systematic review of online health information seeking identifies that patients' main barrier to mentioning their online findings is skepticism over how the physician will react:

> Patients were afraid doctors would perceive them as challenging doctors' opinion if they directly revealed their online findings to their doctors. Patients were mindful in ensuring that doctors played the central role during consultations. They feared that revealing their knowledge gained from internet searches would be an insult to professional health care providers who could feel criticized or have an unchangeable preconceived view […] Patients expressed concerns over how physicians may perceive them as being 'challenging' and 'confrontational' if they discussed their health

> condition from a more informed point of view during consultations. (Tan and Goonawardene 2017)

The second most common barrier for patients that the review identified "was the resistance or discouragement from physicians encountered when patients tried to discuss their internet information research during consultations" (Tan and Goonawardene 2017). Although consulting health information tends to make patients feel more knowledgeable, empowered, and prepared, bringing it up during appointments can lead to conflicts which reduce the patient's trust in the doctor. The review suggests that seeking health information online can actually improve the patient-practitioner relationship when both parties are open to it (Tan and Goonawardene 2017). Other studies have similarly shown that health information seeking behaviour can lead to patients feeling more informed as well as more confident talking to their doctors (Kirschning and von Kardorff 2008; Rains 2018; Lupton and Maslen 2019).

Endometriosis researchers have also begun to write about the importance of building trust around social media in the patient-practitioner relationship to improve endometriosis care. In an article titled "Nocebo effects in the treatment of endometriosis," the authors (several of whom are doctors) describe how to optimize the patient-practitioner relationship to improve trust, suggesting that nocebo effects (negative side effects not directly caused by treatment) are more likely to occur when a patient does not trust their physician (Thiel et al. 2021b). The article talks specifically about the importance of online communities for endometriosis patients and the necessity for practitioners to acknowledge the significance of these communities and be in conversation with them to build trust with their patients. Referring to research on the COVID-19 infodemic, they write that "no amount of high quality evidence from an *untrusted* physician will sway a patient from the ideas and beliefs developed through interactions with other trusted sources" (Thiel et al. 2021b). While it is positive to see this research on improving trust between patients and practitioners emerging in endometriosis research, it is worth noting that the original pre-print version of this report focused less on building trust and much more on positively representing the available endometriosis treatments. The original print suggested that "conversations with the patient should stress and reinforce the positive aspects of therapy" and that doctors should use "positive framing" to present the negative side effects of treatments (Thiel et al. 2021a). This pre-print received negative pushback in online endometriosis communities, particularly from patients who had experienced negative side effects of treatments and not been informed of them in advance by their clinicians. Although this was unlikely the intention of the authors, the original pre-print read as though it was suggesting that clinicians should obfuscate the side effects of treatments to reduce the chance of nocebo, even while admitting in the same piece that "[w]e currently have a poor understanding of how prevalent these effects are and their magnitude in the treatment of endometriosis" (Thiel et al. 2021a).

The changes from pre-print to publication illustrates a critical example of how the online endometriosis community can contribute, or at least tries to contribute, to shaping knowledge-production and patient-practitioner trust gaps in endometriosis care. Although the edits were likely due in part to peer review, I suspect the pushback from social media communities had some effect, particularly because the authors are active on social media themselves and often respond to social media discourse. The presence of online endometriosis communities is becoming more and more apparent in endometriosis research, and, with it, the lived experiences of patients are gaining more and more power and influence.

In response to the nocebo article, it is also worth noting that, of my interviewees who spoke to me about unsuccessful medical treatments (10/22), *all* said that they originally trusted their doctor's recommendations without doubt and only went looking for other patients' experiences and online communities *after* they experienced negative side effects or worsening symptoms. Several of these interviewees explained how, when they were first offered medical treatment, they were not told about the negative side effects of the available treatments and not given a full overview of what to expect. Similarly, some of them had procedures happen during surgery that they did not consent to. This led to their growing distrust of doctors and drive to represent their experiences online. It is clear to see how Thiel et al.'s suggestions for how to build a trusting relationship could very easily break that trust and push patients further away. A few of my participants posted online about how this report seemed dismissive and reminded them of the times their symptoms had been written off as "psychosomatic" or "all in their heads." While symptoms (pain in particular) can have psychological and neurological origins and while placebo and nocebo effects can occur with all kinds of treatments, this example also gestures at the enormity of the knowledge and trust gaps that exist in patient-practitioner communication around endometriosis, where clinicians have long been primed to see their patients' concerns as untrustworthy and patients are thereby less likely to trust them in return (Melzack 2001; Thernstrom 2010; Thiel et al. 2021b).

April 8, 2021: Losing trust

I had a call with my gynecologist, Dr. X, today. I was calmer and more prepared than normal, thanks to conversations with a new online endometriosis friend, 'Alice.' Alice also lives in Montreal and sees the same practitioner. I'd told her about my negative experiences, how Dr. X always pushes the medication I can't tolerate and won't consider another surgery. In response, Alice told me she'd had multiple surgeries with this practitioner and never been pressured to take meds. Were we even seeing the same doctor? I figured the reasons why I was finding my appointments so difficult must have something to do with how I was communicating my symptoms and needs. Before my appointment, Alice offered some tips on what might help. I wrote out a list and a script of everything I wanted to say, as I always do.

For the first time in a long time, I go into an appointment feeling mildly confident, but it doesn't help. Dr. X recommends the same drug I've turned down many times. I tell her, again, that I'm not comfortable taking it due to my history with the side effects, particularly suicidality, and she tells me she's not pressuring me, but that this is the only option she can offer. I say that I understand we're still in a pandemic and that surgery may not be doable right now, but that I want my concerns around the drug to be taken seriously. Instead, she just sounds annoyed.

She asks me if I have "recovered from my brother's suicide." I say something about how that's a lifelong process, but I'm doing my best. I had brought this information up during our last appointment in the hopes that it would convince her that my mental health conditions were a serious enough risk factor not to take the drug. Now I regret ever mentioning it.

She asks me how the Tramodol is working for me. I tell her that it caused me to experience serotonin syndrome. She responds by telling me that serotonin syndrome is extremely rare and unlikely, did I have it confirmed by a hospital? I can tell she doesn't believe *me, as I knew she wouldn't. Luckily, I'm prepared. I tell her my psychiatrist wrote her a note recommending I never take Tramadol again, did she receive it? She says no. I ask whether there are any other alternatives and she again says no.*

She tells me that I shouldn't base my medical decisions on what I've read on blogs about someone else's experiences. I don't think fast enough to respond to this, but I'm confused. I have never mentioned reading anything online in any of our appointments. I've never even mentioned my research topic, as I'm afraid it would make me look unreliable. Even then, my decision not to take the medication has nothing to do with blogs and everything to do with living in my body for 27 years. When I read on the drug's website that suicidality was a risk, I then turned to medical research. That's where I learned about the other side effects: the less severe ones such as hot flashes, joint pain, nausea, as well as the more worrying ones like bone mineral density loss, which may not return to pre-treatment levels, even after stopping the medication ("Endometriosis: An Assessment of Elagolix for Endometriosis" 2018). Despite recommending this drug to me for several years, this is the first appointment in which my doctor even mentions the side effect of bone mineral density loss and she almost whispers it. She does not mention that the drug is only approved for short term treatment and the more questions I ask, the more annoyed she seems. She finishes by telling me we can talk again in the Fall.

After I hang up, it's hard not to second guess myself. Have I actually just been negatively influenced by social media? Has my research topic led me astray? Should I give the drug a try, even if I can only take it for a limited amount of time and that limited amount of time comes with risks to my health and mental wellbeing? Can I trust my own decision making?

Instead of isolating myself, I post an Instagram story. Jules responds with sympathies. Another friend offers to talk to her team in Toronto to see if they might know how I can get care out of province. Madelyn gets angry on my behalf and it helps me feel my own anger. This support means the world to me. I realize that, while social media may be useful for providing information, it also provides support and a place to feel safe in my experiences, because as much as I do believe my doctor has good intentions, I also feel like I no longer know how to trust her.

It’s Hard Work to Create Change

One of the things that makes social media such a key resource for people with endometriosis is the way that information and knowledge are distributed *socially* (Sbaffi and King 2020). Although there are websites with information available, it can be hard for patients to know where to begin and turning to social media allows for methods of learning not only from research but also one another’s experiences. One of my research participants, Emma, describes how she learned that what her doctor was telling her (that she should get pregnant to avoid surgery) wasn’t true:

> I wouldn’t know any of that if it wasn’t for all these different Facebook groups, Instagram profiles […] I think I had to see other people in different parts of that journey and what they were going through to really help myself make those decisions. (Emma 2020)

The importance of shared experiences and the socialness of social media are critical to this study and will be discussed more in the following chapter. But what is also interesting about Emma’s example is the trust that she places in others with the condition. In fact, when Emma (who I knew through mutual friends and academia) first posted about suspecting endometriosis on Facebook, I responded by sending her a bunch of the information that I had amassed over the years to save her the work of having to find it all out by herself. She mentions this in our interview:

> I skipped through a lot of that initial hair pulling frustration because I had people pointing me in the right direction […] I 100% now, if I knew someone was in that position, would be like “I know this is so overwhelming, but I have to tell you this stuff right away.” (Emma 2020)

A lot of the labour that my participants do is aspirational in the sense that it also aims to *prevent* future unnecessary labour and suffering of others with endometriosis. Ten of my twenty-two patient participants mentioned prevention as the reason behind their posting or advocacy. As Jules says during our interview, “I want to save that amount of work for other women” (Ozorio 2020).

Some of this preventative work also comes down to social support and being there for people. Madelyn says the reason she runs her Instagram page is so that “no woman thinks that they’re alone in their pain. […] Because I felt so alone and I felt no one knew what my pain was […] I want to be that person for someone else that does understand”

(Morneault 2020b). Beyond the dismissal that so many people with endometriosis experience, the disease has also been shown to sometimes have a negative impact on relationships, which can make the condition even more isolating (Moradi et al. 2014). Many of my participants participate in a kind of relational labour, not only to grow and connect with their audiences as Nancy K. Baym has theorized (Baym 2015), but also to help prevent this isolation in others. Combatting isolation was one of the major topics covered by my survey respondents, with more than 1/3 of them mentioning in their qualitative answers that social media has made them "feel less alone." One anonymous survey respondent describes how the connections they've made on social media have been "lifesaving":

> I owe my current quality of life to endo advocates on social media. When I'm alone in my bed in severe agony with my heatpack and my phone, I am able to connect with people who understand what I'm going through […] and the people in my life see it. Social media makes me feel less alone. It makes this endo hell bearable, it gives me reason to stay.

But even for this respondent, finding a safe place online is a lot of work:

> I have to pick the spaces I'm in and I've picked spaces that are pretty good. The gendered and non-inclusive language of many endo Instagram accounts or Facebook groups is incredibly hard and painful and triggers my dysphoria.

Social media both "gives them a reason to stay" while also requiring so much of them.

This relational labour has helped create the growing online endometriosis community which, in the last 10 years, has completely shifted the way knowledge around endometriosis is produced and shared. Although this community is fraught (as seen in the previous quotation and upcoming chapters) the different networks of knowledge that exist on social media are substantial and powerful. By creating these crowdsourced databases of knowledge, people with endometriosis are beginning to shape what standardized guidelines for endometriosis care should look like. Although a lot of work must go on behind the scenes to bring these changes into practice (see chapter four), even just these changes in mindset can a have a huge impact.

Kathleen, who wrote her master's thesis on endometriosis and social media, tells me that she's seen a huge shift since the rise in social media:

> Women now have gone from maybe trusting their doctors implicitly, to starting to question them and now with the use of social media in particular […] they are now able to go in and see themselves as equal to their medical team as well. They're able to negotiate a wee bit more and certainly in

> Ireland they're asking for referrals outside of the country because we don't have a lot of doctors who are able to help. (King 2020)

It is no wonder doctors push back on social media if they see it as a threat to their position as experts. However, this perspective ignores the histories of mistreatment that have led so many patients to seek their own sources of information.

Social media has also created centralized space for researchers (like myself) to reach out to people with endometriosis who might not have been represented even ten years earlier. Nancy, in particular, treasures this aspect of Nancy's Nook:

> We try to work with researchers and students like yourself because I have this belief that the more we expose the problems, that information flows out. You know we've got a group of surgeons that are part of a staff of a major university who are doing a follow-up study with our patients later this year. We have a group from Southern California doing a major study with our group. We've started to attract people of influence and access to come and do research with our members. And we try to encourage our members to help the researchers when we have a project, and we try to make sure the project is safe and then we put it up and we remind people that you're here and you're an important part of this, help the researchers out because they are trying to shine a light into the dark parts of this disease. (Petersen 2020a)

Nancy, like most of my participants, sees knowledge and education as a necessary step in changing the endometriosis landscape. Although, right now, people with endometriosis spend a lot of time and energy self-educating, the research and archives they are producing in the process mean that future people with endometriosis may need to do less work. More social media awareness and early education in schools could lead to a huge reduction in the diagnostic delay and, subsequently, less severe disease (Bush et al. 2017; Guidone 2020a). It is important to note that, although my participants perform a lot of labour on social media, many of them are also working just as hard or harder offline to create these changes as well. I will touch on this more in chapter four.

Conclusion: The Messiness of Knowledge

If this chapter has revealed nothing else, it is that the knowledge produced and distributed in online endometriosis spaces is messy and conflictual (just as it is offline), but also that this messiness is not inherently problematic. There are many different forms of knowledge that emerge out of these communities, but they are often reduced to the polarities of “experiential” knowledge versus “biomedical” or “scientific” knowledge, with the latter being considered better or more accurate (Whelan 2009). In reality, these categories intersect: patients might use “science” to validate their claims or researchers may fight to make experience “scientific” by doing ethnographic research (as I am). Further, Emma Whelan’s articles on knowledge-production in endometriosis communities reveals that patients are not the only ones that use experiential knowledge to guide their decisions, but that this is common for practitioners as well (Whelan 2009; 2007). Although science, medicine, and clinicians tend to be lauded as more accurate or factual than patients and their experiences, as was discussed in the first chapter, even medical literature has conflicting opinions on endometriosis and many endometriosis specialists use clinical experience to temper existing scientific research, as does my own physician each time she recommended me the same drug (Whelan 2007; 2009). As Annemarie Mol writes, “different enactments of a disease entail different ontologies. They each *do* the body differently” (Mol 2002, 155). In other words, even the hard sciences have their soft spots, and this is perhaps why knowledge around endometriosis is messy not just in the online world, but also in research and clinical practice. As Wendy points out in our interview, much of contemporary endometriosis care does not reflect the existing evidence and research on the condition: “I think when it comes to evidence-based medicine for endometriosis we need to take a step back and make the subjective information that’s provided weigh a lot heavier” (Bingham 2021).

Disability theorists have long been writing about the embodied knowledge produced by disabled people—the “cripistemologies.” I referred to Alyson Patsavas’s “cripistemology of pain in the first chapter, but it is also important to mention the term “criphystemologies” which draws in all the “undocumented disabilities” that have been oppressed through the diagnosis of hysteria (Patsavas 2014; Mollow 2014). Perhaps there is room for a crip-endometri-ology here. There is no singular kind of knowledge produced within online endometriosis communities and the ways that people engage with what exists is always somewhat subjective. There are, instead, many networks of endometriosis knowledge. Frances, who lives with endometriosis, PCOS, and adenomyosis, tells me how they had to stop using endometriosis Facebook groups because the mixed information was triggering their medical traumas and confusing their decision-making process:

> I'm having a hysterectomy in the next year and there's a lot of mixed information and research about the benefits or [side effects] that can come with having a hysterectomy. […] I think a lot of the problem with the pages in general is that a lot of it isn't science-based and is more opinion and anecdotes which is also sometimes helpful, but I've had to unfollow them because I find, I don't know, maybe it takes away from my own decision on going forward with this surgery and if I read someone who's had a negative experience with it… it's complex and messy. (Frances 2020)

Frances' quotation might reveal the very things Thiel et al. are concerned about, where reading about negative effects can make seeking treatment more difficult for patients. For Frances, these shared experiences make them feel more isolated, whereas for other participants it helps them feel less alone. Like Nomagugu says:

> I can't count the number of times people [on my Instagram] have said to me: "I don't feel alone anymore. Thank you for sharing your story." And you know that's a virtual connection. (Nkosi 2020)

Further, social media can provide some people with the validation they have never been able to receive from doctors. As a survey respondent going by the name Jill writes, "social media validated my symptoms […] where the medical professionals failed repeatedly."

These connections and shared experiences will be elaborated on more in the following chapter, but they are also important contributors to how each patient determines the trustworthiness of information. It's possible that Frances and Chantelle could read the same information and understand it differently. Diane Neal and Pamela McKenzie define this evaluation of information as "affective authority" in their article on endometriosis blogs. That is, the "extent to which users think the information is subjectively appropriate, empathetic, emotionally supportive, and/or aesthetically pleasing" (Neal and McKenzie 2011). The wide range of ways in which people living with endometriosis use social media create many kinds of knowledges and these knowledges are often situated in their bodies and their lived experiences with the disease.

Specific archives of knowledge, such as Nancy's Nook, Endo Knows No Gend-o, @theendo.co, or @endogirlsblog, are incredible objects of study on their own, but they are also situated within a wider web of knowledge and information practices that people with endometriosis enact every day. This "practical knowledge" to quote Jeannette Pols is alive and changing (Pols 2014, 83). As Annemarie Mol writes in her book *The Body Multiple: Ontology in Medical Practice,* disease knowledge is made up through practices, through many people relating to one another, and through those practices "interfering" with each other (Mol 2002, 121). On endometriosis social media spaces, we can see these practices happening, interfering with one another, and even interfering with academic and medical knowledges. Endometriosis knowledge therefore is not fixed, and it is inherently relational, produced through (often conflicting) networks of experiences, information, and feelings—networks of endometriosis. Therefore, to better understand the messiness of endometriosis, we must also consider the relationality, community, and conflict within online endometriosis spaces, and what effect (and affect) those spaces can have.

Chapter 3: Networks of Feeling and Connection

"When you tell someone you have endometriosis and they tell you back, it's like we're already friends."

(Morneault 2020b)

Introduction

The previous chapter explored the online self-education, knowledge-creation, and information-sharing practices of people living with endometriosis as well as the labour these practices involve. To dive deeper into the complexities of these contradictory networks of endometriosis knowledge, this chapter considers the experiences, identifications, and feelings that people with endometriosis explore through social media (the practices of feeling and connection). Pulling from the fields of affect theory, feminist studies, narrative medicine, and disability studies, I explore how endometriosis is felt both individually and socially through social media. Although this chapter talks in depth about feeling and affect, I use the concept of the "bodymind" as well as neuroscientific and pain management research to consider the very embodied effects these networks of feeling and connection can have. Endometriosis is both a physically and emotionally devastating disease. Every single person I interviewed spoke about the emotional toll it took on them. In this chapter, I use the concepts of relationality, interdependence, and "response-ability" to consider how people with endometriosis explore questions of identity and experience in conversation with one another (Haraway 2016). The networks of feeling and connection[48] that are explored in this chapter are created through ongoing practices and constant renegotiations, and this process can be conflictual and difficult. However, looking closely at these messy practices reveals the processes by which endometriosis is shaped and created through social media networks, as well as the value these feelings, embodiments, and connections can have for those living with the disease.

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[48] I use the singular "feeling" and "connection" here as verbs. There are, of course, many feelings and connections within these networks.

Media Practices: Shared Experiences and Connections

Although knowledge production and information-sharing make up a large part of endometriosis social media practices, social behaviours such as experience-sharing, offering/receiving support, and connection are, according to my survey, even more common. Referring back to figure 1, 180 (63.4%) of my survey respondents said they used social media spaces to feel less isolated, 183 (64.4%) used it to offer support, and 155 (54.6%) to receive support. There has been a wealth of research published on the use of online social support groups for health issues which paint an overall positive picture of these spaces. Online support communities have been shown to have the capacity to improve patients' overall wellbeing and quality of life, reduce stress or isolation, increase confidence in future interactions with healthcare providers, improve feelings of support and community, and expand existing and new connections (Bunde et al. 2006; Kim 2014; Patel et al. 2015; Rains 2018; Parsons 2019). However these spaces can also cause negative effects such potential conflicts or disagreements, further feelings of isolation and emotional overwhelm, or the development of maladaptive coping strategies (Malik and Coulson 2008; Shoebotham and Coulson 2016; Rains 2018; Parsons 2019). Within research, these negative effects most commonly appear in reference to pro-anorexia or pro-eating disorder groups (Haas et al. 2011), however recent research has also explored how online anorexia spaces can provide positive forms of social support and, with moderation, can be used to actually encourage recovery and provide helpful information to these communities (Branley and Covey 2017).

Overall, endometriosis researchers tend to be more willing to refer patients to online resources for social support than for information (Leonardi et al. 2020; Shoebotham and Coulson 2016), perhaps because knowledge and information have historically been understood as the work of science and medicine, whereas emotion, caregiving, and wellness are considered the work of individuals, particularly women and people of colour (Mingus 2015; Lakshmi Piepzna-Samarasinha 2018). In the face of this lack of emotional care within certain aspects of western medicine and dysfunctional healthcare systems, there have been histories of some disabled and chronically ill people forming their own communities to provide care and support to one another. In the case of endometriosis and the internet, Laura Sbaffi and Katheen King's research shows that people with endometriosis are increasingly turning to peer-to-peer exchange because it provides the "acknowledgement and validation that is missing in other aspects of their lives, where the condition is often dismissed, minimized or ignored all together" (Sbaffi and King 2020, 387).

Isolation and feelings of helplessness are common for those living with endometriosis who, due to the taboo of the disease or a lack of resources, may not know anyone else with the same symptoms or, because of its "invisibility," feel unseen (Cox et al. 2003; Markovic, Manderson, and Warren 2008; Marinho et al. 2018). The chance to connect with others online can therefore be very meaningful for people with the disease. Many of my interviewees and survey respondents described feeling validated when they found endometriosis social media spaces and saw that there were other people who had experienced the same or similar things to them. As Jules from the Instagram account @endo.days.ontario describes:

> There's a, I would say unspoken but it's also spoken, bond that I think just happens. It happens with anyone with shared experience that involves being not only in so much pain, but dismissed, marginalized in our own ways. If you tell me you have endo, I know what that means and I don't care who you are, I'm here, what do you need? (Ozorio 2020)

Part of what Jules specifies is that these connections come not only from the shared experiences of symptoms, but also the shared medical traumas that are so common in endometriosis care. Although the experiences of people with endometriosis can vary greatly, the connections that can be found in shared experiences were of central importance to many of the individuals I interviewed.

This search for connection and validation by people with endometriosis is not new or specific to the internet. As endometriosis advocate and program director of the Centre for Endometriosis Care Heather Guidone explains during our interview, before the internet was as prevalent, she used to connect with endometriosis pen pals through the Endometriosis Association:

> The EA put out newsletters and they would print people's addresses and I talked to Kate in Timbuctoo or Jenny in Virginia or whatever and it really was a lifesaver for me because I didn't know anyone with endo. My family doesn't talk about illness in that way […] which is strange because my mother comes

> from a *huge* family and I had all this opportunity, but nobody ever talked about it. (Guidone 2020b)

The taboo around endometriosis is so strong that several of my interviewees told me that they didn't even know they had family members or friends with the disease until they started talking about it on social media. Frances, for example, tells me how they had a roommate in undergrad they didn't know had endometriosis until they both saw each other commenting in one of the endometriosis Facebook groups. With social media, this kind of connection is more available than ever, easier to access, and much more immediate. For people like Dr. Wendy Bingham from the non-profit Extrapelvic Not Rare, it wasn't until social media became popular that she was able to make connections with others who had endometriosis. As she says, she "didn't get any care until we were in the social media world" (Bingham 2021).

Social media has also made it possible for people with endometriosis to connect across different geographical regions. Grace from the Canadian endometriosis organization describes how social media has made it possible for her group to achieve a national reach. Nomagugu, from South Africa, describes how her endometriosis friend network includes people from all over the world. Similarly, interviewee @tomis_endo from Israel tells me that she has made connections with people in Germany, Canada, and the United States. However, to reach these worldwide audiences, @tomis_endo tells me she must write in English.[49]

@tomis_endo also tells me that, when she started using social media for endometriosis, she didn't feel knowledgeable enough in comparison to groups like Nancy's Nook, but that she was still able to connect to people by sharing what she "knows and feels." She describes relating to other people by talking about and sharing pictures of her "endo belly," a symptom many people with endometriosis experience that involves painful and often visible bloating. Through sharing her experiences, she was able to connect with others:

> I feel like there is a really strong community, not here in Israel specifically, but around the world […] because everyone experiences basically the same

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[49] Although endometriosis communities exist in many different languages, these differences create some separations within the worldwide endometriosis community. Due to the limits of this project, I have focused only on English-centred groups. Future research is needed to explore how communities may differ between languages.

> thing. At different levels, but people know what you mean. (@tomis_endo 2020)

Like Jules and most of my interviewees, @tomis_endo suggests that the shared experiences between people with endometriosis can create an instant kind of understanding or bond. As endometriosis Instagrammer and patient advocate Madelyn Morneault puts it: "when you tell someone you have endometriosis and they tell you back, it's like we're already friends" (Morneault 2020b). In contrast, one survey respondent described "not find[ing]relief in others telling [them] they have been through the same thing." For some, these shared experiences are just another reminder of how severe the mistreatment of the disease can be.

Although not all my survey respondents felt like the social aspects of social media were beneficial to them, every one of my interviewees spoke about at least one beneficial connection they had made online. Online support groups have been shown to sometimes offer therapeutic benefits, which was reflected by many of my interview participants who described using social media as a way of "process[ing]" or "reflect[ing]" their emotions (Shoebotham and Coulson 2016; Tan and Goonawardene 2017). Others such as LP, April Christina, Kate, and Kyung Jeon-Miranda also specified that, although they found some therapeutic benefit online, they also went to therapy to be able to fully cope with the disease (April Christina 2020; Boyce 2020; Jeon-Miranda 2020; LP 2020). When asked if social media participation changed how they felt about or experienced their endometriosis symptoms, 81.2% (233) of survey respondents said yes, 6.6% said sort of, and 20% (57) specifically mentioned that they "felt less alone," without being prompted (see Figure 7).

The experiences of people living with endometriosis can vary greatly, particularly because of how personal and traumatic living with the disease can be. Although many of my interviewees and survey respondents brought up the importance of "shared experiences" in both online and offline endometriosis communities, this sharing can look very different between people. For some of my respondents, sharing meant being able to dive deep into their traumas and negative emotions, while others preferred to only share their experiences with medicines, treatments, or exercises. As opposed to there being one set structure of shared experiences between all patients, there are many networks of experiences that cross over with one another. Not every person will share the same experiences, but they are likely to share *some* experiences and be pulled together and intertwined through these networks. Although "shared experiences" are a key part of endometriosis social media spaces, they are also one of factors that can make these communities so fraught, as this chapter will explore.

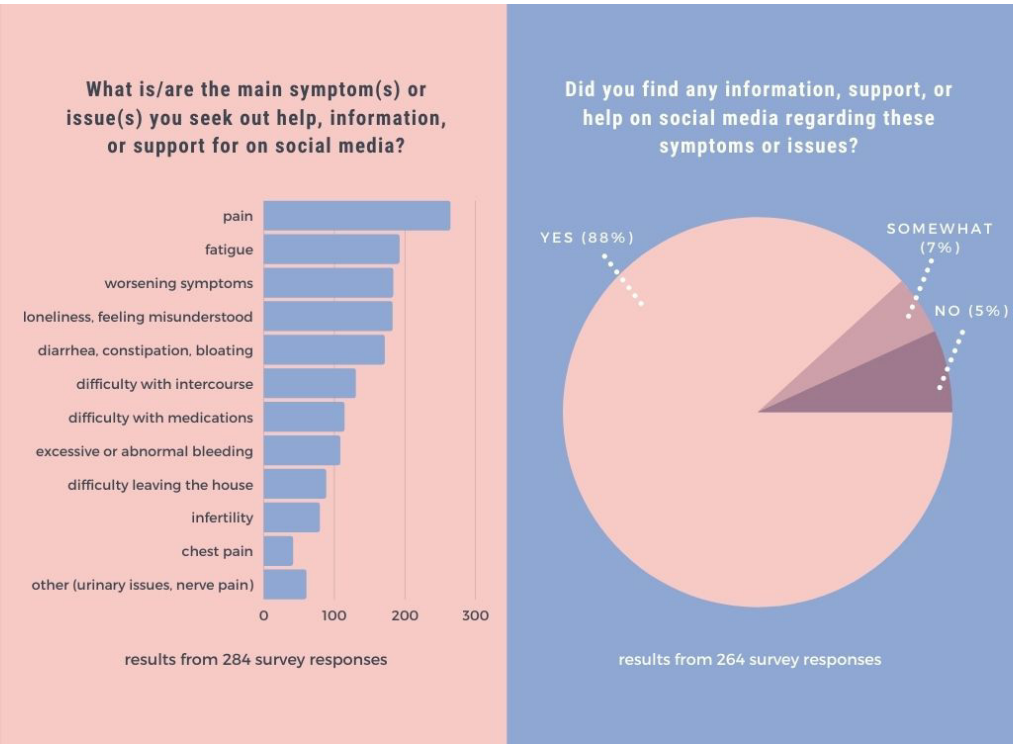

Figure 7: Survey results showing symptom support on social media.

Endometriosis and Identity

The experience of living with endometriosis is extremely personal and emotional. Endometriosis can take an immense toll on mental health and can leave people feeling like they have no control over the disease. Social isolation and loneliness are commonly reported in people with endometriosis and continued dismissal can lead to a negative impact on self-esteem and identity (G. Jones, Jenkinson, and Kennedy 2004; Elaine Denny and Mann 2007; E. Denny 2011; Culley et al. 2013; Cole, Grogan, and Turley 2021). Those living with endometriosis also often face uncertainty about the future due to a lack of a cure and sometimes ineffective treatments (Elaine Denny 2009). All these factors can have a significant impact on the identity of those living with this disease (E. Denny 2011; Clark 2012). Some struggle with denial in accepting the disease whereas others take it on as part of who they are.

During our interview, April Christina describes her emotional experience with endometriosis:

> I started being very depressed and sad all the time because I didn't have no one that could identify with having a chronic illness, so when I'm telling my friends that I can't hang out, I can't go to the movies, they didn't understand because on the outside and the exterior I looked totally fine, but on the inside I was in agony. I was in so much pain, I was emotionally miserable, and I just wanted to be able to find other people that I could vent to. (April Christina 2020)

April Christina's quotation helps contextualize why support groups can be so useful to people with endometriosis who have never been able to have their experiences validated or heard. Every single person I interviewed spoke about the emotional toll endometriosis had taken on them. Many of them referred to their experiences with endometriosis (and endometriosis care) as traumatic or mentioned suffering from medical PTSD. Dr. Wendy Bingham from Extrapelvic Not Rare explained how struggling to find care had affected her self-esteem:

> I lost all my confidence […] It's just really hard and I lost my confidence. […] You don't see my face [online], you see the stuff I do, you don't see me often. Part of that is a self-esteem [thing], it's taken me a long time. […] It's taken a lot out of me. And am I going to say the right thing? Am I going to talk too fast? […] I used to do public presenting a lot when I was in practice [as a physical therapist]. It's been a while and so I've shrunk out of it and I'm really nervous [now]. (Bingham 2021)

Wendy is a physiotherapist and founder of a ground-breaking endometriosis organization Extra Pelvic Not Rare. She's not the kind of person you'd expect to be nervous about an interview, but the way she was treated by doctors had an enormous impact on her mental health, self-esteem, and entire life.

The emotional side of endometriosis is something that often goes unrecognized. As Nancy Petersen tells me in our interview, "there's so much despair and hopelessness [in people with endometriosis that] by the time they get to us they almost don't want to believe there might be help" (Petersen 2020a). The disease can have detrimental effects on belief systems and alter the way one pictures their own identity and their life. Self-harm and suicide are under-researched, but prevalent, in the endometriosis community. As Nancy describes:

> It's unspoken. What happens is that, first of all nobody believes them, and so nobody takes it serious if they ended their life with this disease. And there's no post-mortem exams, there's nothing done to begin to quantify how many women have given up. (Petersen 2020a)

The horror of this information is reflected in my survey results, where several users mention thinking about suicide. One anonymous respondent writes, "I would have been dead from suicide if not for my FB [Facebook] support system." During my research period, I heard of five different incidents of someone with endometriosis committing suicide. A BBC study of more than 13,500 people with endometriosis revealed that half had previously had suicidal thoughts (Bevan 2019). That despair, trauma, and isolation can easily get written into the identities of those living with the disease.

The role that endometriosis plays in people's identities was one of the recurring themes in my interviews. Many of the interviewees described feeling relief when they finally received their diagnosis and could claim the word "endometriosis," but they still usually expressed some hesitation around how much they wanted that word to shape them as a person. For some, such as Kathleen King, describing endometriosis as a part of their identity did not bother them. As she told me, endometriosis is "a huge part of [her] identity because everybody associates [her] with the organization or with advocacy, or with living in severe, constant pain for so long" (King 2020). Jenneh Rische, from The Endo Coalition described a more complex relationship with endometriosis and identity:

> I think I oscillate with this in how much credit I want to give endometriosis for shaping the person I am. I like to think that, without it, I would still be as empathetic as I've become and as passionate about standing up for other people as I am. I would like to believe that. I really like the person I am today. But I feel like I would be remiss if I didn't acknowledge that the suffering I went through with endo didn't ignite that in me. (Rishe 2020)[50]

Jenneh further explained how she has, at times, identified with endometriosis but found that identification to be a difficult space to occupy mentally:

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[50] This is reflective of debates within disability communities around person-first vs. identity-first language. Person-first language, such as "person with disabilities" is sometimes seen as more respectful, but it also obfuscates disability and can potentially portray it as a bad, undesirable thing. In the case of this dissertation, I use person-first language when describing "people with endometriosis", not because I think it is ideal, but because the identity-first options for endometriosis often carry other baggage, such as "endo warrior" or "endo sister." One of the best alternatives I've seen is "endovidual," but this has not really been adopted within endometriosis communities yet.

> I don't ever want to identify [with endometriosis], because I did fall into that, because it happens, especially when you're in the thick of it, where you are your disease and every word out of your mouth is endometriosis and every conversation is about it and I realized that then my identity was just being this sick person and that's not healthy either, you know. I've settled into [the idea] that it's always going to be a part of me, but it's not all of who I am. (Rishe 2020)

Jenneh's book *Part of You, Not All of You* (Rishe 2022) reflects exactly this sentiment and captures an interesting conflict in endometriosis support spaces. On the one hand, as has been described, endometriosis patients are often very familiar with dismissal and deserve to have their experiences validated. On the other, it can sometimes be harmful for people with endometriosis to immerse themselves too deeply in stressful or distressing aspects of the community or identify themselves entirely with the illness. Research shows that stress, distress, and negative perceptions can worsen symptoms which then further worsen mood and perception (Steck and Steck 2015; Marchant 2016). Social media offers both the possibility for someone to improve their relationship to their disease or worsen it. My survey results and interviews illustrate this dichotomy, where some express finding it helpful to vent about their experiences in support groups while others find the negativity in these spaces oppressive.

The term "negativity" here is pulled from the language my interviewees and survey respondents used, sometimes to refer to conflicts, but often to refer to people whose social media practices were considered too "negative," such as those who post primarily about the difficulties they face. Positivity, however, also came up in interviews as something that was often considered (ironically) negative. The line between what is viewed as beneficial and what is seen as dismissive is very slim and subjective in these online spaces. Positivity in posts can often be interpreted as—or become—what the community refers to as "toxic positivity" which places the blame on patients to make themselves better by "thinking positively." The term "toxic positivity" originally appeared in Jack Halberstam's *The Queer Art of Failure*, although the idea of "unrealistic optimism" is something that had been explored in psychology previously (Lecompte-Van Poucke 2022). In endometriosis online communities, toxic positivity tends to refer to messaging that suggests someone with endometriosis can change their situation or control their body, without attending to the structural and physical barriers that might make that impossible. As Margo Lecompte-Van

Poucke writes in her article on toxic positivity in online endometriosis spaces, these representations of endometriosis may not equate to every follower's experiences (Lecompte-Van Poucke 2022). For example, while the term "endo warrior" may be empowering for some, that is not true for everyone. Conflicts often arise on endometriosis social media spaces around these issues of positivity/negativity, largely because of how subjective the experience of the disease can be, but also because of how social media tends to compress complex issues in ways that do not necessarily represent the diversity of everyone's lived experiences.

Empowerment, positivity, and negative are complex concepts in these online spaces and that can be seen playing out in groups like Nancy's Nook as I discussed in the first chapter. For some, Nancy's Nook is an extremely empowering resource for self-education. For others, the group requires an amount of labour that is inaccessible, and the group's representation of what endometriosis is and *what empowerment is* does not align with their own experiences. Endometriosis social media spaces become sites for working out identity in conversation with others. This collaborative work can be deeply significant, particularly for a disease that, for so many, is *felt* and *experienced* before it is ever *defined*. 'What endometriosis means' is something that is continually negotiated and redefined in these communal spaces (as I will explore more in chapter four).

October 21, 2020: Experiencing endometriosis

Day three of debilitating pain. C and E have had to come over to feed me. I haven't been able to move. I'm scared of what the future holds, whether it will get worse and worse like this. I go to the General [Hospital] for an ultrasound. The technician has a phony air of niceness. She calls me sweetie, but she doesn't explain what she's doing. She grabs my legs and moves them without asking or explaining, her fingers are sharp. The wand itself isn't painful but she moves it in ways that are. I hide it, until I can't. I audibly gasp at one point, and she doesn't react. I want to throw up. She leaves the room to get the doctor, but she still hasn't told me what's going on. Fifteen minutes go by, the wand still inside me. I try to look at the ultrasound to understand what they've seen but I can't tell. The doctor comes back with her. They search around with the wand and they still don't say anything. They get another doctor.

Finally, they tell me some things. It's hard to understand, but they say it's nothing to worry about. They say there is no problem, that they found no endometriosis. I don't trust any of them, I wonder how much they've missed, although I know endometriosis doesn't often show up on ultrasounds. I just want answers. I just want to be able to trust them. They mention I should get an MRI, but they tell each other that, not me. Finally, when it's over, the technician explains that I have a septate uterus. She shows me pictures of uteri and how they can be different. I step off the table trying to hold in the goo between my legs and take myself to the changing room. I Google a septate uterus and see that it increases the risks of infertility, miscarriages, and birth difficulties. I walk home in the rain and the autumn leaves. My body aches and I crawl back into bed. Except I can't stay there long—I have my presentation for "Theorizing the Web." I do it through a haze of pain, wishing I could enjoy it. I'm on a panel with a doctor for the first time in my life and I hope he takes me seriously. I joke about transvaginal leechings and I explain endometriosis with the right amount of accuracy and academic distance. I'm always in terrible pain during conference presentations. I don't know if it's irony or coincidence or just an indication of how often I'm in pain. My uterus is heart-shaped and I feel broken, defective. R tells me that's not the part to be worried about, but I don't think he understands how much of this is tied to my identity. I want to have the choice to bear children, even if I don't plan on birthing my own. I want the ultrasounds you see in movies. I want him to be holding my hand, to not be alone, spread out on a table, probably infertile, and in pain.

Theorizing Experience and Affect

Lived Experiences

To understand the ways that experience is understood in endometriosis social media communities, I draw upon feminist theory, disability studies, narrative medicine, and affect theory. These frameworks consider how "lived experiences" can be important tools for validating individuals' lives and knowledge, particularly those who have traditionally been excluded from mainstream forms of knowledge production. The phrase "the personal is political," for example, draws attention to how personal experiences can contextualize and represent larger cultural, social, and economic situations. In the late 20thcentury, feminist scholarship acknowledged that experiences cannot be essentialized to represent *all* individuals, but that considering experience is still a useful way of theorizing differences and creating knowledge (De Lauretis 1984; Scott 1991; Mohanty 1995). As Lauren Berlant warns, saying "the personal is the political" does not mean that "there is *only* the personal" (Berlant 1999, 83, emphasis my own). Experience, as it is represented in contemporary feminist theory, does not signify a whole or pure truth. Rather, as Joan Scott writes, "[e]xperience is at once always already an interpretation *and* something that needs to be interpreted" (Scott 1991, 797). Experiences emerge and are produced *within* the very systems of knowledge that construct them. When contextualized, these modes of production can be revealed. For example, drawing attention to the experiences of people with endometriosis can help illustrate the contemporary landscape of endometriosis knowledge and discourse. The experiences represented in this dissertation all come with their own histories and contexts but can speak volumes when put in conversation with available research, contemporary social media contexts, as well as one another.

Similarly, narrative medicine argues that experiences do not need to be reliable to be valuable.[51] As Arthur Frank writes in *The Wounded Storyteller*, "[t]he truth of stories is not only what *was* experienced, but equally what *becomes* experience in the telling and its reception" (Frank 1997, 22). Experiences are processed, thought through, and felt, and knowledge is created out of these ongoing processes. For many people with endometriosis, experience may be the only kind of knowledge they have available while searching for a doctor who will believe them. As Frank writes, "[e]ndometriosis, although recognized as a disease, is often experienced when it cannot be diagnosed" (Frank 1997, 101). Therefore, drawing attention to these experiences is one of the best ways to illustrate what the disease looks like and imagine possible diagnostic futures.

"Experience" is a vast and not always specific term. In this chapter, I use the word "experience" to refer to any symptoms, emotions, sensations, and embodiments that people feel or live through. My conceptualization of experience crosses over with affect theory, a field which considers how the feelings, emotions, sensations, and rituals of everyday life both structure and are structured by our bodies, discourses, and systems of power. As Zizi

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[51] This is, of course, quite contrary to the way that knowledge is produced in parts of western medicine.

Papacharissi writes, “[a]ffect presents a key part of how people internalize and act on everyday experiences” (Papacharissi 2015, 12). Along these lines and following the work of Sara Ahmed in *The Cultural Politics of Emotion*, we can understand feelings and symptoms such as pain as not only sensations, things that are felt, but also the things that create meaning and shape our understandings of the world. With endometriosis, the symptoms and feelings that people experience due to the disease are significant aspects of endometriosis knowledge-production and meaning-making. Similarly, the feeling-based social media practices of people with endometriosis often reconfigure the meanings of the disease and shape how it comes to be understood more broadly. As Ann Cvetkovich writes in her theory/memoir book *Depression: A Public Feeling*, “emotion can have a collective and public impact” (Cvetkovich 2012, 76).

Although talking about lived experience may seem imprecise, these sometimes-vague experiences can have very real effects on both individual bodies and power structures. It is possible for people with endometriosis, especially those who experience long delays and significant pain levels, to develop central sensitization, a condition where the nervous system becomes hyper-active and worsens the sensations of pain (Aredo et al. 2017; Zheng et al. 2019).[52] Outer factors such as stress and anxiety can also worsen pain experiences and even alter the brain and nervous system (Edwards et al. 2009; Bushnell, čeko, and Low 2013). Similarly, experiences of dismissal and mistreatment can worsen pain experience, and, in some cases, central sensitization is used as a tool to dismiss patients’ symptoms, rather than offer the necessary multidisciplinary treatment, thereby creating a viscious cycle where a patients’ negative medical experiences may only further exacerbate their symptoms (Petersen 2020b; Dumaresque 2020).

A variety of factors can shape pain experience and the structure of the nervous system itself. Similarly, pain experience can shape one’s perception of themselves, their identity, and their disease (Cole, Grogan, and Turley 2021). As Michael Bury writes, chronic illnesses can cause a ”biographical disruption” in an individual, causing them to rewrite the

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[52] Many people with endometriosis or other forms of genital/pelvic pain report being told they have central sensitization before any other alternatives diagnoses have been explored. Many are prescribed anti-depressants or antipsychotics before physical causes are ruled out. In this way, the over-diagnosis of central sensitization has been compared to the historical diagnoses of hysteria (Dumaresque 2020; Guidone 2020a)

narrative of their identity and rethink their understandings of the self (Bury 1982; Cole, Grogan, and Turley 2021). Chronic pain can also (more tangibly) result in the loss of grey matter in the brain, affecting the function of further sensory perception and the ability to have control over one's pain in the future (Bushnell, čeko, and Low 2013). Affect theory in conjunction with neuroscienctific and pain management research provides a way into thinking about how the lived experiences of those with endometriosis can shape the symptoms of the disease itself as well as what those symptoms come to *mean*.

Embodied Experiences

It is also important not to separate the body and the mind when talking about pain. Although research has shown that the body and mind are interconnected, clinical practice in western medicine often treats them separately (Price 2015; Marchant 2016). Mental health specialists operate in separation from general practitioners and communication between multiple doctors per patient is often non-existent. Similarly, although interdisciplinary care has been shown to be beneficial for patients with chronic pain (Gatchel et al. 2014), chronic illness (Tapp et al. 2012), and endometriosis (Ugwumadu et al. 2017), actually accessing proper multidisciplinary care can be much more difficult in practice. Scholars within trauma studies and disability studies have resisted mind/body dualism by adopting the term "bodymind" (Price 2015; Carter 2015). Margaret Price admits that she uses the term partially just for convenience (to avoid having to always say "body and mind"), but also because of how the body and mind "tend to act as one, even though they are conventionally understood as two" (Price 2015, 269). She also uses it to signal the importance of mental disabilities and their physical effects within disability studies.

For my dissertation, I adopt the term "bodymind" to represent how the physical and the mental aspects of endometriosis intertwine. I further want to challenge the notion that emotion or affect take place only in the mind, or that physical sensations occur solely in the body. As Jean E. Jackson writes, "the experience of pain is always both 'mind' and 'body,' mental and physical, simply because the pain experience is always embodied" (J. E. Jackson 2011, 373). Pain, as we feel it, is not just a direct sensation of the inputs our bodies receive, but is an *interpretation* of these inputs based on our understandings of the world (J. E. Jackson 2011, 374). It is therefore not enough to consider pain and other symptoms of endometriosis as existing within a vacuum or a singular body, especially considering the long and political histories of mistreatment and dismissal connected with the disease. Although the disease itself may be physically located within one body, what endometriosis means and how it is treated is shaped collectively.

December 19, 2018: My bodymind

I've been accepted into a doctor's office at Montreal's Pain Clinic for my ongoing chronic pain associated with endometriosis. This is, one would hope, the place where chronic pain patients would find treatment options reflective of the neuroscientific research on pain, especially considering it takes a specific doctor's referral and at least one year to become a patient. To qualify for treatment at the clinic, patients must attend a mandatory orientation, where they sit in hard metal chairs for two hours while a psychiatrist describes in detail what pain is, how it feels, and the negative effects it can have. The man next to me during my orientation rocks back and forth in his chair moaning. Every time the psychiatrist says the word 'pain' (almost every sentence) the man beside me groans loudly. My mother, who attends with me and has never experienced chronic pain, tells me on the ride home: "that was painful."

During my most recent appointment at the clinic, Dr. X (who I consider one of the better and more considerate doctors I have been to) tells me I must choose between a pill that negatively effects my mental health and a life with chronic pain. "You have to decide what is worse" she says, "feeling suicidal or being in pain."

Luckily, I know that these are not my only options. I have the privilege of being able to access and read articles about my conditions and have become familiar with the many misconceptions (even within specialized medical communities) about my condition. But I do not feel as though I can bring this up with her, as her statement itself seems too absurd to comprehend.

The pills that make me suicidal do not cure my pain, but even if they did, a life with suicidal ideation is certainly not a life that is free of pain. Likewise, a life with chronic physical *pain also, by nature, includes mental pain, to varying degrees. Distinguishing physical and mental pain is impossible at this stage of my life and seeing that reflected in the pain management and neuroscientific research I have been reading has been comforting. But where is that same approach in clinical practice? If this kind of work is not happening in a clinic designed to treat and manage pain, then what options do people in pain have?*

But, of course, this is just my experience. I could be alone in this. I tell Dr. X, "I'll think on it."

Shared (and Networked) Experiences

Although one's experience of endometriosis can be extremely personal, it is also shaped by many external factors, from medical care to family systems to communities. As Jackson further writes, "[a] given pain's meaning derives from an individual's history and environment"(J. E. Jackson 2011, 371). In her writing on pain, Alyson Patsavas similarly describes how having her pain dismissed by doctors made her feel personally responsible for not getting better. She suggests that interdependence, rather than individualism, is needed to improve the treatment of chronic pain:

> We are implicated in a system of power that places the doctor in a position of evaluating me and providing me (one part of) the relief I need to survive. I bring with me an individual history of doctors dismissing my experience of pain and a collective history of women in pain being locked up and/or thrown out of offices for "hysterical behavior," just as the doctor brings with him a history of seeing thousands of other patients expressing pain and a collective history of a medical system that trains doctors to view pain and people in pain as suspect. Recognizing our connectivity allows us to respect the weight of these histories while simultaneously establishing a space to talk about pain without losing its materiality, without automatically reiterating the link between disability and pain, and without losing sight of the social and cultural conditions that contribute to how we *feel* pain. (Patsavas 2014, 215)

Patsavas' writing shows how the treatment of pain cannot be localized only to symptoms but needs to considered within larger networks of power and connectivity.

This call to "recognize our connectivity" aligns with writing about pain from within affect theory. Reflecting on a study that showed how watching someone else's pain activates pain-related portions of one's own brain (Bernhardt and Singer 2012), Anthony McCosker writes about the "affective force of pain":

> I argue here that the affective force of pain is located not simply within the perceiving subject, nor the object that 'initiates' sense perception, nor in the impulse striking out between cells in afferent synaptic chains coursing through the body, nor at the synaptic interface or within the nerve cells themselves at the site of a wound […] Rather the affective force of pain lies in the complex interchange of any and all of these elements, along with others, through which bodies act upon one another and in relation to one another within an encounter. (McCosker 2012, 2)

McCosker draws upon the work of Judith Butler to frame his understanding of these "complex interchanges." In *Precarious Life*, Butler writes that every individual is "vulnerable to [a] range of touch, a range of touch that includes the eradication of our being at one end, and the physical support for our lives at the other" (Butler 2004, 31). Within affect studies, feminist theory, and disability studies, "vulnerability" is often used to describe humans' precarious relationships to each other (Titchkosky 2007; McCosker 2012; Butler 2004). Vulnerability, as it is used here, is not synonymous with victimization or weakness, but rather signifies a way of theorizing new methods of care and relationality, of understanding oneself as one part of a network. As McCosker writes, "vulnerability, the fact that we can be so easily injured or harmed, opens a path for affect, ethical conduct and sociality in an encounter with another's pain" (McCosker 2012, 2). Some scholars suggest that the act of inhabiting and understanding vulnerability—embracing it—can become a practice of resistance or shaping worlds (Behar 1996; Hedva 2016; Butler 2004).

In online endometriosis spaces, as this chapter will explore, shared vulnerability—this relationality—can shape the ways the disease is experienced and felt. As Emma Whelan has explored, although personal experience is an important tool for people with endometriosis, it is not their only method of understanding the disease (Whelan 2007). In fact, the social media practices of my participants show that they commonly turn to other people to contextualize their experiences within a broader history of knowledge and feeling. Going online provides people with endometriosis an ability to understand their disease, its symptoms, and their associated feelings *socially*. Just as the body's nervous system is intertwined and circuited together, so too are the networks of feeling and connection that so many people with endometriosis engage with online. Although often represented as "ephemeral," these social media practices can actually lead to very real effects/affects in the body, such as reduced stress or even reduced pain (Bunde et al. 2006; Shoebotham and Coulson 2016; Rains 2018). Affect theory offers a method of thinking about how emotions and lived experiences are moved, shared, practiced, ritualized, and structured through media practices, as well as what gets created in the process (Ahmed 2013; Rentschler 2017).

I use affect theory to build on the work that Emma Whelan began in her 2007 article " 'No one agrees except for those of us who have it': endometriosis patients as an epistemological community." Although written before the rise of online endometriosis communities and social media, Whelan's observations of offline endometriosis communities remain relevant today. As mentioned in my first chapter, Whelan's article considers how those living with endometriosis often use social spaces to understand their own bodily knowledge and experience *socially*. Just as affect theory and neuroscientific research have shown that physical sensations are *interpreted* by our bodyminds, Whelan's research shows that many people with endometriosis interpret their own experiences through "other kinds of knowledge," such as medical research or other experiential accounts (Whelan 2007, 971). As she writes,

> The validation of illness experience as a form of knowledge is done by the community, not by isolated individuals. The notion of illness experience plays several roles in the patient community. It provides a basis for solidarity among patients because the illness experience is constructed as *shared* by the members of the patient community. It defines a boundary around the community based upon knowing through being, and defines outsiders (including medical professionals) as pseudo-experts. (Whelan 2007, 978)

Whelan's research usefully identifies the ways in which certain rules and practices get shaped within endometriosis communities. Drawing on the work of Lynn Hankinson Nelson (Hankinson Nelson 1993), Whelan refers to endometriosis support groups as "epistemological communities." An epistemological community is a group "which shares a body of knowledge and a set of standards and practices for developing and evaluating knowledge" (Whelan 2007). As the last chapter explored, Whelan specifies that, "while communities share bodies of knowledge, standards, and categories, and all members accept some of these, they do not have to accept all of them and there may be no single belief that is shared by all members of the community" (Whelan 2007, 959). I aim to expand upon

Whelan's characterization of epistemological communities by using affect theory to frame these groups as not only knowledge-based but also grounded in emotion, sensations, and feelings of connectivity.

On the one hand, shared experience and bodymind knowledge are key factors in the feelings of connection that emerge out of online endometriosis communities. New York City blogger and women's health advocate April Christina describes how she didn't know her leg pain was a part of endometriosis until she went online (April Christina 2020). Similarly, Alex Kuller from Endo Knows No Gend-o describes how sharing experiences online made it easier for them to go to their doctor and say "I'm having these symptoms and I think they're all connected" instead of just "I'm having this symptom and maybe it's just something completely unrelated" (Kuller 2020). However, connection and validation do not only emerge out of this shared knowledge and experience, they also emerge through shared feelings and affect. As affect scholars have theorized, "affective publics" such as online spaces, help drive feelings of collectivity, engagement, and belonging, as well as sometimes lead to mobilization or activism (Papacharissi 2015; Gregg and Seigworth 2010). Shared feelings and affects shape how we think and how we act (what we *do*) (Wetherell 2012; Ahmed 2013). In this chapter, I use affect theory to explore the connective and emotional social media practices of people with endometriosis as well as what these *do* for endometriosis discourse and care, and what is at stake in that doing.

November 13, 2017: Shared experiences, part 1

Two days after my diagnostic surgery, I post a photo on Instagram announcing my diagnosis and (for the first time) feel justified using the hashtag #endometriosis. Dozens of people I've never met comment on the post or message me, sharing their own experiences with endometriosis. One of them, 'Jade,' tells me she had surgery the same week I did and asks if we can share our experiences with one another. For two months, we stay in regular contact, sharing intimate details of our recovery: our fears our around taking our first showers; our difficulties urinating, walking, and eating; our struggles with anxiety and depression post-surgery; our feelings of helplessness; and more. Jade tells me she finds it difficult to open up to *those around her, that they don't fully understand, and that talking to me has helped her a lot. "Just to know I'm not going insane," is how she puts it. I feel the same way.*

Shared Identifications and Attachments

For many with the disease, feeling an attachment to the word "endometriosis" can provide a sense of validation, as it does for interview participant Emma, who is still waiting for her official diagnosis for both endometriosis and adenomyosis:

> The fact that (despite not having the official diagnosis) I seem to have the same stories as thousands of people that I've read online makes me feel like, I don't know […]There's no doubt in my mind that I have it, but at the same time there's the 1% of me that [worries I'm wrong] and then I [will] get my hysterectomy and they [will] say "it looks fine," and I would be devastated. I think that's an impossible thing to explain to people who are like "wouldn't you be happy that there's nothing wrong with you?" and it's like "NO!" (Emma 2020)

Most people with endometriosis spend years (a worldwide average of 7.5) feeling like something is wrong with them and having to convince doctors, friends, family members, and employers that their symptoms are legitimate. Emma's quotation explains one reason why so many people with endometriosis feel such an attachment to the word. After years of struggling for a diagnosis, the name "endometriosis" can be extremely validating. Madelyn, for example, tells me how she cried when she was first taken seriously as having endometriosis:

> I just started crying because I was like "I don't have to fight you?!" (Morneault 2020b)

For others, such as Frances, the process of diagnosis can be more obscure:

> [I received] all of these weird diagnoses like IBS, Interstitial Cystitis. So I'm not even clear on what I have. Do I have IBS? Do I have IC? Or is endo the root cause of all those things? (Frances 2020)

Frances further describes how they don't like to identify with the disease and some of the names that people with endometriosis take on, such as the common "endo warrior" which was mentioned above.

> I think a lot of people in the group take on endometriosis as an identity and I struggle with that because it's not something that I want to have or experience, so I don't want to claim it as part of my identity. I think a lot of the posts about the endo warriors or, nothing against people who get the

> yellow ribbon tattoos, but […] I don’t connect to that stuff and it makes me feel isolated *within* the endometriosis community because I don’t want this disease to be a core part of who I am, even though it *is* a core thing that makes up my life. I don’t want it to be attached to who I am as a human. I also think it’s okay for people who *do* have that attachment too because it’s such an all-encompassing disease that affects every area of our lives, but personally I just don’t want to be tied to that. (Frances 2020)

For Frances, the word “endometriosis” reminds them of the many traumas they experienced trying to get treatment for their symptoms. Frances’ story is a reminder that the only reason some people become attached to the word endometriosis is because the disease has already attached itself to them. The choice of attachment is already out of the patient’s hands, although they sometimes choose how to shape that attachment. This is where endometriosis gets “sticky” in the way Sara Ahmed describes—where attachments are formed to specific groups and sentiments and drive meaning, actions, and feelings of belonging or estrangement (Ahmed 2013).

Not all attachments look the same. Some prefer the anonymity of Reddit, while others like the casual group format of Facebook, where they can ask questions but aren’t necessarily “part of a group.” On Instagram, many of the predominant endometriosis accounts on Instagram have the word “endo” in the username, such as LP from @TheEndoMonologues or Kate from @EndoGirlsBlog. These users sometimes have their own private accounts focused more on their own lives. Others, like Chantelle or Alysia Dagrosa, just have personal accounts where they occasionally talk about endometriosis (Dagrosa 2020; Nkosi 2020). Chantelle explains to me in our interview that this is because she “can’t separate endometriosis from the rest of [her] life” (Nkosi 2020). Those who have dedicated their accounts to endometriosis are sometimes criticized for being too “attached” to their disease. While this critique largely plays into the patient-blaming that people with endometriosis so often face by implying that they are ‘making themselves sick’ with their attachments, it is also true that social media platforms are designed to be addictive, and that attachments to online communities can sometimes be more unhealthy than beneficial. As Zizi Papacharissi writes, “digital, among other media, invite and transmit affect but also sustain affective feedback loops that generate and reproduce affective patterns of relating to others that are further reproduced as affect” (Papacharissi 2015, 23). The cycle continues and, with it, shared identities can become habitual and self-reproducing.

Dr. Sallie Sarrel from The Endometriosis Summit specifically tells me how some organizations use emotional intensity and shared feelings to promote themselves:

> They want that connection of likes, [so they] might [post] "176 million women" and they choose to say women "worldwide have endometriosis and they all consider committing suicide" because the word 'suicide' will get more likes and it's how you connect. (Sarrel 2020)

Sallie makes the point that the emotional vulnerability that so often comes with having endometriosis can make people very easy to manipulate. This is seen constantly on social media, where scammers will post magic cures in the comments sections of people's Instagram posts or companies will use chronic illness hashtags and language to sell their products. Many people with endometriosis also become members of multi-level marketing companies as they promise a way to make money easily from home. Different endometriosis organizations also use different tactics to try and promote and fund their work. Les Henderson, who tells me about their difficulty navigating conflicts in the non-profit and charity sector, laughs while telling me "we shouldn't have all this drama around a fucking illness. We're all sick" (Henderson 2020). LP tells me something similar during our interview: "we're trying to heal, not be part of the drama" (LP 2020)

But, because of the challenges facing so many people with endometriosis, attachments to things that *do* work can become very strong and emotionally significant. During our interview, endometriosis advocate Alysia Dagrosa describes how many people get attached to the surgeons or organizations that have been helpful to them and can get caught up in conflicts defending those attachments (Dagrosa 2020). Although these debates often getting enacted on the patient-level, many of these conflicts emerge at the organizational or specialist level. While talking to Shannon Cohn about her process of making the endometriosis documentaries *Endo What?* and *Below the Belt*, she describes her surprise at how conflictual the endometriosis landscape is overall:

> There are a lot of politics in the endometriosis landscape that I had no idea about and I think most people don't know about, which holds the disease back unfortunately. Mainly from, quite frankly and candidly, doctors' egos where they kind of get into different factions, where this doctor doesn't like that doctor and that expert doesn't like that expert. I mean it was really strange for me, like 80% of the time, I'd turn off the camera after an interview, somebody would take a shot at another expert that I'd interviewed. It was quite an education for me because I had no idea. And I

> was told multiple times that this kind of politics was holding back the disease and I have found that to be true as I get deeper and deeper into this disease landscape and it's really infuriating as a patient to try and move things forward, but sometimes the gatekeepers don't play nice. (Cohn 2020)

Many of the conflicts that emerge between patients reflect larger conflicts between different organizations or practitioners. For people with endometriosis, the emotional intensity behind these conflicts is attached to years of mistreatment and the fight for improved care. For doctors or specialist-run organizations, this important emotional side often gets neglected and care can be compromised in the process.

Attachments also drive the feelings of belonging and community that are important to so many people with endometriosis. However, these feelings of belonging do not always come easily. In our interview, Nomagugu tells me that she sometimes felt like she wasn't "sick enough" to be part of Instagram endometriosis spaces:

> I think this is my first time saying it out loud, but […] when I mentioned seeing sick people and all the suffering […] I started to wonder if I was sick enough to be a part of this group. I do have a lot of good days; I do have days where my body is kind to me and I have peace on that day. […] So I kind of have to learn to be kind not myself and say, "it's okay that you are okay." You don't have to be sick or unwell or in pain all the time to relate to other people in this space. (Nkosi 2020)

@tomis_endo expresses a similar sentiment and I feel it myself as well, wondering at times if I'm "sick enough" to be doing this research (and other times being too sick to do it). An anonymous survey respondent describes the same experience:

> It's nice to relate to other people going through similar things but I stay away from the [Facebook] groups a lot now after the initial adjustment period as the negativity gets to me and makes me feel like I'm going to be disabled and never going to get better even though my symptoms are well managed and I live a pretty normal, comfortable life or that I'm a 'fake' or must not truly have the condition because my pain isn't 10/10 ruining my life.

Although it is possible to suggest that some people may become attached to this identity of being sick in an unhealthy way, knowing how long and hard so many people have had to fight to claim the word "endometriosis," having some attachment anxiety is also understandable. Further, Nomagugu quotation shows that she is not just interested in her own identity but also in how she can relate to other people in the space. Her anxiety around being "sick enough" is not only about the disease, but also about not wanting to lose the community she has found after feeling isolated for so long. This desire for connection and attachment is a key component of what makes these online endometriosis communities so meaningful, so complex, and so sticky.

The power of these connections should not be undermined. For some, like one anonymous survey respondent, it's their way of "connect[ing] to the outside world when [they] flare up and am bed bound for a week or more." Like many of my interviewees, Nomagugu describes how she commonly has followers tell her that they "don't feel alone anymore" after reading something she has shared on Instagram. For all the people living with endometriosis who have been dismissed time and time again, these kinds of connections and relations can be extremely valuable. As one anonymous survey respondent wrote:

> I have found support simply through the realization that there are many more people who experience these symptoms than I thought, and that there is a valid explanation for the pain. It has been very validating to hear other people's experiences, particularly when it comes to being dismissed by medical professionals when seeking treatment.

Another survey respondent describes how she also values the collaborative environment that social media offers. She appreciates exploring the information available online alone as well as sharing "[her] own experience, and in turn [engaging] in collaborative learning with others." This process of collaboratively learning about endometriosis also takes the weight away from the isolation the disease can so commonly cause, and the sense of connection can lead to feelings of attachment and community.

In response to the question "has your participation in these [social media] spaces changed how you feel about or experience your symptoms related to endometriosis?" a survey respondent named Molly says:

> Yes, they are a little less scary. It's hard when you [sic] body can suddenly swell, or you get a sudden tearing pain that makes you cry out without meaning to. And depressing to realize your language of pain is so nuanced because you have such an intimate experience with it. I realized I was undercutting myself at one point in talking to my doctors because I made distinctions between discomfort and pain. These spaces taught me that there are other people who know these same things, who are on different stages of the path through this disease who are still here, still alive, still strong. I wasn't crazy, I wasn't weak, I wasn't alone.

Not only does Molly's answer illuminate the immense validation that can come from social media connections, but it also suggests something beyond just shared experiences and shared knowledge—that is, a shared *language* of pain that connects her to others with the disease. Later in her survey, Molly says these connections "gave [her] control over [her] disease." Her response suggests that she had to learn how to translate her symptoms to doctors in order to be understood, a skill she only was able to learn from others online.

LP from @TheEndoMonologues describes how simple it can be to become a part of the broad Instagram endometriosis "community:"

> I tend to look every day at the #endometriosis hashtag and you'll have people starting their new accounts and people just [saying] "oh, welcome to the community, it's a shit club to be in, but if you have any questions, please feel free to message me." (LP 2020)

LP further explains that there is a certain kind of supportiveness and protectiveness that occurs in this space:

> I think we're protective of each other [on Instagram]. There are a lot of people making sure that misinformation doesn't get shared and that people can express their feelings on it. (LP 2020)

She goes on to mention an event that had occurred the day before our interview, where a panel of doctors in the United States appeared in a video spreading misinformation around COVID-19, claiming that face masks were not necessary, and that hydroxychloroquine was a cure. After some websites investigated the doctors, the news came out that one of them, Dr. Stella Immanuel, had previously claimed that endometriosis was caused by having "astral sex" with demons (Hawk 2020). This information quickly made its way around the endometriosis Instagram sphere, with users poking fun at the idea and dismissing it. Although the misinformation that people living with endometriosis face is not often as extreme as this case, throughout my research period, I have seen monthly, and sometimes weekly, incidents where the Instagram community comes together to dispel misinformation, often joining together to report or ban the users who post it. Endometriosis communities often structure themselves around a shared rejection of misinformation and the shared experience of being continually dismissed and/or traumatized.

June 1, 2021: Shared experiences, part 2

Although it has been years since I talked to Jade, the friend I made after my first surgery, I still feel a closeness to her for sharing that experience with me. Reading back our messages, I'm shocked by the symptoms I described and just how bad they were. It's a reminder of how easy it is to forget and dismiss your own symptoms when you're not continuously tracking them or having them reflected by people nearby. The medical dismissal surrounding endometriosis can become internalized within my body itself. People with endometriosis often bond not only over their shared symptoms, but also their shared dismissal. This shared medical trauma is one of the stickiest parts of endometriosis communities. It is both the glue that brings people together as well as the muddy feelings that conflicts emerge out of.

Affective Communities

Differences and Conflicts

So far in this chapter, I've explored how endometriosis can become part of a person's identity and how these shared experiences and identifications can bring individuals together online. But it is also important to consider how new collective identities are also *created within* online endometriosis spaces and that multiple— and often conflictual—communities emerge from these differences. Some of the most notable fractures between different online endometriosis spaces are based around gender. A handful of my survey respondents specifically mention feeling isolated from many online endometriosis communities because of their use of gendered language, such as "women with endometriosis," "endo sisters," and so on. One anonymous survey respondent describes how they originally joined a Polish Facebook group but "had to leave very soon because of the very women-centred language and lack of understanding that not everyone is cis[gender]." Another mentions how joining groups of predominantly cisgender women was triggering for them because of the focus on fertility: "I don't want children and it all seemed to be about being a woman = having children." Alex who created Endo Knows No Gend-o describes a similar experience:

> Part of me doesn't want to be part of [many of the groups] because I don't see those spaces as safe places for non-binary or trans people and I think the communities need to be more actively focused on changing the language. And I don't think that's just the fault of cisgender women who have the disease, I think it's also the fault of the medical community in framing endo as a woman's disease.[53] (Kuller 2020)

Alex goes on to explain the opposition that exists in some of the endometriosis groups:

> I've seen queer people post in those spaces about what needs to change to make those spaces safe for them and a lot of especially white, cisgender women being like "well, get out of this space then." Like really toxic, gross stuff. (Kuller 2020)

Although there are certain shared experiences within the endometriosis community, there can also be vast differences in experience that lead to conflicts and even make certain spaces unsafe for people.

Les Henderson from Endo Queer describes how they had difficulty feeling like they belonged in endometriosis communities until they made their own:

> It was very heteronormative. Many people there were like "luckily I don't have to worry about working, my husband takes care of me." I'm like, shit, I don't have a rich woman in my life. I still have to sometimes double up on the Advils and still take my ass to work. (Henderson 2020)

These differences in experience led Les to create their own organization and online space where LGBTQIA+ people could share their own specific experiences. Similarly, April Christina describes creating her Instagram to reach out to other African American people with endometriosis:

> I didn't find anyone that was my colour that was talking about it. And you know, within our community, we don't really discuss the health issues that we deal with [...] I really wanted to find [...] a community for other people that are African American just to see if we could compare notes. (April Christina 2020)

Although there is often a certain sense of collective identity between people with endometriosis due to their shared symptoms or experiences, there are also more specific communities and collectives *within* the broader endometriosis landscape. Each Facebook Group or group of Instagram users operates differently and has its own rules, identities, feelings, and attachments. Identity is not a fixed thing, but something that is practiced and

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[53] As mentioned in the introductory chapter, although endometriosis is most common in people assigned female at birth, it has appeared in those assigned male at birth.

continually being developed and shaped by everyday practices, such as social media posts (Mol 2002; Butler 2005; Poletti and Rak 2014). Similarly, endometriosis communities are constantly redefining themselves and, within that, redefining endometriosis itself. Even the idea of what an "online endometriosis community" looks like differs depending on who you ask, where you look, and when you encounter it.

Defining Community

Despite these complexities of the word "community" and the many different groupings that exist within online endometriosis spaces, "community" is still one of the most common words that my interviewees and survey respondents use when describing their collective and connective experiences. When asked about whether they would call the online spaces "communities," some interviewees agree without question, while others suggest alternative words, such as "sisterhood," "brotherhood," or "tribe." They also use "community" in different ways, sometimes all in one sentence. Chantelle, for example, tells me she feels like endometriosis social media is a community in some ways, but not as close as her in-person (offline) communities. Some of the others explain that they feel like they have communities *within* the endometriosis social media sphere, but don't feel like the *whole space* is necessarily a community, or at least not one they identify with. Frances, for example, does use the phrase "endometriosis community," but explains that they have difficulty identifying with it. Similarly, Emma says she doesn't feel like a part of the endometriosis community, but *does* feel like a part of an endometriosis subculture:

> We have the things in common, we have the shared experiences that make us part of that subculture. But community I feel is so much more complicated. (Emma 2020)

The term "subculture" comes from cultural and communication studies and describes a group of people who are brought together through their shared interests and behaviours that subvert or resist mass culture (Gelder and Thornton 1997). Subcultures are characterized by this opposition and resistance. Along these terms, some of the online endometriosis communities I've described could be qualified as subcultures in how they often resist the dominant narratives of the disease (as will be explored more in the next chapter). For my participants, however, there often seemed to be something very important about the concept of community and the *feelings* of community that they so often described getting from these online spaces. I would argue that the word 'community' evokes some of the messy affective engagements these spaces contain, outside of just the rituals and practices of a subculture.

To be part of an online endometriosis community, individuals 'buy-in' to the idea that they have shared experiences and shared feelings around this topic. One useful framework for thinking through these online communities is through affect theory and Lauren Berlant's concept of the "intimate public." As she writes,

> A certain circularity structures an intimate public, therefore: its consumer participants are perceived to be marked by a commonly lived history; its narratives and things are deemed express of that history while also shaping its conventions of belonging; and, expressing the sensational, embodied experience of living as a certain kind of being in the world, it promises also to provide a better experience of social belonging. (Berlant 2008)

An intimate public can be somewhat insular in its circularity, but it also allows for important forms of connection, reflection, and belonging, particularly for individuals who have never found that intimacy and validation in other communities. Zizi Papacharissi expands on the concept of the "intimate public" with her term "affective publics" which she articulates as people *feeling* their way into political belonging. Affective publics give people meaning and can drive movements and activism, but they can also create feedback loops of affective engagement (Papacharissi 2015). This is all visible in online endometriosis communities: shared feelings can bring individuals with endometriosis together towards a broader understanding of their disease as something collective, historical, and political; but these online affective networks can also prompt forms of engagement that are addictive or laboursome, as explored earlier. In order to be a participant in these communities, there can be a pressure to engage—or engage in specific ways—to feel a true sense of belonging (Papacharissi 2015).

Although the boundaries around what defines the endometriosis Instagram "community" are unclear, there is a degree of collaboration that can come out of just using the hashtags, such as #endometriosis, #endo, or #endowarrior. There is also the possibility to encounter genuine care and form lasting connections. As LP goes on to say:

> I've made some really good friends now in the last 6 months and there are people I check in with more online as opposed to real life because they get it

> and you can kind of message people and go "I've had a really bad day" and you don't have to explain why […] which is really lovely and I think that has really helped my mental health too, just knowing that if I need to talk to someone or if I need to vent about something generally people [will reach out]. (LP 2020)

Many of my other interviewees describe similar, lasting connections. April Christina tells me how two of her bridesmaids were people she met on social media and Nancy Petersen explains how there are people who got relief for their endometriosis 30 years ago and "still come back to [Nancy's Nook] to give other people hope" (Petersen 2020a; April Christina 2020). LP says that, although not every connection is that intense or long-lasting, even smaller connections can provide exactly what is needed at a certain moment.

Sticky (Tricky) Communities

In the introduction to this dissertation, I used the concept of "sticky" affect to theorize endometriosis and social media. In *The Cultural Politics of Emotion*, Ahmed articulates how feelings and bodies get attached to objects, and that "[w]e move, stick and slide with them" (Ahmed 2013, 14). Endometriosis itself is sticky, not only quite literally, in how the tissue can glue organs together, but also theoretically, in how identity, sense-making, and community stick to different understandings of the disease and different bodies. I return here to Margaret Wetherell's concept of "affective practices," which she characterizes as "patterned, communicative, and organized" ways of sense-making and embodied meaning making (Wetherell 2012). The way that feelings and identities get structured around endometriosis—and within endometriosis communities—can shape the way the disease itself gets defined and experienced. This is one of the reasons why online endometriosis communities can be such significant spaces and why some people feel such strong attachments to their specific groups, as has been shown throughout this chapter.

It is impossible to talk about online endometriosis communities without understanding that these communities can be wildly different. Each space comes with its own rules, rituals, and sometimes even definitions of what endometriosis is. Sometimes this is a clear difference, such as one group presenting itself as a support group, or another having very specific rules one must agree to before joining. But these rituals can also be more intuitive, such as the different kinds of posts that are welcome in one space versus another. In one community, it may be the norm to vent about the disease and discuss frustrations and difficulties, whereas another might encourage "empowerment" or uplifting posts. Depending on someone's own affective understanding of and attachments to endometriosis, either one of these groups could be deeply off-putting or antithetical to their understanding of the disease, as seen with the earlier example of the term "endo warriors."

Emma tells me about the difference between online communities for endometriosis versus its sister condition, adenomyosis (a uterine disease). Whereas a hysterectomy does not cure endometriosis, it does treat adenomyosis. When hysterectomies are mentioned within endometriosis groups, it usually leads to a discussion around how someone was mistreated by doctors and had their organs removed without informed consent, or it becomes a debate on why hysterectomies are not a cure for endometriosis. In adenomyosis groups, however, Emma explains that hysterectomies are celebrated:

> [The adenomyosis group] might as well be a hysterectomy prep and recovery group, because every single person in there is posting about prepping to have a hysterectomy, trying to convince their doctor to give them a hysterectomy, or just having a hysterectomy. And I, at this time, was still at a point where I was grieving that I was going to have to do this, whereas now I'm like, eh, it will happen, and every single post was like "It's eviction day motherfuckers!" like, "Here's my cake that I baked last night with a picture of my uterus on it with a big fucking X on it because I'm so excited to go get my uterus taken out. (Emma 2020)

Emma came into the adenomyosis group without realizing the rituals and sentiments that exist within that space and, at the time, they were overwhelming and off-putting for her. Although adenomyosis and endometriosis are often comorbidities, there are different politics between these spaces, and an "eviction day" post would not necessarily translate the same way in certain endometriosis communities.

These "rules" or behaviours are usually unwritten and the only way to learn them is through immersion and repetition and (affective) practice. One anonymous survey respondent mentions how there can be a certain expectation of knowledge in online spaces:

> Because people have to self-advocate with endo so much, most people do a lot of research on it. [But] people are also constantly learning about endo for

> the first time […] Because of this, I think there's often a clash in social media spaces because it seems that the well-researched folks get very annoyed when people who are just beginning their journey ask questions.

However, the conflicts in social media spaces aren't just about differences in knowledge, there are also very strong emotional attachments that shape how people interact. Over the course of my research period, I observed more conflicts than I could count, and they most commonly occurred around issues that people felt very emotionally attached to or that shaped their identity, such as fertility, body image, the classification of the disease, gender, disability, medical trauma, or their other unique experiences, as has also been reflected in other research on fertility support groups (Malik and Coulson 2008).[54] Further, some communities are not welcoming or safe for certain people. As one anonymous survey respondent writes:

> Trans-inclusive endo spaces—they're my community and I support them and feel supported by them.
>
> Cis run endo spaces—not my community. I am not supported by them. I am not even visible to them, or in some cases they actively wish to erase my existence.

Despite the emphasis on shared experiences by many of my interview and survey participants, there are also many instances where experiences do not align and people with endometriosis differ quite vastly, particularly when it comes to differences in race, sexual orientation, gender, and class. Of the 287 survey respondents, 99 (35%) described finding value in connecting to others with "shared experiences" and "shared experiential knowledge." Only 32 (11%) respondents also mentioned "shared symptoms," suggesting that symptoms are not the only factor that make up the "experience" of endometriosis. There were also 36 mentions of "shared experiences" and "shared experiential knowledge" in the interviews. While there is no singular centralized experience of endometriosis, there are connections between patients' experiences and networks of experiential knowledge that can be created by sharing those experiences. But these networks of knowledge depend on who is participating in them and the shared experiential knowledge of a group like

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[54] It needs to be noted that, during this research, I was often aware of conflicts (or just differences) emerging between my interviewee participants. Sometimes it feels a little unfair to put their quotations in conversation with one another when they might personally not want to engage with one another, and yet it is useful to see how even people who disagree with one another both hold to similar beliefs about the value of their own endometriosis social media spaces.

"Endo Knows No Gend-o" will end up looking different than the shared knowledge of another more cisgender-oriented support group, for example.

Ahmed writes *In the Cultural Politics of Emotion* that "emotions in their very intensity involve miscommunication, such that even when we have the same feeling, we don't necessarily have the same relationship to the feeling" (Ahmed 2013, 10). For all the shared experiences that people with endometriosis can have, these do not mean they will feel the same way, and this is perhaps at the heart of why these online spaces can be so conflictual. Although shared feelings bring people together, the online communities can be very affectively charged. Even the definition of what was "positive" and what was "negative" changed between every interview I had. Many of the people I interviewed told me how they couldn't stand the negativity in certain groups, describing what they saw as the "Olympics of suffering." Others felt that the groups that focused on positivity were not accurately describing the disease or representing the experience of endometriosis. As an interviewer, but also someone with endometriosis, I both understood these perspectives while also feeling a resistance to them. I could see how the phrase "Olympics of suffering" could make me feel invalidated in the same way that doctors had invalidated me. At the same time, I also understood how harmful some of the more negative spaces can be to mental health and overall wellness. Despite both perspectives having value, social media tends to exacerbate the dichotomy between them, which can cause conflict, particularly when emotional attachments get involved. Social media feeds on and circulates affect, creating attachments and communities, but also potential conflict and passivity (Papacharissi 2011; 2015). To riff on Ahmed's quotation as well as John Durham Peters' work, communication in its very essence involves miscommunication, and so often social media spaces can feel like just a collection of fragmented miscommunications all ricocheting off one another (Durham Peters 1999). For all the feelings of community and connection that online endometriosis communities can have, they can also be deeply difficult.

In my interviews, "toxicity," "drama," and "negativity" came up as recurring themes, although referring to a variety of different things, such as: misinformation, conflictual political beliefs, toxic positivity, negative attitudes towards illness, interpersonal disagreements, scamming, research conflicts, harassment, and more. Toxicity, negativity, and drama were rarely the focus of my interviews, but the participants also had no hesitancy admitting that these sorts of difficulties often emerge online. At root of the many of these conflicts is emotion and/or attachments to particularly ideas. Alex from Endo Knows No Gend-o aptly describes this behaviour as "comment[ing] in emotion" during our interview. They explain how they try to leave room for this in their Facebook group:

> [I feel] like there needs to be a space for people to share the hard things because this is a hard thing we're going through. And there are no easy answers and feeling hopeless or frustrated or upset is like the natural human response to being in a situation that's awful. (Kuller 2020)[55]

Emma similarly explains how "everyone [on social media is] just in survival mode try[ing] to figure out the best thing to do" which makes the spaces not always the "safest" or most conducive to conversation (Emma 2020). She explains how she tries to "keep the whole thing at arm's length" when there is an argument or conflict taking place for her own wellbeing (Emma 2020). Heather Guidone uses the classic saying "hurt people hurt people" to describe why some of the conflicts emerge and explains how she makes room in her personal life for people to mess up when they're feeling down, for similar reasons as Alex and Emma (Guidone 2020b).

Some of the people I spoke to—like Emma, Heather, and Alex—described having ways of managing the negativity or conflict they encountered online (Emma 2020; Guidone 2020b; Kuller 2020). Others just turned away from certain content altogether. Frances describes having had to stop following the hashtag #endometriosis because it reminded them too much of their medical trauma. Interview participant Kyung Jeon-Miranda mentions sometimes skipping over the posts that focus on suffering because she can't handle them. She describes feeling guilty, because "this is what people who don't experience pain do, skip over and ignore these kinds of posts," but she also has limits on how much she can process herself (Jeon-Miranda 2020). Chantelle describes how she needed to tune out of certain conversations after she received her diagnosis:

> It came to a point that I needed to just put those pages on mute so that I could go to the page when I was feeling like I needed to find some information or just completely unfollow it because it wasn't good for my own mental space to just keep seeing how hard it is for people to live with this

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[55] You can see in this example how people with endometriosis automatically get grouped together through shared experiences—"a hard thing *we're* going through."

> thing. So I had to kind of just separate myself from social media sometimes because it did become overwhelming and toxic. (Nkosi 2020)

One survey respondent describes how social media made them “feel significantly worse about the disorder [endometriosis] overall” due to transphobia in the online spaces. There are also times when people—myself included—don’t recognize that certain content is overwhelming them or worsening their own mental state. During my research period, I became sick of opening Facebook just to see hundreds and hundreds of endometriosis posts. At times, I could look at them solely as a researcher, but when I was in pain or suffering from symptoms myself, it became harder to not engage emotionally, or feel devastated at the toll the disease can take. I explore this stickiness in my research journal.

March 20, 2021: Burnout and overwhelm

I started really burning out at some point during Endometriosis Awareness Month, but I only just noticed. I can see it in my communities and my interviewees as well. The pressure to produce content, to correct misinformation, to share personal stories, to be engaged, can be exhausting. I’m trying to pay attention to everything that is happening this month for my research, but I keep losing track of it. There is just too much to take in.

In her book on endometriosis titled Pain and Prejudice, *Jean Jackson describes her own experience of overwhelm when looking online for endometriosis information:*

> *When I was first diagnosed with endometriosis in 2001, I was relieved to have an answer after years of thinking I was just weak. Trying to understand more about it, I jumped online to look for support groups. What I found horrified me. Comment after comment from women who’d given up work, who hadn’t been able to have sex for years, divorces, relationship breakdowns, unaffordable treatments, poverty, financial ruin, whole lives of singledom—because of pain! Each story was more tragic than the last. But I’d just had surgery and was feeling better. My doctor promised me I’d feel better for years. I didn’t want to become one of those ‘whingeing women.’ I didn’t want to be sick. I didn’t want to be a drag. I logged off and didn’t join another endo group until EndoActive came along.* (G. Jackson 2019)

What strikes me from this quotation is how none of the issues Jackson describes are a product of social media, but rather a product of endometriosis and its mistreatment. Social media often gets a bad rap for ‘making patients negative,’ and while there are aspects of this that are true, that is not the full picture. Social media offers a space where all the awful lived *realities of endometriosis can be visualized and communicated all at once. The overwhelm comes in part from the platforms themselves but is also very much reflective of the overwhelming realities of life with endometriosis beyond the internet. Social media just allows for all these realities to be seen at once.*

I recognize my overwhelm is not just from the content I'm seeing online. I've had two MRIs, an ultrasound, and a dozen different doctors' appointments this month. The heaviness of my own disease weighs on every single post I read.

Conflict and Response-ability

Interpersonal conflict is common in online endometriosis spaces but, as I have touched on, so many of these conflicts reflect larger tensions in endometriosis care, such as debates in the research, differing treatment approaches, and lacking resources. Further, many of the conflicts reflect years of dismissal and individual traumas. Alex tells me that the conflicts they often see in their Facebook group tend to come after a person's desire for a specific response is not met:

> People are sometimes looking for very specific things in how people respond and it can be challenging. I see it play out when people ask for a very specific thing and they don't think that's what they were given. It can feel very alienating or isolating in those times. (Kuller 2020)

A conflict I often witnessed during my research period was when someone would express themselves emotionally, often speaking to a lived experience of dismissal or trauma, but were met in response with facts or information. For example, an argument came up in one of the private Facebook groups in early 2020, where some patients were making the comparison between endometriosis and cancer. People who had experienced cancer themselves or knew someone who had it appeared in the comments to agree or disagree, including an endometriosis specialist. The conversation quickly turned into a hostile argument about which disease was "worse"—endometriosis or cancer. Because a doctor was involved in the argument, some people started to feel like he was dismissing the severity of endometriosis entirely. Many people with endometriosis have had trouble finding treatment because their disease is considered not as serious as cancer and therefore is not prioritized. So, although describing the disease as similar to or as severe as cancer may be factually inaccurate, for some it *feels* emotionally true. Alex even brings up this comparison during our interview, using a mix of fact and feeling:

> [Cancer] is the most similar [to endometriosis]: it is cells replicating where they shouldn't be and wreaking havoc. Finding out the new studies about how the hormone receptors on each lesion can be unique to that lesion to complicate hormonal treatments and how unless you do a clean excision it will just continue to grow. To me, that's cancer. (Kuller 2020)

Conflict often emerges somewhere in the sticky space between (mis)information and what *feels real*. Some groups try to control this by focusing strictly on research (like Nancy's Nook) or support. While sometimes having very strict rules around engagement reduces conflict, this is not true for all spaces. Rather, sometimes the rules themselves can create conflicts, as was discussed in the previous chapter in regards to Nancy's Nook.

Online endometriosis spaces are networks of many feelings, often conflictual, and often both deeply personal and significantly political. At one point during my research period, one endometriosis influencer began sharing information about one of the most recognized endometriosis surgeon's political contributions, arguing that if he supported Donald Trump, he is incapable of acting in the best interests of his women patients and that any advocates or patients who support that doctor are directly supporting Donald Trump. The discussion that followed was sticky and messy and I still find myself feeling stuck within it—between the personal and the academic, my values and my needs, a rock and a hard place. These enormous political questions ricochet off the deeply personal and the traumatic. Does one become a bad feminist by receiving surgery from someone they politically disagree with, even if that's the best option available to them (Gay 2014)? When we rely on a broken system to treat our bodies, what choices are people with endometriosis truly able to make?

In his book *Trans Care*, Hil Malatino writes:

> How can we think beyond burnout? How can we do justice to the fact that we are often triggered by one another in the act of caring but nevertheless *need* one another, in both specific and abstract ways, to get by? (Malatino 2020)

This quotation so vividly represents the conflicts that emerge within endometriosis social media spaces, although Malatino's subject matter is different. By going online, engaging in shared experiences, networking feelings, and forming attachments and communities, people with endometriosis respond to one another in intimate, meaningful, conflictual, and messy ways. This response, at its best, comes with a sense of relationality, of "response-ability" to each other, of care (Haraway 2016). However, in communities of traumatized individuals interacting in online spaces where affect is used to drive engagement, trauma-informed, ethical, and care-oriented responses are not always practiced, and this can make certain (or all) social media endometriosis spaces unsafe and undesirable to many. A wider study of people with endometriosis could show how many people with endometriosis have tried using social media in relation to their disease and chose to stop.

Collaboration and Advocacy

For all the wonderful things that my interviewees and survey participants said about social media and how it helped them gain knowledge and support, they also all acknowledged that it was by no means an ideal space. Perhaps Heather Guidone captured it best when she said during our interview that "the internet is the best and worst thing to ever happen to endometriosis" (Guidone 2020b). But, when there are so few resources offered to people living with the disease, options are limited. My research has revealed that, despite the complicated aspects of social media, the majority of people I surveyed and interviewed felt that it was an overall helpful or important space for them (95% of respondents). As a survey respondent named Erin writes, "yes sometimes people in the groups are looking for a fight or spreading false information which can be stressful, but the good outweighs the bad by far."

Endometriosis advocates are also working hard to make these spaces as informative and supportive as they can be. Heather added during our interview that she doesn't "want people to lose hope:"

> I want them to know that, yeah, everybody's life looks great on the Internet, or on Instagram this person is sicker than you so you shouldn't complain about your symptoms. [But] that's not the reality. The reality is everybody who struggles with this disease has a very valid and real struggle that everybody else should acknowledge. And we should be trying to lift each other up and we should be trying to get to the solutions. (Guidone 2020b)

The desire to be on the same team and support one another was at the heart of all my interviews, even in the cases where conflicts emerged. Despite these conflicts, online endometriosis spaces have led to a wide array of collaboration and advocacy around the disease. As Kate describes:

> I would say a solid few hundred of us on Instagram, even when we are off doing our own thing (we might even bicker), but when shit hits the fan and we need to collaborate we do. We all come together and I love that. And I learn from them too. I've had them come in my DMs [direct messages] and I love this because they're empowered, they'll come at me, [and say] "Well Kate, I don't know, I've read this recently." They'll challenge me and I'm like, “Oh hell yeah. Like oh man she's really getting into it, okay.” (Boyce 2020)

Research on other online health support groups has shown that these spaces can often foster every day and small-scale forms of resistance and activism (Radin 2006). With endometriosis, however, this activism is often quite prominent or even built into the very fabric of the communities.

Those who began working in endometriosis advocacy before social media existed believe that it has increased the speed and quantity of collaboration and advocacy today (such as Nancy, Casey, and Heather). Although many concrete changes (such as adjustments to policy, research funding, treatment practices) happen *off*line, social media has helped to bring attention to the disease and the advocacy work that is happening. As social media scholars have been debating for some time, social media holds both the potential to bring more awareness and attention to social movements (Gerbaudo 2012), as well as obscure a movement’s goals or contexts (Dencik 2015). As we will explore more in the next chapter, change-making and world-building are some of the most complex aspects of online endometriosis practices that people participate in. But for many of the people I interviewed, endometriosis advocacy and activism were also central to their identity. Similarly, for many, this identity was driven by the emotion that comes with having endometriosis, as well as the way those emotions circulate online.

Conclusion: Social Practices of Endometriosis

Whether or not endometriosis makes up a large part of an individual’s identity, the way that people participate in online endometriosis communities can shape how they come to relate to the disease. The way they participate in these communities and in relation to one another can shift the way the disease comes to be felt and embodied, for better or worse. We might call this, to quote Helen Kennedy in the book *Identity Technologies,* "identity-as-practice" (Poletti and Rak 2014) or, via Margaret Wetherell, "affective practices" (Wetherell 2012). With both these theories, the idea is that the way we engage with others, express ourselves, and navigate rituals, behaviours, and connections shape how we come to understand ourselves, our identities, and our embodiments. In the case of endometriosis, participation in an online community may not only bring people together, but also alter the way endometriosis is thought of and experienced more broadly. What takes place within these communities is felt, embodied, and lived by its participants both online and offline, both negatively and positively.

It is common for research about online health communities to focus on either misinformation or the possible emotional benefits of support groups. What is missing from both discussions is the consideration of how these online spaces (and all their complexities) can shape people's identities and feelings, as well as their interactions with one another. What is missing is the "and"—that social media is messy *and also* helpful. As a survey respondent by the name of Polly writes, "sometimes [social media] looks like chaos. But it's better than nothing, and I'm thankful to these groups." The sticky and complex networks of feeling and connection that online endometriosis communities contain open up critical spaces for endometriosis to be reframed and retheorized. These communities offer support not just for individuals, but also epistemologically and affectively. They create a space where endometriosis is understood socially and where knowledge is produced not just through information-sharing but also affective engagements. Networks of endometriosis are not just made up through networks of information, but also networks of individuals and their social networks. Social media offers a place for endometriosis to not just be felt individually, but to be understood relationally, and this is something that often goes missing within western medicine. As Annemarie Mol writes:

> Friends and foes agree that medicine should add up its dispersed findings and treat the patient as a whole. Stranger still, if it wants to do really well, medicine should take into consideration that each whole patient is part of something larger: a family (relevant for the social support it may give or the biological resemblances it may harbor), a population. The circles grow and grow. And the largest circle contains all the others. (Mol 2002, 119–20)

With a disease like endometriosis, which has been so shaped by social and cultural preconceptions, these circles, these networks of feeling and connection, are critical to understanding the impact of the illness and how it is felt.

As I have explored, these affective communities can be emotionally messy and sticky spaces, but these connections and conflicts, these feelings and embodiments, are always in conversation with the bigger picture of endometriosis research, representation, and care. As Papacharissi writes, “affect, feeling, and emotion […] reflexively drive movements that express rationally focused expressions of ideological beliefs” (Papacharissi 2015, 3). The practices of feeling and connection are not separate from the practices of knowledge-creation and information sharing and, as I will explore in the next chapter, representation, and world-building. The practice of participating in these communities can shift the experiences of endometriosis, can influence the bodymind, and, as this chapter has shown, provide a space to *socially* explore feelings and experiences of endometriosis in relation and response to one another.

Chapter 4: Networks of Meaning

We tell ourselves stories in order to live.
(Didion 1979)

Introduction: Media Practices: Meaning-Making and World-Building

The previous chapters explored the information and knowledge practices, and social and communal practices of people living with endometriosis, as well as the messy networks of endometriosis created through these practices. This final chapter builds on the themes in these previous chapters by focusing on the other practices identified in my survey (see Figure 1): life writing, descriptive, and meaning-making practices—such as "describing your experiences" (50.4%), "describing your pain in your own words" (32.4%), and "venting" (31.7%)—and advocacy or world-building practices, such as "raising awareness about endometriosis" (61.3%). For simplicity, I will refer to all these primarily as meaning-making and world-building practices throughout this chapter. Although not as common as social/communal or information-based practices, meaning-making practices still make up an important part of what takes place in online endometriosis spaces. World-building practices are even more common. Although I have discussed advocacy and world-building briefly in both chapters two and three, these practices are best explored in conversation with meaning-making. As I will explore in this chapter, many people's decision to represent and describe their experiences is based on a desire to "raise awareness." Likewise, "raising awareness" often involves representation and/or meaning-making.

The blurry lines between representation and advocacy, between representation and mediation, or meaning-making and world-building, are what this chapter aims to explore. To fully understand the nuances of these terms and the practices that people with endometriosis engage in online, I will begin by exploring the complexities of pain communication, alongside the histories of narrative medicine, pain representation, and life writing/automedia studies. There is no singular movement or depiction of endometriosis that is created through social media. In fact, the story of endometriosis that social media tells can be sometimes nauseatingly complex. Further, as the previous chapters have explored, social media is by no means the ideal space for enacting change around this disease. And yet, the fragmented and messy portrait of endometriosis that social media creates is still extremely valuable. In fact, in messing with the commonly accepted definitions of endometriosis, patients on social media are creating the future of the disease. As I intend to show in this chapter, even the simple everyday practices of communicating about the illness can sometimes create significant changes in how endometriosis gets represented, experienced, and treated on a broader scale. As disability scholar Timothy Jay Dolmage writes, "[a]ll meaning issues forth from the body, but communication also reaches into the body to shape its possibilities" (Dolmage 2014, 89). Endometriosis is a dynamic and messy disease, built through networked narratives. By looking at the meaning-making and world-building practices of those with endometriosis, we can begin to see what possibilities exist for endometriosis on the horizon.

Communicating Pain, Illness, and Endometriosis

There has been extensive research and writing across disciplines on the challenges of communicating pain and illness, particularly between patients and practitioners (Scarry 1985; Woolf 1993; Hadjistavropoulos et al. 2002; Biss 2007; Käll 2012; Gonzalez-Polledo 2016; Dokumaci 2017). Chronic pain and illnesses involve biological, psychological, cultural, and social factors that can make it difficult to assess quantitatively (Craig 2015; Kirmayer 2012). Despite this, throughout western medicine, it is still common for many practitioners to use the "pain scale" in clinical practice, where patients are asked to label their pain on a scale from 1-10. This tool has been critiqued for its subjectivity and, although other alternatives exist, they are not as commonly practiced (Krebs, Carey, and Weinberger 2007; Bullo and Weckesser 2021). Despite the prevalence of chronic pain, it can be common for people with chronic pain to experience disbelief and invalidation from their practitioners, causing further stigma, isolation, and depression, anxiety, or other kinds of emotional distress (De Ruddere and Craig 2016). A recent quantitative study that focused specifically on people with endometriosis showed that medical invalidation, particularly when personalized, is connected to reduced self-esteem and greater depression in patients (Bontempo 2021).


The Endometriosis Summit

One Voice

What does Endometriosis feel like?

"Like a sharp scraping like knife gutting my insides"

"Deep pressure like there is a 20lb bowling ball in my stomach which someone is attempting to pull out forcefully thru my cervix"

"It feels like eating bobbed wire"

"I feel like my organs are glued together and being pulled down"

"Extreme contractions, stabbing, burning and pain radiating into my abdomen and back"

"An open wound that someone sliced with dull knives"

"I feel nothing except the longing for child"

endometriosissummi • Following

endometriosissummit Last week @endometriosis_surgeon shared a video reading what people's endometriosis feels like.
The description was incredible and the responses were eye opening.
What people experiences, mostly in silence often without access to care is mind boggling.
We wanted The Endometriosis Summit to be a place where people with endometriosis matter, a place where the silence is over and you can be heard.
That is why we are a Town Meeting.
Experts, patients, newbies, partners everyone using their experiences to challenge the current treatment paradigm in endometriosis.

Liked by madymorneault and 528 others

FEBRUARY 11

Figure 8: Screenshot from The Endometriosis Summit's February 11, 2021 Instagram post showing an image with different quotations from patients describing their pain.

Although endometriosis does not always involve chronic pain, it is one of the most common symptoms (experienced by at least 92% of my survey participants), and research about pain communication provides a useful way of understanding how endometriosis gets represented, mediated, and created online. Elaine Scarry's formative work, *The Body in Pain*, is particularly useful for framing how pain's seeming unrepresentability can "unmake" an individual subject's world, while also "making" new worlds both despite and because of this unrepresentability. Pain's lack of referential content, its unfathomability, can destroy language, but this objectlessness also "gives rise to imagining" and new forms of meaning-making (Scarry 1985, 162). For many endometriosis patients, the pain can be so severe that it renders a person unable to speak or move. In contrast, the representation of endometriosis on social media is almost incessantly focused on *making that pain communicable*. This is sometimes done through language, as seen in the screenshot from The Endometriosis Summit's Instagram (Figure 8), where descriptions of patients' symptoms are featured. Descriptions include a range of physical pains, such as "deep pressure like there is a 20lb bowling ball in my stomach which someone is attempting to pull out forcefully thru my cervix" and "like [a] knife gutting my insides," as well as emotional pain like "I feel nothing except the longing for [a] child." Endometriosis, and its pain, is also often represented visually online, sometimes through drawings, painting physical wounds on the outside of the body, or photography of a vulnerable moment, as seen in one of Madelyn Morneault's Instagram posts (Figure 9). The externally invisible, but full body, nature of the disease has also been represented through Instagram campaigns such as Dr. Wendy Bingham's #IAmExtraNotRare, where participants were asked to post a photo of themselves with symbols marking where in their body their endometriosis is (Figure 10). In reflecting on the #IAmExtraNotRare campaign, Wendy uses the words "validating" and "powerful" to talk about this act of representing the disease.

madymorneault 🎗️ This is #Endometriosis
💥It's ER level pain, but deciding to stay at home because you know the nurses can't do anything except maybe accuse you for seeking opioids
💥It's feeling like you're on a time crunch to have the baby you know you want before your insides get damaged to the point of no return... but knowing full well you can barely manage your own health let alone care for another life at the moment.
💥It's feeling like your goals are only getting pushed back instead of inching closer to them
💥It's an endless cycle of developing, learning to cope with, and treating new, debilitating symptoms
💥It's being 22, "looking fine", and unable to stand for a shower
💥It's learning to never take the basic function of breathing for granted when every breath feels like someone is wringing out my torso like a wet rag
💥It's doing everything right...
And still having more bad days than good.
🎗️ It's been a rough week. My #thoracicendometriosis has significantly progressed; based on my worsening symptoms and chest spasms I believe that I have endo inside my chest cavity as well as on my diaphragm. Things took such a sharp and painful turn and now vomiting blood is a thing??? I have to start making decisions on where to pursue a second #excision surgery that requires even more high risk elements than my pelvic excision surgery. There is no way to positively spin this... there is no "inspirational angle"... there is no point in sugar coating the reality 💥Sometimes... endo just really f*cking sucks
#endometriosisawareness #endowarrior #1in10 #patientcare #patientadvocate #patienteducation #invisibleillness #extrapelvicnotrare #chronicpain #invisibleillnesswarrior #chronicillnessawareness #endosucks #womxnshealth #fibromyalgia

Liked by **vinamohabir** and **168 others**

SEPTEMBER 7, 2020

Figure 9: Madelyn Morneault's Instagram post from September 7, 2020 showing her in a vulnerable moment of pain in the shower.

extrapelvicnotrare #Repost @endogirlsblog with @get_repost

My name is Kate

I live in #Arizona
I have #ExtrapelvicEndometriosis

Endometriosis was excised from my
#Bladder
#SigmoidColon
#Appendix
#rectovaginalspace

#IAmExtraNotRare #EndoAwareness2020
#Endometriosis
#Endoawareness
#urology
#gastrointestinal #gynecology #gynecologist #obgyn #surgeon
#surgery

91w

Liked by **endo.days.ontario** and **46 others**

MARCH 2, 2020

Figure 10: A screenshot of @extrapelvicnotrare's March 2, 2020 Instagram post showing Kate Boyce from @EndoGirlsBlog as a part of the campaign #IAmExtraNotRare. The X's mark where Kate's endometriosis was.

Although this chapter will go on to complicate the role of representation in endometriosis, finding ways to communicate and make visible the experience of endometriosis clearly plays an important role for many people living with the disease. Further, social media, reveals how many different ways there are to represent the same illness and just how diverse the experience of endometriosis can be. Endometriosis can be depicted as debilitating and dehumanizing (as seen in Figure 9), or it can be shown as just one part of a fully-fledged, complex, and dynamic human being (as seen in Figure 11). In fact, many content creators show both sides, searching for a balance between depicting the pain and impact of the disease, while also finding ways to empower, humanize, and support themselves.

lifeabove_illness I'm not used to seeing bodies that look like mine. Ones where stories of pain and heartache live within each visible scar that you trace.

I've spent years learning to become comfortable in this skin. To love this body. This body that doesn't display the world's version of beauty or perfection that is impossible to live up to.

This body may not be perfect, but it has endured the unimaginable and is still here to tell about it. I will take that over perfection any day.

Figure 11: Jenneh Rishe (@lifeabove_illness) posts a selfie to talk about her relationship to her body and her scars.

As can be seen in many of these examples, selfies and other forms of self-imaging are commonly used in the practice of representing endometriosis online, especially on Instagram. This is likely due in part to how tied to identity endometriosis can be, as was discussed in chapter three, but it is also a result of engaging in the conventions of social media. Many of my interviewees described using the trends and tools of different social media platforms to communicate their message more effectively. Although the practice of taking and posting self-images has often been represented as self-serving or narcissistic, social media and girlhood scholars have explored how it can be used as a form of critical thinking, social commentary, or activist practice (Senft and Baym 2015; Dobson 2015; Holowka 2018). In her work on “auto-theory,” Lauren Fournier argues that practices of self-imaging can also be used “to process, perform, enact, iterate, subvert, instantiate, and wrestle with the hegemonic discourses of ‘theory’ and ‘philosophy’” (Fournier 2018, 643). We will see several examples of this processing, exploration, and critical engagement throughout this chapter.

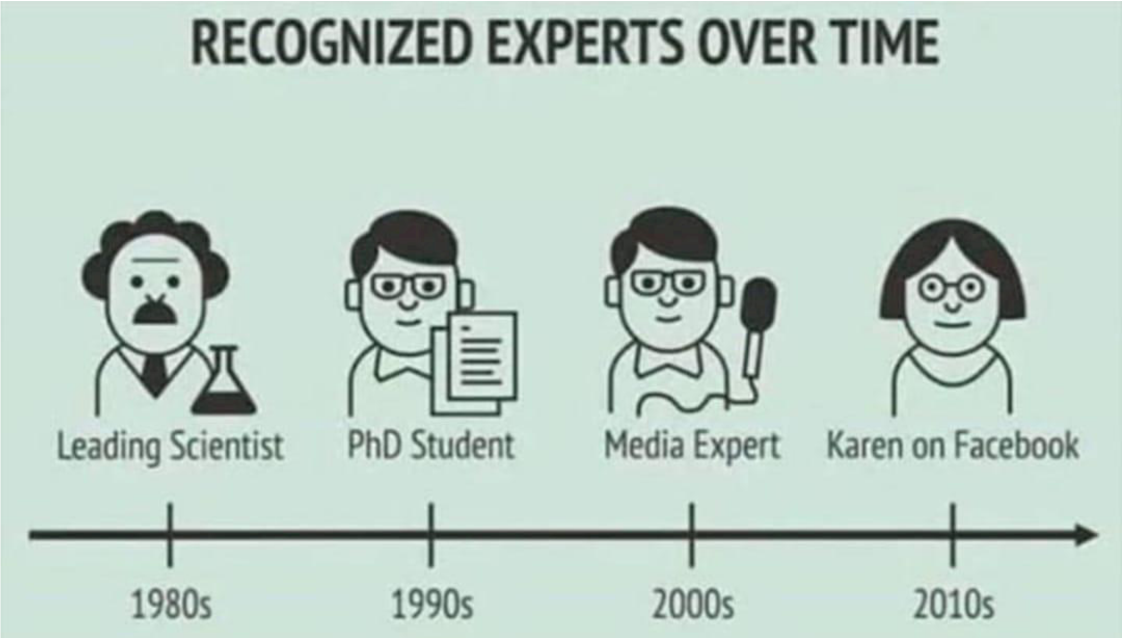

Figure 12: The meme that was posted on Twitter by an endometriosis doctor and academic in May 2021.

Girlhood and social media scholars have also shown how dismissing the online practices of, in particular, girls and women often works to delegitimize their concerns and erase their impact as active producers of culture (Dobson 2015; Mendes, Ringrose, and Keller 2019). This is also true in the case of endometriosis, where patients who post or seek information online are commonly dismissed by doctors and other patients for this behaviour ("you've been reading too much about your illness on social media"; "you can't really be sick if you're taking selfies"; "she's just obsessed with being a victim").[56] As an example of this attitude, in May of 2021, a recognized endometriosis doctor and academic posted a meme to Twitter that showed a cartoon timeline of "recognized experts over time," beginning with a "Leading Scientist" and ending with a "Karen on Facebook" (see Figure 12).[57] The doctor tagged several other endometriosis specialists in his post and

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[56] These quotations are all examples I have heard throughout my life with endometriosis, from doctors and patients alike. At one point during my research period, a self-identified nurse posted in one of the Facebook support groups that, if she caught one of her patients taking a selfie while in the ER, she would not take that patient seriously. This is a common narrative online and there are entire forums dedicated to it (such as Reddit's /r/illnessfakers or /r/munchsnark which focus on select Instagram users who have been identified as alleged illness fakers). If nothing else, these examples show that choosing to make one's illness visible online also comes with a serious risk of being disbelieved.

[57] "Karen" is a pejorative term most often used to refer to an entitled middle-aged, middle-to-upper class white woman. A Karen might be racist, throw a fit about something, or ask to "speak to the manager."

wrote, “How things have changed.” Although it is hard to know if the doctor was referencing endometriosis patients with the post, his involvement in endometriosis research and social media spaces suggests as much and many people living with the disease interpreted it this way. Several responded to the post citing their own experiences turning to social media in response to a lack of care and how they were dismissed by doctors for doing so. The doctor later deleted the post, but the memory of it stands as an example of a common attitude towards social media and endometriosis within the medical/academic field. Alternatively, my interview with endometriosis specialist Dr. Gabriel Mitroi focused largely on the benefits of social media in raising awareness about the disease and how doctors should be careful not to dismiss social media use outright.[58]

Beyond the value of information-sharing, education, and social supports, social media also offers a place where patients can make their endometriosis visible, describe it in their own terms, and even contribute to a new cultural understanding of the disease. Research from Anna Sendra and J. Farré shows that Instagram can change the way patients (particularly those living with fibromyalgia and endometriosis) live with their chronic pain by allowing them to explore self-expression and create their own “illness world[s]” (Sendra and Farré 2020). Social media also allows those who do not explore representational practices themselves to benefit by seeing other people’s representations. As one anonymous survey respondent describes, seeing the experiences of those living with endometriosis represented on social media had a positive effect on their mental health. Patient representations can also be useful for doctors and other clinicians to see, according to Wendy. She tells me how the patient quotations on her website provide doctors with more detailed representations of patients’ pain that are not captured through quantitative measures such as the pain scale:

> Someone says ‘I feel like I have an elephant sitting on my chest and I’m trying to blow up a flat balloon.’ Maybe you don’t know what it’s like to have an elephant sit on your chest, but you know what it’s like to blow up a flat balloon and how hard it is. (Bingham 2021)

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[58] There are many valid reasons for clinicians to be wary about information from social media. But, as I have explored in other areas of this dissertation, research suggests that talking to patients about what they have learned from social media, rather than dismissing it outright, is a more effective strategy for building a healthy patient-practitioner relationship (Tan and Goonawardene 2017; Thiel et al. 2021b).

Patient narratives, descriptors, or metaphors can also be useful for showing how they experience, feel, and understand their pain. For example, in a study by Stella Bullo and Jasmine Heath Hearn, twenty-one women described their endometriosis with metaphors that represented it as an external agent controlling their experiences, showing that they generally felt a helplessness and lack of control surrounding their disease (Bullo and Hearn 2020). While patient representations are never perfect examples of endometriosis (what would a perfect representation be?), the intense, affective, or fragmented metaphors that people use to describe their endometriosis can often reveal the emotional and physical toll of the disease better than a clinical description ever could. As Dolmage writes about disability storytelling and rhetoric, imperfect narratives like these have value—"meaning actually springs forth from gaps and flaws and mistakes" (Dolmage 243). The value of online endometriosis representations is not just about what is created, but about what the practice of representation itself reveals.

Networked Meaning

Online storytelling has been used to give patients a voice and provide a place where they have their experiences heard. For example, Nomagugu Chantelle Nkosi uses the captions of her Instagram posts as a place to share her experiences with endometriosis. Her very first post about endometriosis involves a long caption about her journey to surgery and diagnosis. Some of these stories, like Nomagugu's, read more like testimony or confession than a narrative or metaphorical representation. People with endometriosis will sometimes describe their experiences online in a very linear, clinical, and confessional ways. The collected mass of stories under hashtags like #endometriosis thereby form a kind of "testimonial network," to quote Leigh Gilmore, in which an archive of endometriosis experiences can be witnessed (Gilmore 2012, 307). This archive reveals the enormous toll that endometriosis can take as well as the commonly shared experiences between patients such as medical dismissal, misdiagnosis, and debilitating symptoms. In this way, patients create their own research networks of endometriosis outside of academic or medical institutions. But these archives, or networks, are also complicated and incomplete.[59] These storytelling practices have also been picked up by endometriosis organizations, pharmaceutical companies, and doctors, who often share patient narratives to add an impact to their own posts or sell a product. As Nomagugu tells me during her interview, sharing personal stories gets her the "greatest engagement" on Instagram, so while some may be sharing their stories for their own benefit, others may be using it as an advertising tactic. The online archive of endometriosis stories is unregulated and the intentionality behind posts can be difficult to untangle.

Despite this, the practice of sharing stories online still seems to have a therapeutic potential for many users, as both my interviews and survey showed. Self-silencing has been identified as a coping mechanism used by people with endometriosis in the face of mistreatment, medical trauma, and debilitating pain (Cole, Grogan, and Turley 2021). On social media, this coping mechanism is challenged, and therapeutic self-expression is encouraged. For example, LP from @TheEndoMonologues started her Instagram account on January 1st, 2019 as a "wellbeing project" for herself, using humour and writing to cope with the difficulties of the disease (LP 2020). She thought that Instagram would be easier to maintain than a journal because of its social aspects and was surprised by the attention it garnered. Kate Boyce from @EndoGirlsBlog started in a similar way with her blog. She tells me she initially used her writing as "a sort of release and way for friends and family to see what [endometriosis] was all about" (Boyce 2020). Her blog later led to an Instagram account and extensive online endometriosis network. Similarly, Madelyn identifies how she used online writing as a way to cope with her inability to go out and about during the COVID-19 pandemic: "I have endometriosis on my diaphragm, if I get COVID, I die, because [the endo] might be on my lungs, it might be on my chest cavity, you know. […] So I dove into my writing" (Morneault 2020b). Writing on social media gave her a place to not only

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[59] I use the term "archive" here, like Gilmore, in reference to Ann Cvetkovich's *Archive of Feelings*, where she explores the value of recording the collected memories and feelings of marginalized groups. The theorization of certain social media spaces as "archives of feeling" has been explored by myself and other scholars in more detail elsewhere (Holowka 2018; Pybus 2015; Kasana 2014). In this dissertation I focus more on networks than archives to better think through relationality, the flow of power, and miscommunications. Still, spaces such as the #endometriosis hashtag on Instagram can be valuable archives of feelings and experiences.

express her experiences but also to connect with others while isolated (an act of self-care in community).

kyungjeon • Following

kyungjeon I painted this for International Women's Day. Did you know it is also Endometriosis Awareness Month? In this painting, women are supporting each other while wearing hospitals gowns that merge together into a Safety Net which was used to rescue people. #internationalwomensday #endometriosisawareness #diversityandinclusion #endometriosisaffectseveryone

43w

mongryong_lee ❤🙌❤👏👏👏
43w 1 like Reply

loriganz 😍😍😍
43w 1 like Reply

manvar07299 love it, 🔥🔥🔥🔥
43w 1 like Reply

oppalala66 👏👏👏👏👏
43w 1 like Reply

artefaktfilm 💛 I love this! 😍
43w 1 like Reply

agatka29 You are amazing artist 🖤
43w 1 like Reply

smellybates @jmil0413 ❤

Liked by silviayoung_ and 159 others

MARCH 8, 2021

Figure 13: Art from Kyung Jeon-Miranda posted to Instagram on March 8, 2021 during Endometriosis Awareness Month on International Women's Day.

Not all endometriosis representations on social media are language-based. Artist Kyung Jeon-Miranda tells me how she uses painting to cope with her endometriosis and, although she isn't very active on social media, she also shares these works of art online to spread awareness (see Figure 13). What is significant about each of these examples is that they all go beyond just representation for the sake of representation. They are, instead, representations put into a social context, where they can speak to one another, interact, and develop new meanings. This relationality, where each person's post opens the door to interactions and engagements, is part of what makes representation and meaning-making online so unique. As Judith Butler has written, there is always risk and vulnerability when trying to talk about or "account for oneself" in public, but online these social and ethical encounters are even more complex (Butler 2005). These complexities are what make online auto-affective media practices so generative as well as so potentially destructive (much like endometriosis itself). These posts are not just representative, they are *performative.* They are not ephemeral actions, but embodied practices, that produce and enact endometriosis with every post, recreating what it looks like, what it means, and what it can become (Mol 2002; Barad 2003). Meaning-making can quickly lead to world-building, particularly when practiced in online networks.

Many Endometriosises

In both my survey and interviews, I asked participants the open-ended question, "What does 'endometriosis' mean to you? Has this changed over time?" Some answered with clinical descriptions, some explained their symptoms, others were more metaphorical. While some answers focused on debilitating symptoms, others spoke of hope and growth. For some, endometriosis took on a kind of personality, described as "sadistic" or "controlling." For others, it was not only a disease, but a way of understanding the world, as shown by the answer "[endometriosis] has taught me access to care is unequal." One participant wrote that, "[i]t's something that's forever a part of my life… but won't define it." Another says "it means losing out on my 'timeline' for my own life." The most recurrent themes that people talked about were pain, their lives, and the time endometriosis takes away from them. By putting these answers into a word cloud (see Figure 14), the complexity of endometriosis can be visualized. Endometriosis is not simply one thing and its meaning varies between people, experiences, and lifetimes. Consider the combination of concepts that appear—symptoms ("fatigue," "pain," "cramps," "heavy [bleeding]," "nausea"); temporality ("time," "years," "always"); actors ("doctors," "medical,"); challenges ("struggle," "trying," "work"; "without," "help"); body parts ("organs," "endometrial")—to fully consider the complexity of what endometriosis can mean.

My argument, in this chapter and dissertation more generally, is that there are many endometriosises that are created and lived both on and offline.[60] Social media provides an interesting lens to view the multiplicities and conflicting realities of the disease all at once and this is part of what makes looking at endometriosis social media spaces so fascinating and jarring. *Networks of endometriosis* are not just a product of digital media but are a

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[60] This idea draws on the work of Annemarie Mol (Mol 2002).

reality of a disease that is created and changed through ongoing practices and is the site of so much mess. People with endometriosis actively engage in this meaning-making and world-building every time they attempt to represent their symptoms, make visible their illness, and express the inexpressible.

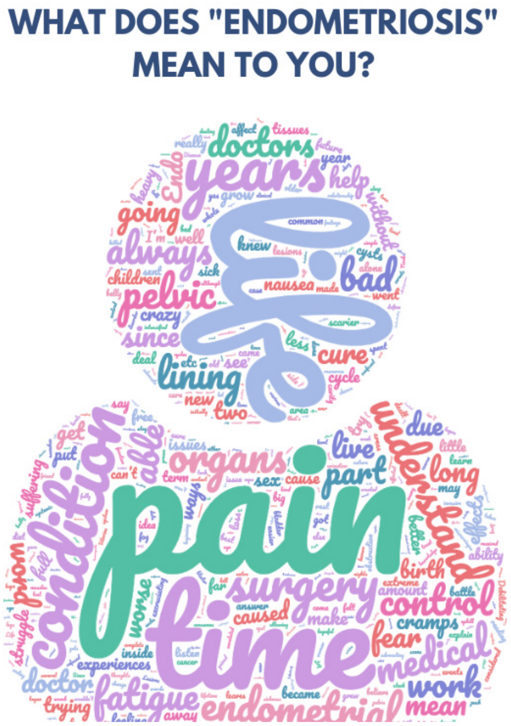

Figure 14: A word cloud based on answers to my survey and interview question "What does 'endometriosis' mean to you?"

April 11, 2020: The limits of language

Pain. It's all I can focus on or do. The world shrinks down, conversations are terse, short, energy reserved for how to breathe in, how to prepare for the next wave. I didn't want the pain to return. I knew it would, that it would filter into this thesis no matter what I did.

Ripping screaming. But really it's just silent, stillness. Fading in and out of reality, perception, becoming just a body in desperation.

Meaning-Making and World-Building

Storytelling and Automedia

To understand these social media meaning-making and world-building practices in context, it is important to establish the background of academic writing on representation and storytelling in narrative medicine, disability studies, and auto/biographical studies. As Zizi Papacharissi explores in her book *Affective Publics*, "newer media follow, amplify, and remediate [previous] tradition[s] of storytelling" (Papacharissi 2015, 4). Chronic illness, chronic pain, and disability have long been framed as both disruptive to narrative (Bury 1982; Scarry 1985; Couser 2009), while also being therapeutic, clinically advantageous, and even transformative (Scarry 1985; Frank 1997; Gilmore 2012; Dolmage 2014; Charon et al. 2017). Although narrative medicine tends to focus more on the benefits in clinical settings and the study of medicine (Kleinman 1988; Charon 2016), both narrative medicine and disability studies provide methods of thinking through the ways that stories shape bodies and experiences (Epstein 1994; Dolmage 2014), These fields consider how a body can be created and defined through the stories that are told about it, as exemplified in how the word "disabled" places individuals in opposition to some constructed notion of what's "normal." The practice of life writing (writing about the self) has been a significant part of both these fields, whether it is the patient attempting to communicate their illness to a practitioner, understand themselves, or simply create new meanings through which to live (Frank 1997; Snyder, Brueggemann, and Garland-Thomson 2002; Charon et al. 2017; Lorde and Smith 2020). For example, works such as Audre Lorde's *The Cancer Journals* and Hilary Mantel's *Giving Up the Ghost* use personal memoir and life writing to reflect on the collective, relational, and inherently political aspects of sickness. These memoirs become radical acts and have helped shape patient advocacy (Couser 2009).

In her essay on chronic pain life writing, Leigh Gilmore describes how self-narratives "reshape the discourses of chronic pain and life writing by centering patients as active producers of meaning who exert agency without mastery" (Gilmore 2012, 95). Privileging the patient-narrative does not mean that the patient has mastery over their illness, but it does offer them new forms of agency and meaning-making with which to engage their illness. G. Thomas Couser writes that, although patient narratives "may not protect women from cancer […] their authorship of cancer narratives is related to their claiming autonomy as patients in determining their own treatment (and as citizens more generally)" (Couser 2009, 4). Similarly, the online life writing practices of people with endometriosis explore alternatives for what it means to embody and live their condition. These practices may be imprecise and experimental, but this agency also opens up the floor for many more ways of knowing, “thinking,” and “processing” these lived experiences (Poletti and Rak 2014).

To fully comprehend life writing and what it makes possible in terms of world-building, it is important to contextualize it within the history of auto/biographical studies. As discussed in my first chapter, auto/biography or life writing studies have traditionally been more tied to literary studies and literary genres such as novels, letter writing, and diaries. More recently, the field has grown to include many other forms of media practices through concepts such as May Friedman and Silvia Schultermandi’s “autobiography 2.0” or Julie Rak’s “automedia” (Rak 2015; Friedman and Schultermandl 2018). What is important to establish, is that the field of auto/biographical studies has always been interested in how the self is created *in relation* to others and *through* practices. As Anna Poletti writes, “[a]utobiography matters—culturally, politically, historically, socially—because it puts individual lives ‘on the record’” (Poletti 2020, 5). What concepts such as autobiography 2.0 or automedia call for is more overlap between auto/biographical studies and media studies, as well as further investment into the “ways in which online life writing is increasingly relational, mediated and inherently dialogic, self-conscious of the impact of audience and reflecting the dominant discourses of the society in which it functions” (Friedman and Schultermandl 2018, 145). Poletti, in particular, draws on media scholars such as Henry Jenkins, danah boyd, Axel Bruns, and Nick Couldry (Bruns 2008; Couldry 2008; H. Jenkins, Ito, and boyd 2015) to consider how life writing has become more established within media studies and how the fields cross over in their consideration of how identity/life practices are always engaged in culture (Poletti 2017; 2020).

Life writing and automedia understand the self as something that is unfixed and always in the process of becoming and changing. As Butler writes, accounts of ourselves are always “partial” and “always undergoing revision” (Butler 2005, 40). Therefore, automedia is not just a singular act, but a practice, one that has become quite ordinary and repetitive in the social media landscape. On social media, this repetition is also a product of the predictability of the form and the specific conventions of the platforms that individual users adopt and play into. There can be certain experimentations within these conventions as Magdalena Olszanowski has explored in her work on feminist self-imaging, but there are still limits to the expression (Olszanowski 2014). This ordinariness, these repetitions, are often popularly dismissed as unsubstantial, but as Sara Ahmed writes (referencing the work of Judith Butler) “it is through the repetition of norms that worlds materialize” (Ahmed 2013, 12). Wendy Hui Kyong Chun (2016) further theorizes habits and repetition in her book *Updating to Remain the Same: Habitual New Media.* She writes that “[r]epetition is not simply exhaustion: not simply repetition of the same that uses up its object or subject. [Rather, repetition can create] constant ethical encounters between the self and other” (Chun 2016, 91). Chun’s definition of repetition allows for a creative and generative understanding of habit. As Arthur Frank in his book *The Wounded Storyteller* writes “[r]epetition is the medium of becoming” (Frank 1997, 159). The repetitive practices of social media life writing and automedia, particularly with endometriosis, resist singularity and simplicity by putting complex individual narratives in conversation with one another. That is not to say that social media is complex and medicine is simple, rather that social media provides a uniquely visible representation and exploration of the mess(es) of medicine. In the face of the complexity of the disease, many social media endometriosis posts insist upon complexity, worsening symptoms, and the repetitions and mundanity of illness. As Annemarie Mol writes, medicine tends to handle medical uncertainty and variation through “single objects” or (as Kate Seear calls them) “single narratives” which are “designed to smooth over differences and uncertainties” (Mol 2002, 117; Seear 2014, 63). In the case of endometriosis (a full body and interdisciplinary condition) this singular approach has resulted in years of misdiagnoses, mistreatment, and ongoing suffering. By insisting upon complexity and messiness within endometriosis, patients create new meanings and new ways of inhabiting their condition simply through their everyday, habitual social media practices. These habits become ritualized methods of being—being-in-community, being-in-illness, and being-in/as-process.

Life writing has rarely been about just narrative, but also about the performativity of creating the self through the act of writing. Automedia similarly extends beyond just narrative, building on the history of life writing to understand other social media meaning-making practices, such as self-imaging, meme-making, video-sharing, drawing, and more. Automedia allows us to consider more than just language and objects, but *practices*—the things that we do to make us who we are (Mol 2002; Barad 2003; Butler 2005). As Umit Kennedy and Emma Maguire write in the introduction to their special issue on "Automediality," automedia involves "processes: processes of being, doing, creating, and distributing the self, in relationship with media and their affordances, limitations and participants" (Kennedy and Maguire 2018). Automedia also considers the importance of mediation in these practices. This means considering how each post not only engages with the self and others, but also the platform it is posted on, the conventions it is following, and how meaning is being made at each of these steps. The feelings and embodiments of endometriosis that are communicated through automedia are filtered through discourses,[61] languages, and habitual practices and this filtering/mediation creates gaps and complexities in communication that reflect how we understand the disease (Foucault 1972). There is no singular meaning that emerges from any of these examples, rather the meaning of endometriosis is (re)created with every social media post. In fact, meaning springs forth in the gaps of communication and the contradictions of endometriosis. Some of my participants found their meaning in religion, some in their symptoms or medications, others in their communities, some in their self-expression, others in a combination of all these. The ways endometriosis is mediated reflect the unstable and complex nature of the disease itself. It cannot be easily pinned down and these mediations and complexities, these messy networks, are felt in the body.

In the last chapter, I brought in the term "bodymind" to discuss the role that affect can play in the processing and experience of symptoms such as pain. The experience of pain and illness are shaped by a variety of complex factors, including subjective and hard-to-trace aspects such as affect, emotion, and cognition (Melzack 2001; Käll 2012; McCosker 2012; Steck and Steck 2015). As Jean Jackson writes, pain is not just a direct sensation of the inputs our bodies receive, but is an *interpretation* of these inputs (J. E. Jackson 2011, 374). The previous chapters have shown how information-sharing and community-oriented practices can shape people's experiences with endometriosis, but this is also true for meaning-making and world-building practices. When these stories (and broader

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[61] Whenever I use "discourse" throughout this chapter outside of a quotation I am referring to discourse not as a synonym for rhetoric or language, but as a production of knowledge through practices, drawing on Michel Foucault and Karen Barad (Foucault 1972; Barad 2003).

automedia) are put into social media networks, the possibilities for connection, affective responses, and collaborative knowledge production expand and, as mentioned earlier, this can have bodily affects. In the words of Papacharissi, "[t]he bodily connection gives shape to and is shaped by affect. Our experience of an emotion is defined by affect, by a variation in a mind/body state" (Papacharissi 2015, 14). Although affect (like social media) can feel ephemeral, Margaret Wetherell argues that we "need to locate affect, not in the ether, or in endless and mysterious circulations, but in actual bodies and social actors, negotiating, making decisions, evaluating, communicating, inferring and relating" (Wetherell 2012, 159). The way people with endometriosis think, feel, and communicate their thoughts and feelings *create* endometriosis. The representative and storytelling practices of people with endometriosis do not just change language and thought, they can change the very way the disease comes to be embodied and felt. As Sara Ahmed writes, "the very words we […] use to tell the story of our pain also work to reshape our bodies, creating new impressions" (Ahmed 2013)

These storytelling and automedia practices, and their affective nature and responses, can have significant impacts on people's lived and embodied experiences. As discussed in chapter three, my survey results showed that 78% (223) of participants said that their participation in endometriosis social media spaces changed how they feel about or experience their symptoms. All but two of the people who answered "yes," said that social media made them feel better in some way, whether physically or emotionally. Their answers described things such as "feeling more hopeful," "feeling validated or empowered," "feeling more educated," "feeling less alone," "feeling acceptance," as well as discovering tools such as pain diaries and finding strategies to talk to their doctors. All these answers suggest that the meaning made on social media can be more than just symbolic, it can define bodies and experiences. For those living with endometriosis, this may be realized through the information they share online (chapter two), the people they meet and connect with (chapter three), or even the stories and automedia they share and engage with (chapter four). Further, as one survey respondent said, "storytelling is so powerful and is an important aspect to advocacy."

This impact of social media storytelling is often minimized but, particularly in the case of endometriosis, where other forms of care and recognition are often lacking, it can be quite profound. As LP from @TheEndoMonologues shares in regards to her experiences on Instagram: "It's bonkers, daily messages, just people asking for advice or just saying *that really resonated with me* or just being able to say *oh actually you've given me the confidence to share my story now* and that's great, that's fantastic" (LP 2020). The stories that LP shares inspire others to share their stories which inspire others to share their stories (and so on). But it's not just about the telling that matters, it's also the listening; the witnessing of a massive web of endometriosis experiences that are all being shared at once with a level of visibility that has never been seen before. Annemarie Mol writes that illness takes shape through witnessing in both material and active ways. The "illness is something being done to you, the patient. And something that, as a patient, you do" (Mol 2002, 20). This *doing* is visible on social media and this active role in understanding and shaping the illness

through meaning-making and world-building on such a grand scale brings with it new levels of agency and power.

What Social (Auto) Media Tells Us About Endometriosis

The endometriosis meaning-making practices seen on social media often have common themes that inform how endometriosis gets understood in these spaces and beyond. A common story that people share on endometriosis spaces on both Facebook and Instagram is their journey with diagnostic surgery or other surgical procedures. Many of these posts discuss complicated feelings, such as gratitude over finally having a diagnosis, complications around getting surgery or diagnoses, and the process of coping with a chronic illness. For some, like Nomagugu, her surgery post introduced her to endometriosis social media community (see Figure 15). Her story reflects her own process of coming to understand what endometriosis means for her:[62]

> On 21 November 2019, my gynecologist informed me that I have endometriosis. To be more specific, her words were "you have endometriosis, there is no cure for it, so you just have to remember to take your meds and embrace it. It's a part of your life now." Words I will never forget. A pretty coy way to let someone know that they have a chronic, incurable condition. Yet, as matter-of-fact as she was, I wasn't fazed. I had no emotional reaction. I just remember asking a lot of questions. My mind was in

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[62] Chantelle mentions "excision" surgery in her caption, but not all laparoscopies are excisions.

> "so what can be done about it?" mode. Time was and is of the essence because she expressed to me that my condition had slightly advanced. Like cancer, endometriosis comes in stages. I don't know what stage [of endometriosis I have]. The consultation was quite brief. (Nkosi 2020)

In the comments of this post, some people offer support, and others offer their own, similar stories with difficult symptoms and medical procedures. One user writes, "i think i've got it [endometriosis] but i really don't know how to push my mom to take me to the gynecologist. this gave me the courage and made me feel better that i'm not necessarily on my own."

nomagugu_chantelle • Following
Life Care Rose Acres Primrose

nomagugu_chantelle_nkosi
#TriggerWarning
There. I said it. In this picture, I'm showing you my dressed scars. It's raw and it may seem like TMI but I cannot protect you from reality - from what is now my reality.

Here is my story.
On 20 November 2019, I had my first diagnostic laparoscopic surgery (aka excision surgery). The purpose of the surgery was to remove a cyst (about 4cm) that was growing on my right ovary.
The surgery was successful but a new diagnosis came about and that's what this post is about.
On 21 November 2019, my gynecologist informed me that I have endometriosis. To be more specific, her words were "you have endometriosis, there is no cure for it, so you just have to remember to take your meds and embrace it. It's a part of your life now." Words I will never forget. A pretty coy way to let someone know that they have a

Liked by **kmo_mo** and **112 others**
NOVEMBER 28, 2019

Figure 15: Nomagugu Chantelle Nkosi's Instagram post about her surgery from November 28, 2019

Another common theme is to reference the global and communal aspects of endometriosis, most commonly by using the "1 in 10 women have endometriosis" statistic. Others, like @EndoQueer, offer alternate representations of endometriosis, by talking about how it can affect people of all genders. Endometriosis itself is commonly represented with drawings or images of uteruses, with lesions, or angry faces, or knives (despite it not being a uterine disease). Others, like @ExtraPelvicNotRare, instead reflect the multi-

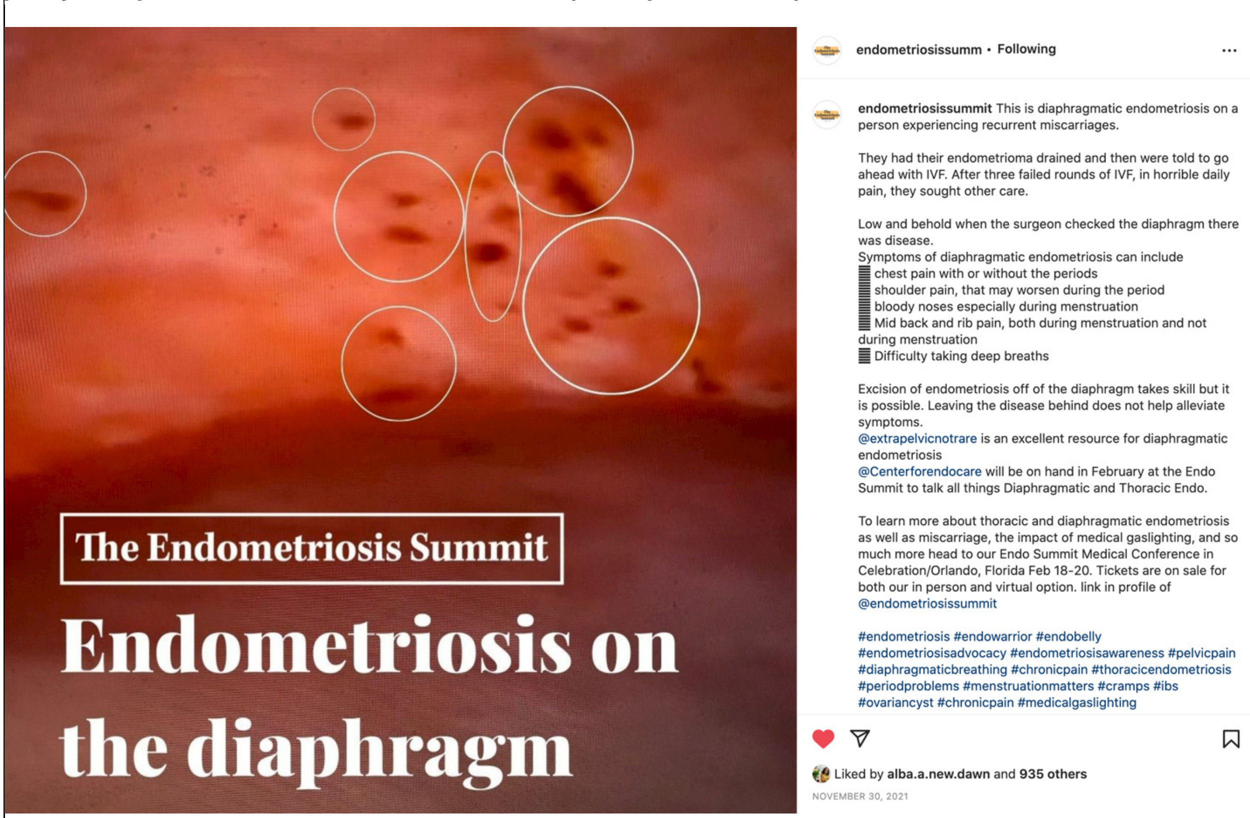
imaprilchristina • **Following**

imaprilchristina #repost @themightysite
. . .
It can be hard to communicate your experience when you live with a condition that's "invisible." That's why we're sharing this story from @imaprilchristina — part of @sufferingthesilence's nine-part portrait series shot by @amcrommett. It's proof that while not everyone "gets it," talking about what you're going through has power among those who do. 💪
•••
"Because you can't tangibly see my condition, it makes it even more hard when you are explaining that you don't feel well. With my hair and makeup,

Liked by **endo_black** and **270 others**

OCTOBER 17, 2019

Figure 16: October 17, 2019 post from April Christina's Instagram showing her with "Endometriosis" written on her arm. One part of the caption reads "It can be hard to communicate your experience when you live with a condition that's 'invisible'."



endometriosissumm • **Following**

endometriosissummit This is diaphragmatic endometriosis on a person experiencing recurrent miscarriages.

They had their endometrioma drained and then were told to go ahead with IVF. After three failed rounds of IVF, in horrible daily pain, they sought other care.

Low and behold when the surgeon checked the diaphragm there was disease.
Symptoms of diaphragmatic endometriosis can include
▤ chest pain with or without the periods
▤ shoulder pain, that may worsen during the period
▤ bloody noses especially during menstruation
▤ Mid back and rib pain, both during menstruation and not during menstruation
▤ Difficulty taking deep breaths

Excision of endometriosis off of the diaphragm takes skill but it is possible. Leaving the disease behind does not help alleviate symptoms.
@extrapelvicnotrare is an excellent resource for diaphragmatic endometriosis
@Centerforendocare will be on hand in February at the Endo Summit to talk all things Diaphragmatic and Thoracic Endo.

To learn more about thoracic and diaphragmatic endometriosis as well as miscarriage, the impact of medical gaslighting, and so much more head to our Endo Summit Medical Conference in Celebration/Orlando, Florida Feb 18-20. Tickets are on sale for both our in person and virtual option. link in profile of @endometriosissummit

#endometriosis #endowarrior #endobelly #endometriosisadvocacy #endometriosisawareness #pelvicpain #diaphragmaticbreathing #chronicpain #thoracicendometriosis #periodproblems #menstruationmatters #cramps #ibs #ovariancyst #chronicpain #medicalgaslighting

Liked by **alba.a.new.dawn** and **935 others**

NOVEMBER 30, 2021

Figure 17: November 30, 2021 post from @EndometriosisSummit showing lesions on the diaphragm

systemic nature of endometriosis by sharing images that represent endometriosis' full body effect. Sometimes endometriosis is represented artistically on the body with paint or digital effects to visualize the otherwise "invisible" disease, while others choose to share medical images, so that people can see the interior damage the illness can cause (see Figure 16 and Figure 17). Some post as an organization and others as themselves. Some have accounts entirely focused on endometriosis, while others use their personal account to talk about endometriosis.

endo.days.ontario • Following

endo.days.ontario ~ Quotations from Bell Hooks ~
I don't feel well right now. At this moment in time, in this world, I feel like "wellness" is a very foreign concept. I have been doing a lot of thinking & reading & unlearning & having my mind & thoughts transformed b/c I'm turning (400 yrs too late) to the ppl who have the answers & always have: Black. Womxn. I'm paying them for their knowledge & getting a fuck of a return. I have been thinking about how I have NEVER actually thought about what it is like to be Black in this world. I've never had to & I've never forced myself to b/c I'm a hippie Aquarius who thought we could just hug our way to righteousness. Then I was having a

Liked by **jess.mousseau** and **30 others**

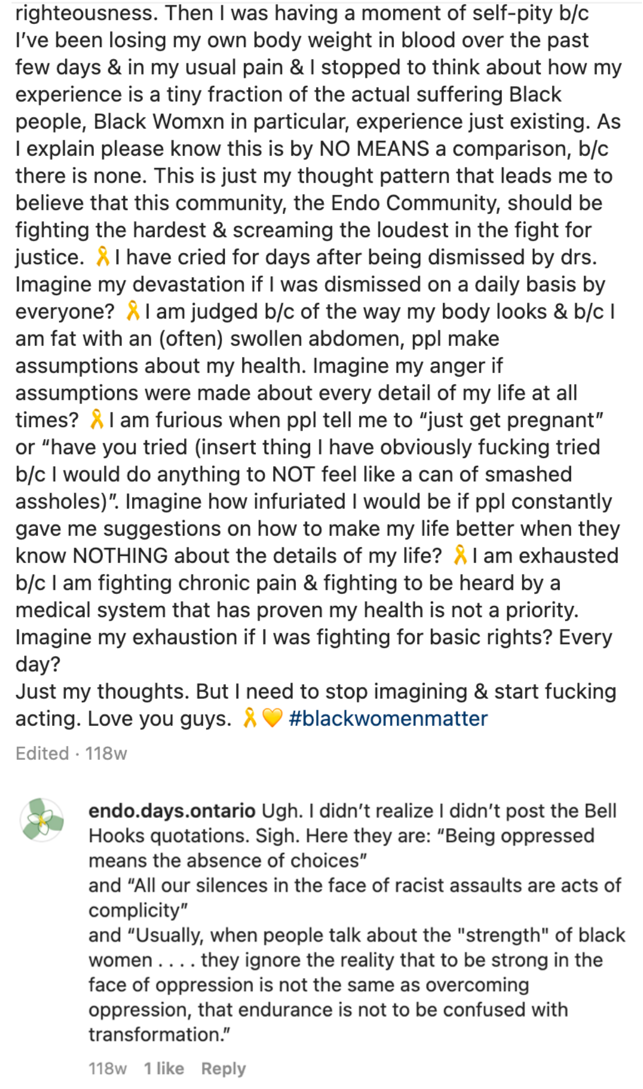
JUNE 16, 2020

Add a comment...

Post

Figure 18: A selfie of Jules from @endo.days.ontario accompanied by a long caption, posted June 16, 2020. Caption continued in next figure.

In a beautiful illustration of the complexities of representing and mediating the self, others, and endometriosis online, Jules from @endo.days.ontario shares a selfie with a caption that begins by referencing bell hooks and then discusses wellness in regards to the Covid-19 pandemic and Black lives, the need for collective action for health justice, as well as her own struggles being dismissed by doctors (see Figure 18 and Figure 19). The post is a complex portrait of an individual living with an illness in conversation with others living through and amongst illness(es) and their collective vulnerability to one another. Jules (like endometriosis) is in a constant state of becoming, captured in this moment on June 16, 2020 in the midst of change and shifting conversations. Jules, like April, and Chantelle, and all the others who post online are constantly negotiating themselves in relation to one another, as well as to endometriosis. Each social media enactment of this illness "*do[es]* the body differently," to quote Annemarie Mol (Mol 2002, 176). Endometriosis is not only talked about in new ways but experienced through newly created worlds.



righteousness. Then I was having a moment of self-pity b/c I've been losing my own body weight in blood over the past few days & in my usual pain & I stopped to think about how my experience is a tiny fraction of the actual suffering Black people, Black Womxn in particular, experience just existing. As I explain please know this is by NO MEANS a comparison, b/c there is none. This is just my thought pattern that leads me to believe that this community, the Endo Community, should be fighting the hardest & screaming the loudest in the fight for justice. 🎗️ I have cried for days after being dismissed by drs. Imagine my devastation if I was dismissed on a daily basis by everyone? 🎗️ I am judged b/c of the way my body looks & b/c I am fat with an (often) swollen abdomen, ppl make assumptions about my health. Imagine my anger if assumptions were made about every detail of my life at all times? 🎗️ I am furious when ppl tell me to "just get pregnant" or "have you tried (insert thing I have obviously fucking tried b/c I would do anything to NOT feel like a can of smashed assholes)". Imagine how infuriated I would be if ppl constantly gave me suggestions on how to make my life better when they know NOTHING about the details of my life? 🎗️ I am exhausted b/c I am fighting chronic pain & fighting to be heard by a medical system that has proven my health is not a priority. Imagine my exhaustion if I was fighting for basic rights? Every day?
Just my thoughts. But I need to stop imagining & start fucking acting. Love you guys. 🎗️💛 #blackwomenmatter

Edited · 118w

endo.days.ontario Ugh. I didn't realize I didn't post the Bell Hooks quotations. Sigh. Here they are: "Being oppressed means the absence of choices"
and "All our silences in the face of racist assaults are acts of complicity"
and "Usually, when people talk about the "strength" of black women . . . . they ignore the reality that to be strong in the face of oppression is not the same as overcoming oppression, that endurance is not to be confused with transformation."

118w 1 like Reply

Figure 19: Second half of caption and additional comment from Jules' June 16, 2020 Instagram post.

Although Jules' post is more overtly political than the majority on Instagram, her post also draws attention to the complex relation between the self and other, the public and private, that occurs in general on social media. As Papacharissi writes:

> Online technologies thrive on collapsing public and private boundaries thus affording opportunities for expression that may simultaneously empower and compromise individuals. Moreover, the convergent nature of online media creates confluence between social, political, economic, and cultural realms, leading to expressions that blend and borrow from all of the above spheres of activity. (Papacharissi 2015, 94).

Every post in which a person with endometriosis attempts to create meaning is a significant act. Even the most seemingly 'ordinary' or apolitical post about endometriosis (sharing a picture of a heating pad, venting about symptoms) is entangled in messy political, social, economic, and cultural conversations and, through the social nature of Instagram and Facebook, these complexities are revealed. This is one reason why arguments often break out online, but it is also the reason why so many who engage in these spaces become interested in "justice," even when they do not know exactly what that justice might look like or how to achieve it. The overwhelming story that these messy endometriosis worlds reveal is a need for things *to be better*.

This is not to say that Instagram and Facebook endometriosis spaces are filled with utopian and coordinated activism. Far from it. Facebook is full of infighting and discord between different groups, including different endometriosis charities and organizations. Capitalism and exploitation infect these spaces and these stories. The Instagram hashtag #endometriosis and some of the less-restricted Facebook groups are full of advertisements from pharmaceutical companies, businesses, clinicians, and "coaches" advertising products and services with varying degrees of benefits (or harms).[63] Sometimes these advertisements also come from people with endometriosis who have been sponsored by different companies to share their products. Further, both Instagram and Facebook are plagued with racism, misinformation, sexism, and transphobia. The stories that people tell online oftentimes obscure or erase the perspectives of those with more marginalized

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[63] As an interesting side note: most people I've dated has, at some point, been targeted by ads about endometriosis or menstrual products. The algorithm knows all my business. Some Canadian people with endometriosis have reported receiving ads from pharmaceutical companies on Instagram, even though direct-to-consumer pharmaceutical advertising is restricted in Canada.

experiences. For example, an initial scroll through the hashtag #endometriosis on Instagram will show predominantly white, cisgender women. These systemic problems are apparent in the stories that are told on endometriosis social media spaces as well as in the ways that those with endometriosis try to grapple with and understand their disease. It should not be surprising that patients have not been able to concisely manage all these complexities in unregulated online spaces when so many of these issues plague endometriosis care as a whole. These are sticky and messy spaces, but to blame the patients relying on them disregards the broader political factors at play in dehumanizing those with endometriosis and chronically ill people more generally.

In fact, it is actually quite impressive just how much people with endometriosis have accomplished in these difficult spaces, reflecting a long legacy of sick and disabled resistance. Disability scholars such as Arseli Dokumaci and Aimi Hamraie have written about the ways in which disabled people make space for themselves where there is no space for them. As Hamraie writes, "disabled people are experts and designers of everyday life" in learning how to navigate a largely inaccessible world (Hamraie and Fritsch 2019, 2). Dokumaci uses the term "activist affordances" to describe how disabled people go about "*making up* and *making real* worlds that we were not readily given by *making do with* what we have" (Dokumaci 2023). We can see these forms of creation and design in endometriosis social media spaces, where people learn and use the tools of social media (Facebook groups, hashtags, reels, memes, stories, etc.)[64] to their advantage and to build new worlds for endometriosis going forward. These individual efforts to make and take up space can be exhausting and dehumanizing when done in isolation (although, as we've discussed, they can be tool for survival), but when done in social spaces, or as an organized group, they can make bigger waves and sometimes take less of a toll. Nancy Peterson from the "Nancy's Nook Endometriosis Education" Facebook group shares a quote from Margaret Mead during our interview:

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[64] One of the more recent tools for endometriosis that I have seen emerge during my research period is the platform "Clubhouse," where people can meet virtually in an audio call and either host talks or panels or even do group support sessions. It is hard to know how much influence this platform will have so far, but it allows for more intimate conversations to take place in what is still quite a public space.

> Never doubt that a small group of thoughtful, committed citizens can change the world: indeed it is the only thing that ever has.[65]

Meaning-Making and World-Building in Community

The stories that are shared on endometriosis social media are often everyday, habitual, and ritual acts. They repeat each other, reflect one another, and introduce slight differences that get adopted as new norms (such as using gender-neutral language or not using the uterus to represent the disease). As mentioned earlier in this chapter, social media practices are often dismissed despite their potential for everyday forms of activism and resistance (Mendes, Ringrose, and Keller 2019; Dobson 2015). This has been written about predominantly in terms of youth and women, but the same argument can be made for disabled, crip, sick, or mad people, gender-marginalized individuals, and, of course, people with endometriosis. Although an individual post on Instagram may not be ground-breaking on its own, when put into conversation with the millions of other posts under the hashtag #endometriosis, the possibilities for revolution emerge. As Zizi Papacharissi writes:

> Technologies network us but it is narratives that connect us to each other, making us feel close to some and distancing us from others. As our developing sensibilities of the world surrounding us turn into stories that we tell, share, and add to, the platforms we use afford these evolving narratives their own distinct texture, or mediality. In doing so, media do not make or break revolutions but they do lend emerging, storytelling publics their own means for feeling their way into the developing event, frequently by making them a part of the developing story. (Papacharissi 2015, 5)

In online endometriosis communities, we can see the ways people “feel themselves into” movements. I use this term “movements” instead of Papacharissi’s “events” because it better reflects the continual state of becoming and processing that can be seen in social media spaces. For many of my interviewees, like Chantelle and LP, they found themselves feeling their way into advocacy and activism when they never expected or intended to, simply because they wanted to share their own stories online in a community. Their stories no longer just spoke to their singular experiences but were part of a larger conversation about endometriosis as a whole.

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[65] I was able to find many citations of this quotation online, but not an original printed source.

Endometriosis is not just a solo experience, particularly on social media. Scholar Anthony McCosker draws together the social sciences and neuroscience to argue that pain cannot be defined by only one body. As he writes,

> [T]he affective force of pain is located not simply within the perceiving subject, nor the object that 'initiates' sense perception, nor in the impulse striking out between cells in afferent synaptic chains coursing through the body, nor at the synaptic interference or within the nerve cells themselves at the site of a wound […] Rather the affective force of pain lies in the complex interchange of any and all of these elements, along with others, through which bodies act upon one another and in relation to one another within an encounter" (McCosker 2012, 2).

Although pain and illness are always embodied individually, they are also structured through relations and cannot be divorced from the power structures that come to situate their meanings, feelings, and affective dimensions. Endometriosis comes to be felt through complex relations within ourselves, but it is even further constructed through social relations, the support of others, our experiences in medical institutions, our conceptions of ability and disability, our understandings of pain, our desire for productivity, and our media practices. These many networks of endometriosis cannot be measured simply by numbers or even symptoms and, I would argue, to do so is to do it a great disservice.

Disability scholar Alyson Patsavas similarly writes that "we never experience pain in isolation" (Patsavas 2014, 209). Pain, according to Patsavas, is constructed through cultural discourses and external expectations, such as the ableist and individualist insistence that it is an individual's personal responsibility to get better. Although she admits that pain can be extremely isolating , she also argues that the experience of pain also "exceeds the boundaries of individual bodies" (Patsavas 2014, 213). Using Margrit Shildrick's concept of "leaky bodies," Patsavas describes how the experience of pain leaks between bodies in the same ways that the body and mind leak into one another. She frames this leaking as a kind of connectedness between bodies in pain, something that allows her to "imagine pain beyond just [her] bodily experience" (Patsavas 2014, 213). This concept is made increasingly visible in endometriosis social media spaces, where many stories of pain and illness intersect, conflict, reflect, and mediate one another.

As I have discussed throughout this dissertation, there are many different actors at work on social media, and many differing viewpoints and experiences. While it is important to remain cognisant of the influence this may have on misinformation, I argue that this complexity is an extremely important part of what makes social media so interesting for endometriosis.[66] Currently, social media is offering a subjective, complex, and messy view of endometriosis that is rarely being represented clinically or even within research. That is not to say that clinical practice or research aren't similarly messy (they are), but rather to argue that people's social media practices help make that messiness visible. People with endometriosis should not be dismissed for using messy methods of survival when for so long they have been dealing with messy treatments and care. Through posting and creating on social media, people with endometriosis are influencing how the illness gets talked about and challenging the simplistic ways that it has been addressed thus far.

The resulting networks of endometriosis are a beautiful and messy archive of experience, knowledge, feelings, and connections. These networks are built collectively by many actors: patients, doctors, pharmaceutical companies, businesses, and more. The complexities of these relations only enhance the political density of these spaces and the potential resistance people with endometriosis engage in by participating. In a world where neither online or offline worlds are safe from healthcare inequalities, many with endometriosis are using social media to try and create an alternative. As Elena Gonzalez-Polledo so eloquently writes of chronic pain communication on Tumblr, "in social media pain is reframed as a political issue as it is transformed from an individual, potentially disabling event that has the capacity to put life on hold to an inherently social, actionable, collective, *issue*" (Gonzalez-Polledo 2016, 2, emphasis as written). Those who engage collectively in these spaces "resist epistemic injustice and create inhabitable pain worlds" (Gonzalez-Polledo 2016, 2). By paying attention to the social media practices of those with endometriosis, we get not only "pain worlds," but *endometriosis* worlds, where the present and future of the disease can be reimagined.

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[66] There are likely other conditions that benefit from social media in similar ways to endometriosis, particularly other gendered and dismissed diseases such as fibromyalgia, adenomyosis, ME/CFS, POTS, and PCOS. The overlaps between these conditions came up during my research but were outside the scope of this project. There has also recently been a rise in content about neurodivergence (particularly ADHD and autism) on both TikTok and Instagram. Common amongst all these conditions and their social media content are themes of dismissal, misdiagnosis, gendered discrimination, and histories of patient advocacy, which would be an interesting topic for future research to explore.

While this online engagement, and these endometriosis worlds, may not always change the dominant narrative, if we consider the long history of endometriosis—including the continued dismissal and mistreatment of patients and the influence of sexism, racism, and classism—even the sheer volume of patient voices on Facebook and Instagram is already an enormous change. With social media, people with endometriosis have a place to connect, discuss, and learn from one another in ways that have never before been possible and this historical relevancy should not be underestimated. Through connective and collective communication, endometriosis social media networks can, at their best, bring into focus the systemic injustices, power dynamics, and complex relations that make endometriosis what it is—to make visible the messiness of this diease. They can also strengthen the impact of patient experiences, care practices, and communities within these broader networks.

Nov. 12, 2020 – The necessity of going online

I am completely incapable of convincing Dr. X that when I say, "I have done my research," I am not referring to a Google search or random blog posts. I have never mentioned what my PhD is about because I'm convinced it would only make her think worse of me. I know her attitude towards social media.

It's typical to meet skepticism when you approach a doctor with your own research, no matter how extensive or meticulous it is. And maybe doctors are right to be jaded, maybe they too often encounter patients who are seriously misinformed about their treatment. That might even be true for many endometriosis patients. But there are also so many people living with this disease who are so extremely well-informed about their own illnesses. They have *to be if they want to receive care, if they want to manage the constant inflammation, fatigue, and pain. As Alex Kuller from Endo Knows No Gend-o says during our interview, "I think we've really had to become the experts and advocates for ourselves because truly no one else is going to do that research or connect those dots for us"* (Kuller 2020)*. It's funny how doctors so often dismiss patients for turning to social media, when we so often turn to social media because they dismissed us in the first place.*

Martin Hand, in the piece “Visuality in Social Media: Research Images, Circulations and Practices” mentions "mapping patterns" as a way into ethnographic, qualitative social media research methods (Hand 2018). This is a useful methodology for my dissertation, but it's also the methodology many endometriosis patients need *to use to understand their bodies and their illness: mapping out their patterns of symptoms; noticing that their nosebleeds are associated with menstruation; finding that eating bread worsens symptoms, etc. This is how we make it through the networks of endometriosis, map our own way into meaning and being.*

I can't say that all people with endometriosis have crystal clear understandings of their illness, or flawless research methods—they would likely even prefer to hand over that role to doctors—but I do think it's important to recognize them as researchers of their own experiences and bodies, who each have unique methodologies that they often must employ “in order to survive” (Didion 1979)*. What do their methodologies tell us? And is anyone listening?*

Building New Worlds for Endometriosis: From ‘Changing the Narrative’ to Changing Institutions

In social media studies, there has been an ongoing debate about whether online activism can lead to tangible change. The reality is somewhere between techno-utopianism and dystopianism. On the one hand, social media can lead to increased risks of symbolic forms of action that erase and invalidate the work of organized offline activists (Morozov 2012). But it can also be used for awareness-raising, assembling, mobilization, or to create public spaces for those who cannot ‘take to the streets’ (Gerbaudo 2012; Keller 2014; Papacharissi 2015; Mendes, Ringrose, and Keller 2019). I do not have enough data to show whether endometriosis social media spaces have led to legislation or policy changes for the disease *on their own*, but they certainly have *contributed*. Throughout my research period, I witnessed many mobilization and awareness efforts, some of which were linked to broader moves for legislation and policy change, such as the push for a national action plan for endometriosis in Canada by Endo Act. Further, 61.3% of my survey respondents identified that they used social media for awareness-raising (to varying degrees). One anonymous respondent described how their participation in online spaces led them to “become more and more passionate and determined to change the narrative surround[ing endometriosis].” Of the twenty-two people I interviewed with endometriosis, all were involved in some form of change-making or world-building. While some have made advocacy their full-time jobs, even those who rarely spoke about endometriosis online still occasionally used it to share information or raise awareness.

Already in this chapter, we have seen a few examples of awareness-raising, such as in Wendy’s #IAmExtraNotRare campaign. Even during my research period, I witnessed a rise in conversations on Instagram and Facebook about extra-pelvic endometriosis in response to Wendy’s hard work. Looking back to chapters two and three, we have also explored multiple examples of community-organizing and information-sharing in groups like “Nancy’s Nook Endometriosis Education” or “Endo Knows No Gend-o.” All these actions work towards building new worlds for endometriosis and are in conversation with the long-standing work that has been happening in patient advocacy groups for years. In fact, patient advocacy is a central component of health advocacy, particularly for diseases like endometriosis which have historically been undermined (Vicari 2022; Landzelius 2006).

Heather from the Centre for Endometriosis Care, for example, tells me about how the organization’s social media efforts are only the tip of the iceberg of the work they do:

> So we try to evolve organically with the community and I mean, I don't TikTok certainly, but we have Instagram, we have Facebook, we have a Pinterest […] That's sort of patient-facing. But we're much more active on the institutional side. You know, educating other doctors, training other doctors, working against the medical institutions that decide everything about us without us, educating legislatures, seeking research funding, fighting for that research funding, and then making sure the right research is funded. (Guidone 2020b)

Although the centre shares some of this work through their website and social media, so much of the more substantive change-making cannot be easily translated to these platforms. Policy change, education, and research are very slow, detailed processes, while social media is concentrated on fast, short snapshots. Although I have seen amazing efforts from my participants to share complex research in accessible ways through social media, one of the biggest disadvantages to these spaces is how individual posts can end up oversimplifying very complex ideas. Although I have talked about the importance of not disregarding mess and complexity in this chapter, that messiness is still often very frustrating, limiting, and at times harmful to communicate.

Social worker and endometriosis and fertility advocate Casey Berna also tells me about how slow policy change can be, even with online action:

> I created a petition against ACOG [The American College of Obstetrics and Gynecologists] to try and change standards of care**.** And we got thousands and thousands of signatures […] that hopefully will help put some heat on those in power. I like to harass ACOG a lot on social media. [But] they've been so slow to change and they don't really have financial incentive to change and changing will cause them to admit that they've been really messing up care. […] We try to put pressure on them. I also feel like social media has helped us form powerful collaboratives of different organizations and I think there is power in collaboration. (Berna 2020)

As discussed earlier, one of the most significant powers that social media carries for people with endometriosis is the ability to connect them to one another so that they do not always have to advocate alone. It also provides a way to share advocacy resources for patients who are looking to get further involved. For example, in Canada, there is also a multidisciplinary, collaborative initiative to try and drive policy action on endometriosis called "Endo Act." Endo Act has used social media to share patient stories and, more recently, share their toolkit for lobbying politicians for a national action plan on endometriosis. By making this a collaborative effort—between patients, researchers, clinicians, and more—they have increased the possibilities for change to truly take place.[67]

In chapter two, I discussed how problematic it is that those living with endometriosis must perform so much labour to try and get care. This is unfortunately common in many disability and chronic illness communities. In an article on "Access Fatigue," Annika Konrad writes that, "logics that motivate disabled people to be independently responsible for their own access often do not take into account how confronting and managing how others think and feel about disability is a mentally and emotionally exhausting activity that is, at times, simply not worth the effort" (Konrad 2021, 181). It is common on social media to see calls for individuals to "just advocate" for themselves when that is something that many may not be able (or know how) to do.

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[67] There is also a lot of fear in endometriosis social media spaces about initiatives like Endo Act that seek to change guidelines, predominantly because previous guidelines updates have made accessing excision surgery and certain treatments *more* difficult for many patients instead of easier.

Advocacy is more effective when this work is spread out across many individuals to share the load. Heather emphasizes that she wants people to know that they are not fighting on their own, even when it feels like it: “I assure anybody who is feeling left out or isolated or forgotten, I promise you, you are not. We are here. We are fighting for you every single day, and it’s a long road” (Guidone 2020b).

For my interviewees who work in endometriosis organizations and do offline advocacy, bridging the divide between patients and practitioners is one of their major goals. While social media has connected patients more, and while there are some doctors like Dr. Gabriel Mitroi who do use social media, endometriosis spaces are mostly composed of patient voices that are not necessarily heard by practitioners. This is, in one part, why I chose to write this dissertation and is something that inspired many of my interviewees. For example, Shannon Cohn tells me how her team screened her documentaries *Endo What?* and *Below the Belt* at MIT, Harvard, and other universities for doctors. Wendy similarly uses her doctorate in physical therapy to “bridge that gap into medicine” for others in the endometriosis community (Bingham 2021). She has been working hard over the last couple years to fund and conduct a survey of patients with chest cavity, diaphragm, or lung endometriosis so that she can represent patients within scientific/medical research.

Several of my interviewees spoke to how their individual advocacy on social media led them to bigger, collective forms of advocacy—"feeling their way” into bigger movements. [68] For example, April Christina tells me that “in the beginning it was literally just [her] making graphics on Instagram and Facebook and hoping someone sees it and understand” (April Christina 2020). As of January 2022, April Christina has a following of over 7,000 and her work involves running events and collaborating with others. Similarly, Jenneh’s organization Endo Co. came out of a small group of people who just wanted to bring more attention to endometriosis on social media. She says,

> At that time the endo presence was really sad. It was a lot of really defeated people and, of course, because we all are, but we just really wanted to bring some kind of hope to this, like acknowledge that this is real (never have a toxic positivity spin on things), acknowledge that this sucks, but at the same

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[68] In the conclusion I will grapple with my own journey getting involved in endometriosis advocacy through social media.

> time what can we do to try to make change and that’s kind of where the Endo Co was birthed, just to spread awareness, advocate for people, and empower others to feel like they can do the same for themselves. (Rishe 2020)

As of January 2022, The Endo Coalition has almost 20,000 followers on Instagram and Jenneh has her own following of just over 16,000. In the time between interviewing her and writing this dissertation, Jenneh has published a book (*Part of You, Not All of You)* and done countless media interviews about endometriosis (Rishe 2022).

Every one of my research participants carries a different level of hope about advocacy and change for endometriosis. The picture that Heather paints shows a messy and slow process. Having worked in endometriosis advocacy for almost 30 years, she would know:

> There are a lot of conflicting interests, there's a lot of personal agendas in endometriosis institutionally. The standards of care are not just failing but they're abysmally failing. And there are people just caught out there in that and it's very difficult to fight day after day after day and see very little progress but then, occasionally, we get a win. We know that we'll get a win and we'll know that we made a little bit of progress. That's what I kind of look for, the little wins. (Guidone 2020b)

Although change in endometriosis care is slow, April Christina tells me that it has already “come a long way,” and my interview participants all expressed a commitment to pushing for change and improvements. Despite emphasizing the complexities of change-making, Heather also confidently tells me during our interview, “if it doesn’t exist, we’re going to create it” (Guidone 2020b). Throughout my research process, I have been continually astonished by the amount of work, collaboration, and advocacy that people living with endometriosis continue to do, despite their symptoms, and despite the mess they have to wade through.

October 30, 2021: Just one more network to navigate

I went into this research project knowing that there was something special about these online spaces. I was maybe a little techno-utopian at first, despite already having seen some of the conflict in these communities.

And yes, that conflict certainly existed and, at times, surprised me with just how vitriolic and all-consuming it could be. But, at the same time, I remain completely taken aback *by how supportive these communities—and I do feel that this the right word for them—continually prove themselves to be. I never expected to make such close friends, to see so much change in endometriosis care—so much media and political representation—to understand my own body so much better, and to be surrounded by so much love and appreciation each time I shared my research.*

Social media, much like endometriosis, is messy. Maybe that's why people with endometriosis can be so good at navigating it. They have years of experience living in bodyminds that are full of sticky webs of endometriosis. What's social media if not just one more network to learn how to navigate?

Conclusion

As we have seen in the previous chapters, alongside this one, online endometriosis spaces are fraught and difficult. Based on my survey results, interviews, and the continued practices of people with endometriosis on social media, I argue that these complexities do not make the spaces useless or insignificant, rather they highlight the complexities of endometriosis itself and the many political, social, cultural, medical, affective, and embodied aspects of the disease that people attempt to untangle online. In this chapter, I have highlighted the impressive meaning-making and change-making practices that people with endometriosis perform online as they try to navigate their way through these networks. These networks of endometriosis allow for complex, messy, collaborative, patient-led portraits of the disease to arise and take hold. The stories that people with endometriosis tell create impacts beyond social media, stretching into institutions, politics, healthcare, and—most significantly—the bodymind. Endometriosis has never been seen or understood in this way and on this scale before, and the possibilities that emerge from this beautiful, difficult mess deserve to be recognized as a part of endometriosis research, as a significant moment in the disease's history, as well as an illuminating look into the efforts patients must put in to receive adequate care.

Chapter 5: Conclusion

If it doesn't exist, we're going to create it.
(Guidone 2020b)

The Story/Stories So Far

I end where I began: in the fall of 2017, a week into starting my PhD, I had my first surgery for endometriosis. At that point in my life, at the age of 23, I had been through more than ten years of symptoms, medications, and referrals. Despite all these efforts, my first introduction to endometriosis came through Googling my symptoms. It was one day, after an attempt to bike home from university left me vomiting in the middle of Westmount Park, that the algorithm finally led me to a name for my disease.[69] And it was only through bringing that self-diagnosis to my doctors that I was able to access my first surgery and get a diagnosis.

Unfortunately, I hadn't fully done my research and I didn't find a specialized doctor. The surgery I received was ineffective and poorly done. I was left alone in the hallways of the hospital for hours without medication and the medication I was eventually given was injected without my consent. I was sent home with nothing but naproxen, which didn't touch the pain. A day after the surgery I passed out trying to get to the bathroom and, on the prompting of my partner, called the number the doctor had given me. She was having a family gathering, I could hear kids in the background. I told her I had passed out from pain, should I be worried? She told me it was normal, to go to emergency if I needed anything, not call her.

A couple weeks after surgery, I was told that I was "all better." I wasn't told that they had left endometriosis next to my rectum, and that they didn't even know what they were looking for or how to effectively remove it. Following the recovery guidelines, I attempted to go to class, but there were no seats available on the bus and I didn't feel like I could ask for one because I "looked fine." I arrived at the university, vomited in the toilet, and called an Uber home. This is what the months after the surgery were like. When I went back to my doctor three months after the surgery and told her that I was still in pain, she told me I

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[69] I apologize for all the times I have vomited across Montreal thanks to endometriosis.

"must just be one of those people who is in pain all the time" and waved me out of her office. I tried taking hormones again, on her recommendation, and all the joy melted out of my life. I experienced multiple mental health crises before I finally let myself quit the pills.

Slowly, I came back to myself. I waded my way through waitlists and referrals and found a new doctor at a pain clinic who was said to be a specialist. She introduced me to pelvic physical therapy, TENS units, and muscle relaxants which greatly helped my pain, but did nothing to treat the underlying disease. For a while, she validated my symptoms and experiences but, as I continued to experience pain and advocate for another surgery, she became less kind and accommodating. She told me to take more medication, but I refused, telling her the medications make me suicidal. She told me I could choose between being suicidal or being in pain. I cited research to her about the medication, such as how it can't be taken for too long and that it only helps manage symptoms. She told me to stop reading blogs. Every appointment left me hopeless.

At this point I was a few years into my dissertation, and I'd found communities through social media that helped me feel better informed and less alone. I'd completed my essays and classes and comprehensive exams, even went to conferences, all while in pain. I'd started working with my brother and a team on a video game and we had completed a demo that we were going to pitch Sony. I was in pain, but it wasn't at its worst. Days before we were going to pitch Sony, my brother was accused of abuse on Twitter. The fallout was a very public denouncement of him across social media. Friends he'd had his whole life Tweeted about him before they spoke to him because they were scared their public silence would lead to their own condemnation. He committed suicide a few days later and, in announcing his death on Twitter, I was targeted by online harassment and separated from several communities I'd spent my entire adult life building.

Although my endometriosis communities remained surprisingly separate from all of this, my optimism about social media had all but dissolved. If I could barely stand to look at it without panic attacks, how could I possibly research it? I paused work on my dissertation and rested. I signed up for a human physiology course in a feverish attempt to change careers and become a nurse. I lasted for two weeks and failed every practice exam. After not experiencing pain for a few months after my brother's death (shock is a hell of a drug), it re-emerged. In a desperate attempt to get my doctor to stop recommending medications and approve me for surgery, I told her that my brother had committed suicide. Maybe then, I thought, she would believe in the severity of my own suicidality. This failed and, at the next appointment, she asked me if I'd "gotten over my brother's suicide yet?" That, of course, has not happened, however, I did eventually make my way back to my research and defended my dissertation proposal in February 2020.

Just as I was beginning to surface (a little) from the grief and get ready to do my research interviews, the pandemic hit. A month later, despite every precaution, I got sick with a fever and a cough and the inability to take full breaths. Experiencing constant inflammation and anemia from endometriosis has always made me more susceptible to illnesses. I tried to get tested for covid, but at the time the tests were reserved for healthcare practitioners. I didn't get better for months. Even four weeks after infection I was still barely able to walk up the hill from my house without wheezing and seeing stars. I started Googling again and learned about Long Covid. Patients were naming the disease and advocating for treatment (Callard and Perego 2021). Few others believed it was real. This was all so familiar to me— the skills I'd learned from endometriosis became more valuable than gold.

I slowly started healing and doing my research interviews. I had horrible brain fog (a combo of long covid and trauma and endometriosis, I imagine) and I knew I wasn't as articulate as I could be. The participants were kind and understanding. Who would understand better than other sick folks? I listened to their stories, at times overwhelming, at times so familiar, at times surprising. I slowly emerged back into the world through listening, through stories of advocacy, and through these reminders of community and resilience. I was shocked by how much their stories paralleled my own:

> I started my menstrual cycle when I was 9, I wasn't diagnosed until my late 20s, so it was a large time of me just trying to figure stuff out on my own. (April Christina 2020)
>
> I lived with my mother and my grandparents growing up and my grandparents were really into the old wives tales and my grandmother would say "[…]you run around barefoot and you eat too much ice cream, that's what's causing all that pain." (Henderson 2020)
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> I very distinctly remember [being] in the fetal position on the floor in my classroom in grade 7 and 8. […] Sobbing on the bus because I was in so much pain *always* and it was never taken seriously. It was always like […] "yeah

cramps are bad, sorry." So it just got worse and worse and worse and then in my late 20s it was to the point where I was like, this level of pain cannot possibly be normal. (Ozorio 2020)

[The doctors said] “you should take pills and just go home, relax, maybe you were nervous about your exams,” because I was in high school finals and also in Israel when we finish high school we have to go to the army. So everyone immediately assumes that you're saying you have pains because you don't want to go to the army. (@tomis_endo 2020)

I would say that my gastro issues kind of got worse over the years but again [the doctors] would say it was all chalked up to my nervous stomach, which didn't really make much sense to me, but I started birth control probably around 19 years old and I would say before that even on the pill I started having chronic fatigue. (Berna 2020)

[My doctors] thought they just needed to go in and laser my nerves off. […] They told me I needed to get [my nerves] ablated and I was like, no, and they said, alright then we can't do anything to help you and then I left and then I never saw that doctor again. (Morneault 2020b)

And then, all of a sudden, I was getting my period twice a month. That was 2017. And I was like noooo, noo we can't do this. Cause I'm having like really long, like nine, ten, eleven day periods, and twice a month. That's the whole month! (Dagrosa 2020)

You get to a certain age and all of a sudden it just gets *so* much worse. Like it goes from being awful to being so awful you need to find answers right now. (Emma 2020)

Nobody wanted to diagnose or entertain you if you weren't over thirty. “You were too young,” and all the usual things that we hear. (King 2020)

I had a long delay […]I probably had symptoms for over 20 years before I was diagnosed. (Grace 2020)

The day I found out about [endometriosis] was the day I was told I had it. Which is wild to me because of how commonly occurring the condition is. (Nkosi 2020)

[My gynecologist] said, you know you've got endometriosis.[…] And he threw a whole lot of information at me. He said, you know, this is a lifelong disease, you're probably not going to have children, we're going to put you on the pill and you just stay on that and you'll be okay. I was like, okay, again I’m in my very late teens, I was like *he knows, the doctor knows best, what do I know?* So I kind of just went about my business and I never felt better because he hadn't treated the disease. (Guidone 2020b)

When I was diagnosed it was just a whole other vortex of trying to get effective treatment. (Cohn 2020)

I had my first laparoscopy, and unfortunately this doctor was not skilled in removing endometriosis lesions. He determined that the endometriosis was everywhere but so thin that laser burning the lesions would cause me more pain. So he stitched me back up and put me on birth control pills, always throwing away the last week of pills in order to stop my period from coming. (Jeon-Miranda 2020)

[My doctor] put me on birth control and this was on top of my IUD already and this was to help with the pain. Of course it didn't. So then for probably another good 6 months we were trialing and erroring a number of different birth controls and nothing's helping, nothing's working. And at this point I'm eating ibuprofen around the clock to get through work. I was on 600 and I would take it just around the clock, just start my day with it and just proactively take it. (Rishe 2020)

I was put on Gabapentin, that's a nerve thing […] so I eventually worked up to the max dose you can have a day [but it] wasn't touching the pain, and I kept saying, how is this a nerve thing? They said you have centralized pain and I was like no no no, I've got inflammation going on. It's an active disease process, that's not touching it. And I was eating ibuprofen like crazy and then I was finally starting on the stronger prescription stuff we have and nothing was touching it. I would drink a bottle of wine to try and numb the pain but the pain was so bad and [being] on the Gaba I couldn't drive, I couldn't pick my son up. (Bingham 2021)

The [birth control] pill kind of seemed to help, like it reduced the lengths of my periods but not necessarily the severity of them and then things just kind of got worse, so I was taking time off uni, I was off school, I couldn't have sex and it got to the point where I was 24 and I started to have a permanent pins and needles sensation in my pelvis and I was like, you know what, this isn't normal, I'm going to go to the doctor's. (LP 2020)

I got another opinion and the doctor said […] we can try to scrape some of [the endometriosis] out but generally it always comes back and so you need a hysterectomy. I bought that because my hemoglobin was so low. I was so miserable I could hardly stay on the job. So they did a complete hysterectomy, took the ovaries. Six weeks later my back and leg pain had not improved so they said, well, it's not from endometriosis, you need a back surgery. (Petersen 2020a)

My symptoms were getting worse. I was always being tested for lupus, my systemic systems like my joint pain was so bad, I eventually ended up with a neurologist getting tested for Multiple Sclerosis. It was just a total disaster. And at this point I see no one's giving me answers. I end up in the ER. My first ER visit was so terrifying and I had these episode before where I'd be on the floor and I couldn't even reach my phone to call 911. (Boyce 2020)

[My first surgery] was a trauma, a five day long trauma. (Frances 2020)

> The only reason why I knew about excision [surgery] was because a celebrity had gotten pregnant after excision. (Sarrel 2020)
>
> [The pain] became really debilitating and there was, gosh, probably about 2 years where I was having to take off work at least once a week for pain. I went to the ER a bunch of times, went to some different OB-GYNs [...] I had one doctor tell me that my endo was in remission so my pain was just chronic pain and that I had pelvic floor dysfunction and I was prescribed benzos and I went to pelvic floor PT for a while before finding an endo specialist in my area through probably Nancy's Nook or something like that. (Kuller 2020)'

The stories were so full of pain, a familiar pain, both emotional and physical. I put them here together to illustrate the impact that just twenty-two endometriosis stories can have when you see them built into a network. In the words of Kate Boyce:

> I feel like so many of our endometriosis stories are similar. So I don't always have to go into too much detail, you know. When you're talking with someone who's unfamiliar with the disease, you have to really drive home the patient experience, but I know that you understand it. (Boyce 2020)

Fueled by these stories, their similarities and differences, I began writing my dissertation. I also began volunteering with endometriosis organizations. I used the funds from my brother's game company to start an impact fund for underrepresented game developers with a new (and very dear) friend Jennie. We called it Weird Ghosts. Things were happening, but I was stuck with my endometriosis and my pain was getting worse. With the pandemic, the chance at getting surgery in Canada was even less possible than before. I tried getting in with some of the other (limited) Canadian specialists but was either turned away or put on endless waitlists. Because they were out of province, I would also need to pay out of pocket. I began to seriously consider going out of country for care. Even though I hated the idea of private healthcare, the money my brother had left behind made it possible, and I didn't know what other options I had.

You've heard this story, all these stories, in fragments throughout this dissertation, and this is where we arrive at the conclusion. Not the conclusion of these stories but a conclusion of everything that has emerged in this research, these communities, and my own life throughout the process of writing this dissertation: the values and dangers of social media; the stickiness and power of community; the labour of creating change; and the past, present, and future of endometriosis. So much of this dissertation has paralleled my own journey of trying to find answers for this disease, of trying to find care.

This is where we arrive:

Networks of Endometriosis

Above, I map out my journey through my PhD as a person with endometriosis and a person on social media. As I've said from the beginning of this dissertation, *I am a part of this research* and my own auto-affective media practices are part of these networks of endometriosis, just as much as my auto-ethnographic excerpts are part of this dissertation. My own relationship to social media, endometriosis, and social media endometriosis spaces has been complex. Doing this research has, at times, helped me access better care and spend more time learning about my disease. At other times, as I've explored, it has made it harder for me to access community support and take care of myself. These networks of community care are critical for disabled people but can be difficult to find within academic spaces, particularly during a pandemic. So much of my ability to continue in this academic program has been due to the networks of care I have found and created outside of academia (see my

Acknowledgements). These community spaces, this care work, is what I want to focus on in my conclusion, as I believe it ties together (one could say networks) everything that has been explored up until now.

This dissertation began with an exploration of the systemic failures inherent in endometriosis research and care, both historically and today. I argue that the ways endometriosis has been deprioritized, underrecognized, and mistreated has in many cases made this condition more disabling than it would be on its own. To better understand how endometriosis comes to be understood, as well as how social media plays a role in articulating this disease, I theorize that there are many *networks of endometriosis* in which power and meaning flow. These networks of meaning may conflict and undermine each other, but these (mis)communications are inherent in understanding what endometriosis means, in all its complexities. Social media both networks us, but also reveals just how networked we are. I structure my research around the auto-affective media practices used by people with endometriosis on social media to trace the role they play in shaping and understanding these networks.

Chapter two explores the conflicting networks of knowledge that are articulated through the information-sharing and knowledge-creation practices of people with endometriosis. I explore the labour that people with endometriosis must perform to access care and how social media can both reduce or reproduce this labour. I describe the ways many people use social media to practice self-empowerment, self-education, and self-care, while also recognizing these are not universal, or universally accessible, experiences for all people with endometriosis. Not everyone has the same access to these resources or the capacity to make use of these resources, even though social media has improved information accessibility to some degree. I describe how social media itself has begun to contribute to the knowledge and trust gaps between patients and practitioners and argue that these social media practices need to instead be validated by researchers and doctors, even when they are imperfect. Although misinformation is important to combat, it is also necessary to do so, while also acknowledging the affective importance of these online communities and the incomparable feelings of agency they can provide for some. Endometriosis knowledge is messy and contradictory even between researchers, and patients should not hold the burden of responsibility for misinformation when they are simply trying to become more active in the networks of knowledge surrounding their disease.

Chapter three builds on the previous chapter to explore how networks of feeling and connection bring people with endometriosis together around certain shared values, experiences, and ideas. I explore how endometriosis can become embedded in people's identities in ways that some find positive and others negative. I also explore how strong emotional connections to endometriosis drive much of the community and conflict within these online spaces. I describe the importance of shared experiences in online endometriosis communities, while also exploring the cases where experiences vary and contradict. I use affect theory and the Ahmed's concept of "sticky" affect to articulate how certain communities attach themselves to different ideas, how networks converge and break apart, and why conflict can be so prevalent in these spaces (Ahmed 2013). I show how social media can help make visible many of the complex ethical entanglements that have been a part of our networks of endometriosis for centuries. By making these networks more apparent, communities on social media can start to reach beyond self-preservation and individuality to address the complex networks of power at play within endometriosis. By coming together in online communities, we can see many people begin to recognize and address systemic failures as well as practice forms of community care.

In chapter four, I build on this discussion by considering in more detail the way meaning-making works in these auto-affective media practices. I use theories from life-writing studies and pain communication to illustrate how writing about (or inscribing) the self is not an individualistic act, but one that draws attention to our ethical relations and vulnerability to one another. In other words, not only are people with endometriosis connecting by sharing knowledge and experience, but they are also collaboratively creating the meaning of endometriosis (networks of meaning) by putting their stories in conversation with one another. Communication may, as I explored in the beginning of this dissertation, always be miscommunicative, but by mapping themselves in relationship to one another through these auto-affective media practices, people with social media are actively articulating and creating their own networks of endometriosis. Although patient perspectives have always existed, social media provides a space where people can find each other more easily and where their networked practices can carry more weight.

The main conclusion I draw from this analysis is that, although endometriosis social media spaces are fraught, they are (as of this moment and in lieu of better options) necessary and valuable. The significance that self-expression, community validation, and access to knowledge can have for people with endometriosis cannot be undermined. Even though these spaces may be imperfect, they are often just as flawed as most of the clinical care offered to endometriosis patients at this time. In both my interviews and surveying, medical dismissal was a common theme (see Appendix 1: Table of Themes). Take for example, one survey respondent who wrote:

> I have not found a reliable healthcare provider who knows what the hell they are talking about. For 20+ years, I have been dismissed, misdiagnosed, ignored, mocked, and humiliated by the very healthcare providers and system I was seeking help from.

Although each story of dismissal was slightly different, similar tales of dismissal and neglect pervade my research results. This dismissal, as seen in my survey results and interviewees' stories, pushes patients to other seek options such as social media. As another survey respondent named Rachel writes:

> I only wish I could have found [Nancy's Nook] before my diagnosis 5 years ago because I suffered for a long time and honestly trusted my doctors TOO much when they blew me off about my concerns. By the time I finally found a doctor who listened to me, I ended up losing one of my fallopian tubes and the other was so damaged that I can never get pregnant naturally. […] If anything, finding information in social media groups like this can be empowering—we know our bodies, we know when something is wrong, and too often women with endometriosis suffer silently for too long.

This does not mean that these social media spaces are without fault or serious risks, as this dissertation has explored, and as this next anonymous survey response describes:

> I have been verbally attacked [on social media] for not knowing that endometriosis can be diagnosed without surgery[70]—called me a waste of space at a pretty low point in my life to where it caused suicidal ideation. But that interaction taught me that everything I've been told about endometriosis could be potentially wrong and caused me to educate myself further.

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[70] Even this example is loaded. Endometriosis can only be confirmed through removal and pathology, but it can often be spotted and suspected through imaging (Hsu, Khachikyan, and Stratton 2010).

While this interaction online made this one survey respondent experience suicidal ideation, for others, these spaces keep them alive. As another respondent writes: "I would have been dead from suicide if not for my FB [Facebook] support system." For others, medical neglect is what left them suicidal. There is no simple solution or easy narrative in these experiences and these quotations illustrate that messiness. On the one hand, so many patients have reached the end of their options for clinical care, on the other social media can be extremely upsetting and harmful. Until patient needs are addressed, there will be some people with endometriosis who turn to whatever options are available, even if those options come with their own risks.

I argue that understanding how endometriosis gets explored and created on social media can help us better understand how to treat it and research it from a patient-centred approach. People with endometriosis' continued and expansive use of social media despite its downfalls proves that they are in many cases desperate for care and are often willing to deal with a lot of difficulties to access that care. I conclude this dissertation by leaning into these contradictions, this mess. In doing so, I propose a future where we *work through* the discord between clinical practice and social media (doctors and patients) to create a productive collaboration, one in which people with endometriosis can play a central role in their care and knowledge-production. I believe it is only by turning *towards* miscommunications and messiness that we can truly begin to improve endometriosis research and care. That's why I believe it is so important that researchers and clinicians read this work and recognize why people with endometriosis go online. As a survey respondent named Mary put it: "I wish sometimes doctors joined these groups just to understand how their words and actions affect women who [are] already suffering."

Findings

In summary, my research shows that people with endometriosis who use social media use it for a variety of reasons including: information-and-knowledge-sharing and self-education; social and communal practices; meaning-making and storytelling; and advocacy and/or activism. The three most popular things that the survey respondents identified using social media for were "feeling less isolated" (63.4%), "offering support"

(64.4%), and “raising awareness about endometriosis,” suggesting that many people with endometriosis who use social media are not only thinking of their own needs but are also interested in providing or improving care and preventing others from going through the same struggles. Although my survey respondents suffered from a variety of symptoms, 92% of them identified experiencing pain, and they waited on average ten years for care. This is somewhat longer than the estimated worldwide delay in care (Hadfield et al. 1996; Arruda et al. 2003; Huntington and Gilmour 2005; Ballard, Lowton, and Wright 2006; Nnoaham et al. 2011; E. Denny 2011; Bullo 2018). Because many of them mentioned turning to social media *after* experiencing medical dismissal, it is possible that individuals who experience more medical dismissal are more likely to turn to social media, however this cannot be argued conclusively from these results. Overall, 95% of respondents said they found social media helpful, or somewhat helpful in managing or living with their endometriosis, with 92% saying it had taught them something new. Although these results cannot speak for all people with endometriosis, it does suggest that some people with endometriosis are getting valuable things from social media, including, but not limited to, community, connection, experiential and medical knowledge, validation, information, reduced isolation, resources, and research (see Appendix 1: Table of Themes.) Finally, my research shows that the messiness of social media in many ways reflects and reproduces the messiness of endometriosis care, research, and practice in general.

Addressing the Mess

June 15, 2021: Stuck in the mess

It's funny. The more research I do, the more stories I hear, the less sure I am on how to navigate my own endometriosis. I think that’s telling.

I thought I might come out of this dissertation with a better understanding of my illness and how to treat it and, while that’s true to degrees, it has also become stickier and messier and ever more confusing. It’s not just the complexity of the illness itself, but of the worlds around the illness (the networks of endometriosis) that influence what it means to live with this disease. Do I leave Canada to receive care, despite hating the private healthcare system? Do I tell my doctors about my research topic, despite my trauma? Should I try *hormones again, despite my lived experience? Is my endometriosis really* that *bad compared to others, despite what I feel? Should I bother responding to the swarms of people on Twitter telling me that endometriosis online affects "females" only and that I'm erasing women by using the word "people," despite feeling less and less like a woman myself?*

All aspects of endometriosis are overwhelming.

I have recently started working with the Endometriosis Educational Organization of Canada (the EEOC) as well as lobbying my members of parliament for a National Action Plan for Endometriosis using the toolkit created by Endo Act Canada. I've been involved with the Citizen's Climate Lobby and have been creating a fund for underrepresented game developers in Canada (Weird Ghosts). I've had my hands deep in the mud in the ruelle verte, pulling up weeds and learning the names of the plants. I'm realizing how much time and effort and cooperation and conflict-resolution and organization and boring labour and bureaucracy it takes to create change. I'm realizing how social media both does and doesn't support this organizational work. Social media can bring us together, but it also oversimplifies complexities despite complexity making up every aspect of its structure. It connects us and pulls us apart. And yet endometriosis can be so isolating without it.

Conflict and Difficult Conversations

As various conflicts emerged in endometriosis spaces throughout my dissertation, I kept trying to think about what could help bridge these gaps, particularly when the conflicts responded to ongoing tensions in the broader endometriosis landscape or broke out between patients and practitioners. I would fantasize about what it would look like to bring various people in conversation with one another with a mediator and get them to work it out in person rather than behind their screens. *If only we could get people off social media and into a room together!* I thought.

This is something that I explored, in a small way, during a panel I hosted for the 2023 Endometriosis Summit. The panel, looking at the patient-practitioner relationship through a lens of trauma-informed care, gave patients the opportunity to talk about medical dismissal and informed consent to an audience of both practitioners and patients. Informed by my research on the dismissal of social media practices, I aimed to facilitate a conversation that bridged the trust gap between patients and practitioners. I was in a lucky position, where the clinicians attending the conference were some of the most understanding and informed endometriosis specialists out there, and the patient-panelists were already interested in the work of bridging the divide. The Endo Summit is widely attended by people who are already engaged in these kinds of conversations and ideas. Most of the clinicians who need to hear this information were not at the conference so, while my panel may have had some small influence beyond its setting, I also know that the trust gap and deeply engrained conflicts at the heart of endometriosis care run much deeper. Much more difficult conversations need to be had to foster that change and that is what I plan to work on going forward.

Research on patient-centred care looks at the importance of difficult conversations in improving the patient-practitioner divide. In their article on shared decision-making in chronic care, Vibeke Zoffman, Ingegerd Harder, and Marit Kirkevold write that "[e]xploring rather than avoiding the sources of increased tension [between patient and practitioner, such as 'difficult feelings and different points of view' has […] been linked with an ability to exploit both parties' potential for change" (Zoffmann, Harder, and Kirkevold 2008, 683). In other words: difficult conversations between patients and practitioners need to be had, rather than avoided. This includes letting patients know if there are limited options for care or if one is not specialized enough to treat a patient as well as understanding why they might turn online if they don't get adequate care. It also includes broaching the subject of social media in a nuanced and receptive way. But there are many factors that make this difficult, including a lack of training on how to go about these conversations. Instead, these difficult conversations become conflicts and, as we've seen exemplified throughout the dissertation, these conflicts bubble up online.

The messiness, the stickiness, and the difficulties of endometriosis social media spaces are some of the most revealing aspects of this dissertation. It is easy to dismiss these areas as problematic and to write off the importance of social media. It is much harder, but more necessary, to "stay with the trouble" and see what that trouble calls up (Haraway 2016). I evoke Donna Haraway here because of how she conceives of "trouble" as something that necessitates a response. "Response-ability," as she puts it, our ability to respond, calls for a recognition of our relationality to one another, our vulnerability, and our need for practices of care. Whereas the responsibilities of disability and chronic illness are often placed on the individual, they are actually collective and social matters. “Staying with the trouble” of endometriosis social media spaces involves considering one’s response-ability towards the content being produced, the people behind that content, and the broader state of endometriosis and chronic illness care.

This is not always easy. I know first-hand how strong the desire (and sometimes necessity) to turn away and turn off can be. But these social media spaces cry out for a response. Oftentimes, this response is not necessarily what is needed. A post invites “likes,” “comments,” and “follows,” but often the underlying invitation is for change or for action. This raises the question of how social media can be mobilized to create more impactful responses? We’ve seen some good examples of this throughout the dissertation, but it is also something I have become personally invested in throughout my PhD.

In my time at the Endometriosis Educational Organization of Canada (EEOC), I worked on creating the visual templates for our Instagram and Facebook content, as well as helped brainstorm (and sometimes research) each month’s content. Eventually, I also started creating reels. It was a useful thing to do to fully realize just how much labour goes into content creation and understand some of my research participants better. It also led to some very interesting conversations about how to best meet our organizational goals through our social media posts. At times, social media almost became a distraction for the more tangible actions of the organization, such as creating and distributing educational content, organizing events, and so on. At other times, social media provided the tools to mobilize people to get involved in a campaign, share information, or take action.

“Staying with the trouble” of endometriosis social media communities involves reflecting on what these groups need and how those needs can best be met. Haraway writes that response-ability is a “praxis of care and response” (Haraway 2016, 105). Writers Leah Lakshmi Piepzna-Samarasinha and Hil Malatino describe a similar kind of relational responsibility with their use of the term “care work,” particularly considering practices of care in disabled, queer, and underrepresented communities (Lakshmi Piepzna-Samarasinha 2018; Malatino 2020). These practices of care help shape the culture of a community. As Malatino writes,

> An ethos emerges from an ensemble of practices; when we shift collective practice, we reconfigure ethos. Practices of care are always part of an emergent ethos. Because care isn't abstract, but only ever manifested through practice—action, labor, work—it is integral to our ways of doing. (Malatino 2020)

The care work that does happen in online social media spaces is ever shifting and reconfiguring and it is not without conflict. As Piepzna-Samarasinha describes, conflicting needs and the failures of interdependence emerge even in much smaller communities than social media (Lakshmi Piepzna-Samarasinha 2018).

By looking at the social media practices of people with endometriosis, as I have done throughout this dissertation, it becomes clear that, despite all the mess and complexities of social media, there is also accountability and response-ability—practices of care and relationality—that are being developed, evolved, and explored each day within these spaces. We see this in the posts that call on websites or news articles to correct misinformation, in the campaigns for endometriosis visibility such as #IAmExtraNotRare, or even simply in the daily selfies and comments that bring humanity to this long-neglected disease. And yet not everyone in these spaces is engaged in these practices of care, or their practices of care look different. As Kathleen King and Nancy Petersen both said, social media is a "double-edged sword" (King 2019; Petersen 2020a). So why do so many of us keep using it?

September 13, 2022: A sometimes-necessary evil

I've been thinking about how Nancy's Nook and so many endometriosis advocates encourage self-education and empowerment. I've been thinking about the value these things can have, but also how much support and work is required to make them possible. Not every person is able to achieve this kind of 'empowerment.' I've seen this reflected in the mentorship work I've been doing recently with Weird Ghosts. We've learned that it's not enough to just tell our investees that they can ask for things during mentorship. Rather, we need to let them know exactly what they can ask for and how to go about asking. Even then, we often need to offer before they feel willing to ask. To bring it back to endometriosis, while it's great to *encourage self-education or self-empowerment, if people don't have the resources or time or energy or space to do these things, then it won't happen.*

Sometimes endometriosis social media spaces help make these resources available. As I've witnessed, people with endometriosis use social media in incredible ways and they create incredible archives of information and representations. But the organization and cohesion of these online spaces is tenuous, and this can make accessibility, communication, and advocacy very difficult.[71] *And it's always up to patients to find their way themselves.*

Feelings abound on social media. Feeling in endometriosis social media spaces becomes a way of knowing and being in community. Feelings pull people together and pull them apart. Community-building and community-maintenance take tons of time, energy, and resources. I return here to the questions I raised in chapter two, of who exactly can do this kind of work? And do people with endometriosis really want or need to add more labour *to their lives? Why do we go on social media if it exhausts us?*

Recently, I've been limiting my social media time on the advice of my doctors in an attempt to take care of myself and my traumas. It's good, but it's hard because it also means being detached from my endometriosis communities. I like not knowing everything that's going on, but I also miss out on a lot. The other day, however, I made a reel (see Figure 20).[72]

There has been another surge in writing about online "illness fakers" and how disability is becoming a trend on social media. In an article by Suzy Weiss, published in Common Sense and then copied by Emma James in The Daily Mail, the authors claim that social media is making people "addicted to being sick." Chronic and often gendered diseases such as endometriosis, Rheumatoid Arthritis, PCOS, are lumped together by the authors as conditions that people on social media say they have. The articles are poorly researched, unethical, easy to disprove, and likely designed as clickbait to drive website traffic. However, they confirm a lot of the general population's fears and ableism and hit home for a lot of disabled, sick, crip, and mad folks who have experienced these attitudes at large.

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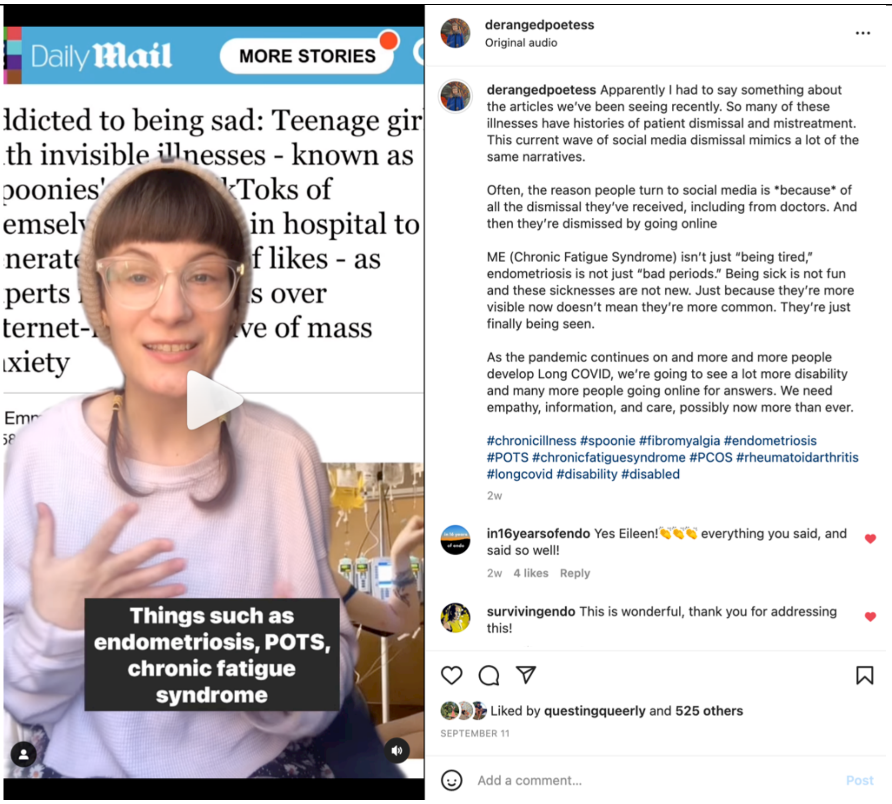
[71] To add to these reflections, even understanding the protocols of social media spaces and understanding endometriosis can be barriers to joining these communities as a "newcomer."

[72] To see the full reel, go to: https://www.instagram.com/p/CiX6-B0A_Qr/



derangedpoetess
Original audio

derangedpoetess Apparently I had to say something about the articles we've been seeing recently. So many of these illnesses have histories of patient dismissal and mistreatment. This current wave of social media dismissal mimics a lot of the same narratives.

Often, the reason people turn to social media is *because* of all the dismissal they've received, including from doctors. And then they're dismissed by going online

ME (Chronic Fatigue Syndrome) isn't just "being tired," endometriosis is not just "bad periods." Being sick is not fun and these sicknesses are not new. Just because they're more visible now doesn't mean they're more common. They're just finally being seen.

As the pandemic continues on and more and more people develop Long COVID, we're going to see a lot more disability and many more people going online for answers. We need empathy, information, and care, possibly now more than ever.

#chronicillness #spoonie #fibromyalgia #endometriosis #POTS #chronicfatiguesyndrome #PCOS #rheumatoidarthritis #longcovid #disability #disabled

2w

in16yearsofendo Yes Eileen!👏👏👏 everything you said, and said so well!

2w 4 likes Reply

survivingendo This is wonderful, thank you for addressing this!

Liked by **questingqueerly** and **525 others**

SEPTEMBER 11

Figure 20: Instagram reel I made in response in response to articles about social media and chronic illnesses.

I decided I wanted to respond. (I felt a response-ability.) It took me all morning to make the reel. I had to do dozens of takes per cut and I ended up having to film the entire thing twice due to technical difficulties. By the end of the morning, my anxiety was extremely high. The reel was doing well, but I needed to turn of social media to catch my breath again. I felt good about sharing information, but I also knew that the reel was mostly reaching those already within online chronic illness communities (and maybe the few practitioners who follow me). And, although I was glad to have made it, I needed a long break from social media after to calm my nervous system.

Social media is clearly no longer very healthy for me, at least not right now and not in big doses. And yet, it also is. Only just one week ago, I used my Instagram community to crowdsource some extremely helpful and detailed advice on how to manage some new pain symptoms I was experiencing. I wasn't able to get these resources from my practitioners. Sometimes, I just really need these networks to survive.

So why do I share this? What does it add to my research?[73] *I can already envision the rebuttals to these personal reflections: Clearly this author is biased. Clearly social media is not healthy and they just don't realize it. Clearly, based on their earlier arguments in chapter three, people* do *get attached to their illnesses online. Clearly some people* are *faking.*

And these aren't entirely wrong, but they are also not the full picture. Social media does eat me alive. I have seen it, more than once, contribute to the deaths of people. But it also sustains me, as it sustains others. Social media has made it possible for endometriosis advocacy and awareness to surge. It has created space for people living with the disease to be heard and validated, to share information, and to connect with others. But social media is also a mess. It is sticky and overwhelming and problematic.

Social media offers a chance at agency in exchange for consenting to a system that strips us of agency. It's hypocritical, but we use it when we use it because sometimes we just have to. We grab at any opportunity we can get because that's what we do to survive. It is a double-edged sword. It is a sometimes-necessary evil, but it also gives us a platform for which to build new alternatives. To imagine what those would look like. To dream in public.

Stories for the Future

October 25, 2021: Here comes the sun

After a weekend of walking like my Baba because I could barely move due to the pain. Of dry heaving in the toilet next to L and then crying after because I was so disappointed in my body. After reading about the control of pharmaceutical companies in Canada and then trying to find an unaffiliated endometriosis specialist (Ford and Saibil 2010)*. After trying desperately to figure out how to even fax my referrals to a Canadian, likely-pharma-affiliated doctor when their office tells me only my GP can fax them and my GP insists I can fax them myself. After that, all that, I reach out to the Bucharest Centre for Endometriosis Care in Romania and the Centre for Endometriosis Care (CEC) in Atlanta, Georgia.*

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[73] The fact that the academic and the personal have merged in this chapter is not unintentional.

Both respond in under 2 hours. With love, empathy, options for surgery, questions about my pronouns, my trauma, my needs, my history. They ask for my story. They listen. All within a day. One day!

So why am I left feeling like I'm betraying my country? Like I'm doing something wrong? Why is this level of care only available privately? Why isn't this the standard of care everywhere? I feel guilty for being able to afford it with the money my brother left behind. I know I am lucky and I am so traumatized and I am terrified to believe that this care could be good, that I could ask for it, that I could allow it. Can I hope for this? Dream for this?

(Does all this thinking, this work, still count as a "thesis day"?)

Social Storytelling and "Science Fictional Behaviour"

At the beginning of this dissertation, I established what I called "auto-affective media practices." These are practices that engage with affect and feelings, as well as practices that explore the self in relation to the other through meaning-making. "Auto-affective media practices" encompass all the practices I outlined throughout the dissertation: information-sharing and knowledge-production; social and communal; and representational, world-building, and activist. It encompasses, as well, my own practices. At the heart of all of these is a form of social storytelling, of feeling out the self in relation to others, of world-building and dreaming for the future, of shaping the networks of endometriosis.

In her book *Emergent Strategy: Shaping Change, Changing Worlds* adrienne maree brown describes strategies for creating systemic change in a world that is constantly itself changing. Early in the book she coins something she calls "science fictional behaviour" which she articulates as behaviours that are engaged with or dreaming towards the future. This involves "being concerned with the way our actions and beliefs now, today, will shape the future, tomorrow, the next generations" (brown 2017, 16). We can think of endometriosis social media practices along these lines too. Not at all of them are science-fictional, but many are, particularly the ones coming from those who live with endometriosis, such as the participants in this study. People with endometriosis use social media to build archives of information, to find and maintain communities and connections, but also to write better futures for themselves and others, and even to organize politically.

For brown the idea of "science fictional behaviour" emerges in part from her childhood spent watching Star Trek. This resonates for me, as a fellow Trekkie-since-birth and someone who has used Star Trek to carry me through the worst pain days. Star Trek presents a future that is hopeful, where conflicts and differences emerge, but where these differences create more strength and harmony than disjunct. This may seem fantastical, but brown also breaks these future imaginings into more practical guidelines. She asks: "how do we shift from individual, interpersonal, and inter-organization anger toward viable, generative, sustainable systemic change?" (brown 2017, 147). This question is useful for endometriosis social media spaces where the effect/affects of algorithms and histories of dismissal rightly lead to a lot of anger. At times this anger is channeled into forms of change-making, but at other times it becomes a (potentially harmful) feedback loop of conflict and dis-ease. Luckily, brown also offers three steps to guide how we can "shift to a culture in which conflict and difference is generative" (brown 2017, 132):

1- "Why? Listen with 'Why?' as a framework"
2- "Ask yourself/selves: What can I/we learn from this?"
    a. (What can this teach me?)
3- "How can my real-time actions contribute to transforming this situation (versus making it worse)?"
    a. ("Real time is slower than social media time, where everything feels urgent.") (brown 2017, 149)[74]

If I were to finish off this dissertation with tangible steps towards how we can make better use of endometriosis social media spaces and possibly make them more sustainable, these would be my recommendations. (I may even make these into an Instagram post myself.) Although the urgency of social media, its affective "drive," is part of what can facilitate change, it can also quickly oversimplify and exacerbate conflict, preventing progress, as it has between patients and practitioners (Dean 2010). In fact, I believe these guidelines can also be applied to patient-practitioner interactions, where listening, slowing down, and learning from the other can create more generative dialogue and potentially better care. Each of these guidelines practice response-ability and an awareness of our entanglements

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[74] I've summarized here. brown goes into more detail about each of these points in her book.

as relational human beings. Many of my interviewees and survey respondents cited "preventing others from going through the same thing" as their motivation for posting online, suggesting that response-ability is a core component of their online participation.

Social media spaces are imperfect and people with endometriosis are imperfect storytellers. Although my degree is in communication studies, at times it does feel like it should be called *mis*communication studies, as the gaps and the conflicts in communication are often what produce the most meaning. To return to the work of John Durham Peters, the point of communication is not to seek perfection, but to explore and live with these flaws and differences (Durham Peters 1999). This dissertation is a call to be less critical of the imperfections of endometriosis communications, to instead stay with their trouble and see what they can offer us—what we can learn from them. In the case of this research, looking at the social media practices of people with endometriosis reveals that patients often must make impossible decisions in order to survive. Social media alone cannot be solely blamed for reproducing mistakes and conflicts that are already so present in the disease's care. Rather, observing the social media practices, and subsequent networks, of people with endometriosis reveals a need for transformative change and justice in endometriosis care, specifically around issues of misinformation, patient dismissal, knowledge-sharing, education, access, informed consent, the patient-practitioner divide, and patient agency.

Limitations and Recommendations for Future Research

I am also an imperfect storyteller. There are gaps and limits to this research project that should be addressed in future studies. Because I recruited entirely through social media, this dissertation only considers the practices of people with endometriosis who are already online and know or suspect they have endometriosis, which makes the fact that they found social media helpful less surprising. My interview and survey respondents were also fairly active online, with 46% of the survey respondents reading others' posts about endometriosis every single day and 35% reading them a couple days a week. With that said, just *how* helpful the survey respondents found social media was still somewhat surprising to me, even as a person who is active in these spaces.[75] There is certainly a very large population of people with endometriosis who have never used social media that this dissertation does not apply to or who use social media but do not have access to these spaces. If I were to conduct this study with more time and resources (and practitioner support), I would recruit through clinics and patient groups as well as online. Although my study was global, the participants largely came from North America and my recruitment was limited to participants who could speak English. While there were some aspects of race, gender, sexual-orientation, disability, and class explored throughout this dissertation, there are still many intersectional experiences absent from this research. Further, this study could have benefited from more collaboration with patients as co-research/co-creators. Future projects may consider running focus groups with patients to develop the research methods and analyze the data collectively. A larger research team could also help reduce bias and address some of the accessibility needs of working on a project with patient-researchers.

Since I began this project, the social media spaces I considered have already changed quite a lot. Instagram has started to focus more on Tik Tok-style short video content, different participants' popularity has grown and diminished, and popular media representations of endometriosis have become more common. This dissertation captures a very specific window in time and, although certain aspects remain the same, these spaces are always changing. This study offers one very patient-centric view into the world of endometriosis and social media and should be considered alongside other perspectives for a fuller picture.

Epilogue

In May of 2022, I flew down to Atlanta, Georgia with P and got excision surgery at the Centre for Endometriosis Care. Up until the day before surgery, I was questioning the

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[75] Anecdotally, when I presented at the Endometriosis Summit in March 2023, I asked how many people in the audience found help with their endometriosis on social media and almost every single person raised their hand.

decision. What if all this time on social media had really led me astray? What if this doesn't help and I've just invested everything in a false hope? What if I really *am* crazy?

Once I met the surgeon at my pre-op, I knew that I would be okay. I had never been so heard, so well cared for. I had never been so well-informed by a physician.

The differences between my first surgery (in Montreal) and my second (in Atlanta) were comically vast. I was able to keep my belongings and to have my partner nearby. I was almost never left alone, only to change, and every member of the surgical team came to check in on me and let me know what they were about to do. I was asked multiple times what surgery I was getting, to make sure I understood. I was told each medicine I was being given and why. It felt like absolute heaven to me and it was only later that I realized this is what basic healthcare should be for everyone. I was so used to being medically traumatized that I forgot what it felt like to believe that I deserved care. The doctor came to check on me before and after surgery, full of jokes and reassurances. Before I went under, he held my hand. I gripped it harder than anything else in my life.

When I woke up, I was pain free. I'd just had an almost three-hour surgery but I was pain free. As the hours went on, I needed the occasional pain medication, but not much. I was sent home with a massive bottle of opioids—something I'd been needing for years to help with the bad pain days—and I only ended up using a few. I slept a lot, I healed, but the pain of recovery was nothing compared to the pain of endometriosis for all those years. The flu-like symptoms I had every time I got my period were gone. Something I was always told was in my head had left my body.

Then it started to hit me: I'd been right all along. I *had* needed surgery. I *had* been dismissed continually for more than fifteen years now. I *did* know what was right for my body. I *hadn't* been led astray by social media. Perhaps I should have been reassured, but the trauma of realizing these things led to another, severe mental health crisis. Perhaps this makes me sound hysterical. In a way I am, thanks to years of medical dismissal. I think again of LP's Instagram post (see Figure 4): "why yes, being misdiagnosed time after time does make me hysterical."

The dismissal of endometriosis social media practices is a continuation of the long history of dismissal in the treatment of endometriosis. When we actually analyze what people with endometriosis are using social media for, we see them resisting this exact type of dismissal through patient-led practices. Information is crowdsourced, communities are formed, stories are shared, and better futures are imagined and created. Gaps are identified and sometimes even addressed. To repeat Heather Guidone once again: “If it doesn’t exist, we’re going to create it” (Guidone 2020b).

In one of the journal excerpts featured in chapter two I wrote, “*Do [doctors] know how crazy we already feel? Do they understand just how engaged, how informed, how desperate we are? If not, how do we tell them?*” The telling is one part of the equation for sure, but to be heard, we need to first be listened to. I am reminded of a series of videos Dr. Wendy Bingham put together for The Endometriosis Summit in 2022. In them, she plays the role of the dismissive doctor, while excision specialist Dr. Abhishek Mangeshikar from the Indian Centre for Endometriosis plays the role of the patient trying to advocate for care. The videos (edited by endometriosis advocate Alexandra Mitchell from the Instagram account @InvisibleIconic) are useful for giving patients an example of how to effectively advocate for themselves, but they’re also funny and carnivalesque in their reversal of the doctor-patient power dynamic. Dr. Mangeshikar sits forlornly in the office, his hospital gown open in the back (see Figure 21). He looks powerless, even as he tries again and again to make valid points. Wendy, who spoke to me in her interviews about her lack of self-esteem thanks to years of dismissal, stands with authority and shoots down each of his concerns effortlessly.[76]

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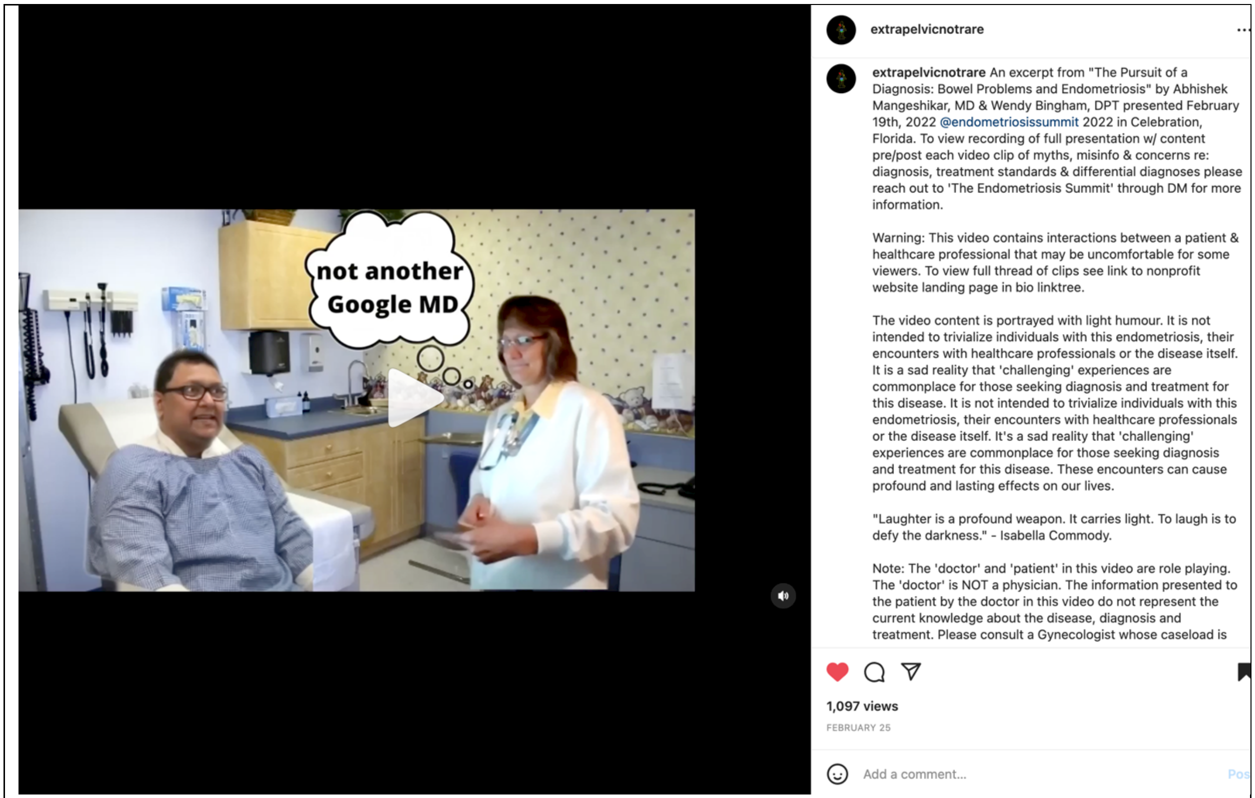
[76] To full the full series of videos, see the playlist on the Extrapelvic Not Rare YouTube channel: https://www.youtube.com/watch?v=9nRDI4f9xp8&list=PLw71iMwAmw1Pw6YMtknj_UdVswcJIJvF3&index=1



extrapelvicnotrare An excerpt from "The Pursuit of a Diagnosis: Bowel Problems and Endometriosis" by Abhishek Mangeshikar, MD & Wendy Bingham, DPT presented February 19th, 2022 @endometriosissummit 2022 in Celebration, Florida. To view recording of full presentation w/ content pre/post each video clip of myths, misinfo & concerns re: diagnosis, treatment standards & differential diagnoses please reach out to 'The Endometriosis Summit' through DM for more information.

Warning: This video contains interactions between a patient & healthcare professional that may be uncomfortable for some viewers. To view full thread of clips see link to nonprofit website landing page in bio linktree.

The video content is portrayed with light humour. It is not intended to trivialize individuals with this endometriosis, their encounters with healthcare professionals or the disease itself. It is a sad reality that 'challenging' experiences are commonplace for those seeking diagnosis and treatment for this disease. It is not intended to trivialize individuals with this endometriosis, their encounters with healthcare professionals or the disease itself. It's a sad reality that 'challenging' experiences are commonplace for those seeking diagnosis and treatment for this disease. These encounters can cause profound and lasting effects on our lives.

"Laughter is a profound weapon. It carries light. To laugh is to defy the darkness." - Isabella Commody.

Note: The 'doctor' and 'patient' in this video are role playing. The 'doctor' is NOT a physician. The information presented to the patient by the doctor in this video do not represent the current knowledge about the disease, diagnosis and treatment. Please consult a Gynecologist whose caseload is

Figure 21: February 25, 2022 Instagram post from Dr. Wendy Bingham (@ExtraPelvicNotRare) where she plays a doctor dismissing a patient. "Not another Google MD" she thinks. https://www.instagram.com/p/CaaiHa2BsPb/?hl=en

If you tell me today that I was right about needing surgery, I'll still have trouble believing it. That's the toll endometriosis has taken on me. Not just the disease itself, but the worlds around it, the networks of endometriosis that I fed off every day. The only way I escaped was through finding and creating networks of my own, run by patients. Without social media, it is unlikely that I would have found better care. I am not cured, but my life now is better than I could have once imagined. Social media helped me believe in the possibility of a different future.

But that is just my story—my story in a network of stories, a network of endometriosis to which this dissertation contributes. Social media can be overwhelming and deceiving. It can also be used to change lives. In this dissertation, I have tried to pull back from the broad scope of social media to focus on the people behind the posts we see and *their* stories and practices. I draw attention to their important work to solidify these contributions within endometriosis research and draw attention to the significant role that patients can play in these networks. This dissertation represents just one small piece of endometriosis social media spaces, their value, and everything we can learn from them. I hope that presenting these stories and these networks here, in this way, can lead to less dismissal and more listening and response-ability in the future.

Appendices

Appendix 1: Table of Themes

The following table represents all 101 of the themes and topics coded throughout the various parts of my research. The first column "Health and Research Journal" refers to the observations I recorded during my research phase and is what eventually became the auto-ethnographic sections of this dissertation. I coded these thematically so that I could incorporate them into the dissertation later. The "Social Media Posts" column reflects the themes I coded based on various Instagram and Facebook posts I saved throughout the research period from my interviewees. The "interviews" section refers to the interviews I conducted and the "Survey results" section represents all the *qualitative* answers to the survey results. The quantitative data from the survey has been reflected elsewhere throughout the dissertation. I used all these codes in conjunction with the qualitative data from the survey to identify the main themes of the dissertation as well as to structure the chapters.

These themes and ideas were coded using Dedoose and Notion using *in vivo* and values coding. For the interviews and surveys, in most cases the respondents' own language was used where applicable but, as seen below, some of the codes are used as placeholders to connect back to readings and observations I had made (such as "auto-ethnography/life-writing"). The twenty most commonly mentioned codes are: advocacy (beyond self); community (as a descriptor); connection; dismissal (medical); emotion/affect; excision surgery; experiential knowledge and shared experiences; fertility and infertility; hysteria (feeling crazy); information-sharing; isolation (feeling less alone); knowledge; misinformation (from doctors *or* online groups); pain; research (patients as researchers); self-advocacy; self-education (online); support (receiving or giving); surgery (general); and "toxicity" (conflict, negativity). These concepts shaped the structure of the dissertation and helped determine which posts, quotations, and personal observations were included, as I tried to represent the concerns that were most present for my participants, as well as areas that are more often overlooked, such as race, gender, and finances (money/cost).

Coded Themes	**Health & Research Journal**	**Social Media Posts**	**Interviews**	**Survey Results**	**Total Count**
Accessibility of social media			4	7	**11**
Advocacy (beyond self)			52	11	**63**
Alternative medicine	1			7	**8**
Artistic representations of endometriosis	4		5		**9**
Attachment (to disease)			3		**3**
Authenticity			5		**5**
Auto-ethnography/life-writing	7				**7**
Awareness-raising			2	15	**17**
“Big pharma” and pharmaceutical companies	5	8	5	1	**19**
Body image	1			2	**3**
Cancer (comparing to endo)			2	5	**7**
Cannabis use				17	**17**
Capitalism	5				**5**
Caregiving			11		**11**
Community (as a descriptor)	1	3	49	23	**76**
Confidence				17	**17**
Connection			54	71	**125**
Control (loss of)				3	**3**
Cooperation & collaboration	1	2		2	**5**
Covid-19	9			2	**11**
Delay			10		**10**
Depression (because of or separate from endo)			11	15	**26**
Disability	1		6	8	**15**
Dismissal (medical)			30	64	**94**
Doctor experiences (in detail)			33		**33**
Doctor unreliability	12			33	**45**
Emotion/affect	2	2	44	33	**81**
Empowerment			14	11	**25**
Endo belly (symptom)	2		1	8	**11**
Excision surgery	3			87	**90**
Experiential knowledge & shared experiences		2	36	99	**137**
Family (mentions of)	4		5	37	**46**
Fatigue (symptom)	3			17	**20**
Feminism(s)	1	4			**5**
Fertility (infertility)	4		10	50	**64**

Food/diet	2			31	**33**
Gender	4	2	14	20	**40**
Grief		3		2	**5**
Healthcare (commentary on)		1	19	7	**27**
Hopeful (due to social media use)				17	**17**
Hopelessness and despair (due to social media or endometriosis)			10	8	**18**
Hysterectomy/oophorectomy			7	21	**28**
Hysteria (feeling “crazy”)	10	4	36	37	**87**
Identity (in relation to disease)	2	2	16	4	**24**
Information-sharing			32	76	**108**
Inspiration	1			3	**4**
Isolation (from the disease)			11	8	**19**
Isolation (feeling *less* alone)				101	**101**
Knowledge		10	56	36	**102**
Labour	2	4	35	1	**42**
Lupron	1		2	13	**16**
Meaning making			11		**11**
Medical advice online	3		14	5	**22**
Medications, pharmaceuticals	5	6		35	**46**
Mental health	4	2		20	**26**
Misinformation (from doctors *or* online groups)	9		20	40	**69**
Mistreatment (medical)			18	15	**33**
Moderation (of online spaces)	5	1	14	1	**21**
Money/cost	6	6	19	4	**35**
Naming (validation in the name)			10	1	**11**
“Normal”				55	**55**
Not on social media			14		**14**
Orilissa	2			4	**6**
Overwhelmed (by aspects of social media spaces)				35	**35**
Pain	6	5	25	184	**220**
Patient-informed care			9		**9**
Politics	2	5			**7**
Positives of chronic illness			5		**5**
Practices	2		15		**17**
Prevention (helping others)			15	11	**26**
Queer			5	9	**14**

Race	3		4	1	**8**
Reels (Instagram)		2			**2**
Representation		4	21		**25**
Research (patients as researchers)	8		16	56	**80**
Resources & tips			15	35	**50**
Self-advocacy	4		9	48	**61**
Self-education (online)	6	5	26	131	**168**
Selfie	3				**3**
Sexual intercourse (intimacy)	2	1		11	**14**
Sexism (direct mentions of)	1		7	7	**15**
Shadowban		2			**2**
Shared symptoms				32	**32**
Stealing content		1	2		**3**
Storytelling and sharing	5	5	10	20	**40**
Suicide	2			5	**7**
Support (receiving/giving)		2	32	129	**163**
Surgery (general)	6	4	3	51	**64**
Surgical images or “gross” imagery	5			1	**6**
Systemic issues		2		20	**22**
Therapy (psychology)			8		**8**
Thoracic endometriosis	2			8	**10**
“Toxicity” (conflict, negativity)	3	10	54	52	**119**
Transphobia	1	1		9	**11**
Trauma	5		4	1	**10**
Travel (for care/surgery)	2			10	**12**
Trigger warning use	1	1		3	**5**
Understanding (of self or of disease)			4	34	**38**
Validation			18	31	**49**
Work and career				3	**3**
World / change-making			14		**14**

Appendix 2: Interview Questions

General One-on-one Interview Questions for All Participants

1. Did you already complete a survey? If so, what is your email, so I can make sure not to duplicate your answers?
2. What does endometriosis mean for you? Has this changed over time?
3. Why do you use social media in relation to endometriosis? What brought you to these spaces?
4. (a) What social media spaces do you use in regards to chronic pain?
   (b). What, if any, is/are the main symptom(s) you seek out help or support for on social media? (If they have difficulty coming up with one, I offer these suggestions, but they should feel free to say multiples or other things.)
   - **a.** Pain (abdominal, genital, or other)
   - **b.** Difficulty with intercourse
   - **c.** Diarrhea, Constipation, Bloating
   - **d.** Excessive or abnormal bleeding
   - **e.** Infertility
   - **f.** Worsening symptoms
   - **g.** Isolation / Loneliness / Feeling misunderstood
   - **h.** Difficulty with birth control or other medications
   - **i.** Chest pain / cough / breathlessness
   - **j.** Fatigue
   - **k.** Difficulty leaving the house
   - **l.** Other (please specify)

   (c). Did you find any support or help online regarding these issues?
5. Did social media expose you to any other or new pain management treatments/tools? Did it teach you anything new about endometriosis?
6. Overall, have you found social media helpful in managing or living with your endometriosis? How so?
7. Have you found these social media spaces difficult to engage with in any way? (ex: overwhelming, frustrating, toxic environments, lack of information, etc.)
8. When were you diagnosed with endometriosis (if you are diagnosed) and how long had you been experiencing symptoms before getting a diagnosis?
9. Where did you first hear about endometriosis?
10. Did social media play any role in getting your diagnosis or learning about the illness?
11. Have you made any lasting connections with other people through endometriosis-related social media groups?
12. What are the main things you use these social media spaces for? (If they have difficulty saying one, here are some suggestions, but they may mention others)
    - **a.** Describing your experiences
    - **b.** Putting your pain in your own words
    - **c.** Feeling less isolated
    - **d.** Offering support
    - e. Getting support

    f. Sharing medical advice
    g. Receiving medical advice
    h. Raising awareness about endometriosis
    i. Other… (please explain)

2. Is there one post in particular that you read or have made that was particularly important/significant for you? Why?
13. Have you learned anything about endometriosis through these social media groups that you did not hear about elsewhere?
14. What social media platforms do you most use in regards to chronic pain? Why did you choose these?
15. How often do you post?
16. How often do you check or read other people's posts?
17. Do you find these social media spaces to be beneficial for folks with endometriosis? Please elaborate.
18. Has your participation in these spaces changed how you feel about or experience your symptoms or pain related to endometriosis?
19. How would you describe the way you "relate" to other people in endometriosis social media groups?
20. Have you made connections with other people with endometriosis through your participation in endometriosis-related social media spaces?
21. Do you have any concerns around your data or privacy when posting about endometriosis in these spaces?

For Instagram users:

1. Is the fact that Instagram focuses on images and visualizations important to your endometriosis-related posts?
2. Why do you post using endometriosis-related hashtags?
3. Are your digital practices more something you do for yourself or something you do to share or participate in a community? Or both?

For administrators of an endometriosis digital space:

1. What was the inspiration behind creating this page/group/space?
2. What challenges have you experienced along the way and how have you managed them? (ex: moderation issues, admin labour, etc.)
3. What techniques have you learned for maintaining this kind of space?
4. What else have you learned through this journey that you feel might be important for a project on online endometriosis communities?
22. Do you consider yourself someone who does advocacy or activism about endometriosis? (If yes, ask below questions.)

For those who identify as doing activism or advocacy about endometriosis:

1. Why did you choose the platform(s) as a medium for your activism/advocacy?
2. What was your reasoning behind wanting to do activist work in regards to endometriosis?
3. Why did you decide to do this work on social media?

4. What challenges (if any) have you faced in doing this work? (ex: negative attention, trolls, etc.)

Final Question

23. Do you have recommendations for any other people I should interview about this topic?

Appendix 3: Survey Questions

First page of Google survey:

Thank you for your interest in participating in this research. Before the survey begins, please read over and fill out the following consent form. This is a mandatory step in the research process according to Concordia University's ethics protocols and is necessary for your interview answers to be considered within the research.

INFORMATION AND CONSENT FORM FOR SURVEY

Study Title: Social Media, Social Pains: Mediating Chronic Pain
Researcher: Eileen Mary Holowka
Researcher's Contact Information: eileenholowka@gmail.com
Faculty Supervisor: Dr. Sandra Gabriele
Faculty Supervisor's Contact Information: s.gabriele@concordia.ca

You are being invited to participate in the research study mentioned above. This form provides information about what participating would mean. Please read it carefully before deciding if you want to participate or not. If there is anything you do not understand, or if you want more information, please ask the researcher.

A. PURPOSE

The purpose of the research is to observe and analyze the social media practices of people with the gendered chronic pain condition endometriosis and to see how people with endometriosis manage and mediate their pain online. This research aims to privilege the voice of individuals with endometriosis through interviews.

B. PROCEDURES

After completing this consent information, you will be asked a number of survey questions. If you participate, you will be able to identify however you prefer. You will have the choice to withdraw at any time during the interview or skip over any questions you wish. Once you hit submit, however, your answers will be recorded and cannot be withdrawn.

In total, participating in this study will take approximately 15-20 minutes.

C. RISKS AND BENEFITS

You might face certain risks by participating in this research. These risks include:
- Potential discomfort with some of the questions asked.
- Feeling vulnerable about discussing personal experiences.

Potential benefits include:
- Using the interview to put forward your voice and what you wish to be known about living with endometriosis.

D. CONFIDENTIALITY

We will gather the following information as part of this research:
- The answers to the interview questions.

We will not allow anyone to access the information, except people directly involved in conducting the research. We will only use the information for the purposes of the research described in this form.

The information gathered will be anonymous. That means that it will not be possible to make a link between you and the information you provide, unless you wish to be identified.

We will protect the information by storing it on a password protected computer. However, data from the surveys will be stored by Google and we cannot guarantee full confidentiality.

The only time information will be shared in ways outside of the participant's consent is if they reveal a reportable offense, such as child abuse or anything that threatens someone's wellbeing.

We will destroy the information five years after the end of the study.

F. CONDITIONS OF PARTICIPATION

You do not have to participate in this research. It is purely your decision. If you do participate, you can stop at any time. However, once you submit your answers, they cannot be withdrawn.

There are no negative consequences for not participating or stopping in the middle of the survey.

G. PARTICIPANT'S DECLARATION

I have read and understood this form. I have had the chance to ask questions and any questions have been answered. I agree to participate in this research under the conditions described.

If you have questions about the scientific or scholarly aspects of this research, please contact the researcher at eileenholowka@gmail.com. You may also contact their faculty supervisor.

If you have concerns about ethical issues in this research, please contact the Manager, Research Ethics, Concordia University, 514.848.2424 ex. 7481 or oor.ethics@concordia.ca.

Questions:

Introduction to the survey.

1. Are you over 18 years old?
    a. (if no, cannot continue)
2. Do you have endometriosis? If not, what brings you to this group?

If yes.

1. What does endometriosis mean for you? Has this changed over time?
2. Why do you use social media in relation to endometriosis? What brought you to these spaces?

    (a) What social media spaces do you use in regards to chronic pain?

    (b). What, if any, is/are the main symptom(s) you seek out help or support for on social media? (Can check multiple options).
    - **m.** Pain (abdominal, genital, or other)
    - **n.** Difficulty with intercourse
    - **o.** Diarrhea, Constipation, Bloating
    - **p.** Excessive or abnormal bleeding
    - **q.** Infertility
    - **r.** Worsening symptoms
    - **s.** Isolation / Loneliness / Feeling misunderstood
    - **t.** Difficulty with birth control or other medications
    - **u.** Chest pain / cough / breathlessness
    - **v.** Fatigue
    - **w.** Difficulty leaving the house
    - **x.** Other (please specify)

    (c). Did you find any support or help online regarding these issues?
3. Did social media expose you to any other or new pain management treatments/tools? Did it teach you anything new about endometriosis?
4. Overall, have you found social media helpful in managing or living with your endometriosis? How so?
5. Have you found these social media spaces difficult to engage with in any way? (ex: overwhelming, frustrating, toxic environments, lack of information, etc.)
6. When were you diagnosed with endometriosis (if you are diagnosed) and how long had you been experiencing symptoms before getting a diagnosis?
7. Where did you first hear about endometriosis?
8. Did social media play any role in getting your diagnosis or learning about the illness?
9. Have you made any lasting connections with other people through endometriosis-related social media groups?
10. What are the main things you use these social media spaces for? (You can select more than one option).
    - **a.** Describing your experiences

  - **b.** Putting your pain in your own words
  - **c.** Feeling less isolated
  - **d.** Offering support
  - e. Getting support
  - f. Sharing medical advice
  - g. Getting medical advice
  - **h.** Raising awareness about endometriosis
  - **i.** Other… (please explain)

11. Is there one post in particular that you read or have made that was particularly important/significant for you? Why?
12. Have you learned anything about endometriosis through these social media groups that you did not hear about elsewhere?
13. What social media platforms do you most use in regards to chronic pain? Why did you choose these?
14. How often do you post?
15. How often do you check or read other people's posts?
16. Do you find these social media spaces to be beneficial for folks with endometriosis? Please elaborate.
17. Has your participation in these spaces changed how you feel about or experience your symptoms or pain related to endometriosis?
18. How would you describe the way you "relate" to other people in endometriosis social media groups?
19. Have you made connections with other people with endometriosis through your participation in endometriosis-related social media spaces?
20. Do you have recommendations for any other people I should interview about this topic?
21. Do you have any concerns around your data or privacy when posting about endometriosis in these spaces?
22. Would you be interested in being contacted for further interviewing?
    - **a. Yes/ No (provide email if yes)**
23. Would you like to have the final research shared with you?
    - **a. Yes/No (provide email if yes)**
24. If you are interested in hearing about this research later (ie: reading the dissertation or any related publications), please include your email here:

Bibliography

Access Alliance Multicultural Health and Community Services. 2011. *Community-Based Research Toolkit: Resources and Tools for Doing Research with Community for Social Change*. Toronto: Access Alliance Multicultural Health and Community Services.

Adamson, G. David, Stephen Kennedy, and Lone Hummelshoj. 2010. "Creating Solutions in Endometriosis: Global Collaboration through the World Endometriosis Research Foundation." *Journal of Endometriosis* 2 (1): 3–6. https://doi.org/10.1177/228402651000200102.

Ahmed, Sara. 2013. *The Cultural Politics of Emotion*. Abingdon: Routledge.

Allen, Amani M., Yijie Wang, David H. Chae, Melisa M. Price, Wizdom Powell, Teneka C. Steed, Angela Rose Black, Firdaus S. Dhabhar, Leticia Marquez-Magaña, and Cheryl L. Woods-Giscombe. 2019. "Racial Discrimination, the Superwoman Schema, and Allostatic Load: Exploring an Integrative Stress-Coping Model among African American Women." *Annals of the New York Academy of Sciences* 1457 (1): 104–27. https://doi.org/10.1111/nyas.14188.

April Christina. 2020. Interview.

Aredo, Jacqueline V., Katrina J. Heyrana, Barbara I. Karp, Jay P. Shah, and Pamela Stratton. 2017. "Relating Chronic Pelvic Pain and Endometriosis to Signs of Sensitization and Myofascial Pain and Dysfunction." *Seminars in Reproductive Medicine* 35 (1): 88–97. https://doi.org/10.1055/s-0036-1597123.

Arruda, M.S., C.A. Petta, M.S. Abrão, and C.L. Benetti-Pinto. 2003. "Time Elapsed from Onset of Symptoms to Diagnosis of Endometriosis in a Cohort Study of Brazilian Women." *Human Reproduction* 18 (4): 756–59. https://doi.org/10.1093/humrep/deg136.

Ballard, Karen, Karen Lowton, and Jeremy Wright. 2006. "What's the Delay? A Qualitative Study of Women's Experiences of Reaching a Diagnosis of Endometriosis." *Fertility and Sterility* 86 (5): 1296–1301. https://doi.org/10.1016/j.fertnstert.2006.04.054.

Ballweg, Mary. 1997. "Blaming the Victim. The Psychologizing of Endometriosis." *Obstetrics and Gynecology Clinics of North America* 24 (June): 441–53. https://doi.org/10.1016/S0889-8545(05)70312-0.

Ballweg, Mary Lou. 2017. "Primary Dysmenorrhea — Menstrual 'Cramps' — Matters!" *National Women's Health Network* (blog). May 9, 2017. https://www.nwhn.org/primary-dysmenorrhea-menstrual-cramps-matters/.

Barad, Karen. 2003. "Posthumanist Performativity: Toward an Understanding of How Matter Comes to Matter." *Signs*, no. Spring: 801–31.

———. 2007. *Meeting the Universe Halfway: Quantum Physics and the Entanglement of Matter and Meaning*. Durham: Duke UP.

Bauer, Greta R., Rebecca Hammond, Robb Travers, Matthias Kaay, Karin M. Hohenadel, and Michelle Boyce. 2009. "'I Don't Think This Is Theoretical; This Is Our Lives': How Erasure Impacts Health Care for Transgender People." *The Journal of the Association of Nurses in AIDS Care: JANAC* 20 (5): 348–61. https://doi.org/10.1016/j.jana.2009.07.004.

Baumann, Eva, Fabian Czerwinski, and Doreen Reifegerste. 2017. "Gender-Specific Determinants and Patterns of Online Health Information Seeking: Results From a

Representative German Health Survey." *Journal of Medical Internet Research* 19 (4): e92. https://doi.org/10.2196/jmir.6668.

Baym, Nancy K. 2015. "Connect With Your Audience! The Relational Labor of Connection." *The Communication Review* 18 (1): 14–22. https://doi.org/10.1080/10714421.2015.996401.

Behar, Ruth. 1996. *The Vulnerable Observer: Anthropology That Breaks Your Heart*. Boston: Beacon Press.

Bennett, Louise, Michael Bergin, and John S G Wells. 2020. "Exploring Dimensions of Empowerment from the Patients' Perspective in One Specialist Epilepsy Service in Ireland." *Journal of Patient Experience* 7 (6): 1189–96. https://doi.org/10.1177/2374373520948405.

Berlant, Lauren. 1999. "The Subject of True Feeling: Pain, Privacy, and Politics." In *Cultural Pluralism, Identity Politics, and the Law*. Ann Arbor: University of Michigan Press.

———. 2008. *The Female Complaint: The Unfinished Business of Sentimentality in American Culture*. Duke University Press.

Berliner, Lauren S., and Nora J. Kenworthy. 2017. "Producing a Worthy Illness: Personal Crowdfunding amidst Financial Crisis." *Social Science & Medicine* 187 (August): 233–42. https://doi.org/10.1016/j.socscimed.2017.02.008.

Berna, Casey. 2020. Interview.

Bernhardt, Boris C., and Tania Singer. 2012. "The Neural Basis of Empathy." *Annual Review of Neuroscience* 35: 1–23. https://doi.org/10.1146/annurev-neuro-062111-150536.

Bevan, Georgie. 2019. "Endometriosis: Thousands Share Devastating Impact of Condition." *BBC News*, 2019, sec. Health. https://www.bbc.com/news/health-49897873.

Bingham, Wendy. 2021. Interview.

———. n.d. "Extrapelvic Not Rare." Extrapelvic Not Rare. Accessed February 8, 2021. https://extrapelvicnotrare.org/.

Biss, Eula. 2007. "The Pain Scale." *SN Review*, 5–25.

Bontempo, Allyson C. 2021. "The Effect of Personalized Invalidation of Symptoms by Healthcare Providers on Patient Depression: The Mediating Role of Self-Esteem." *Patient Education and Counseling*, October. https://doi.org/10.1016/j.pec.2021.09.034.

Bougie, O., Ma I. Yap, L. Sikora, T. Flaxman, and S. Singh. 2019. "Influence of Race/Ethnicity on Prevalence and Presentation of Endometriosis: A Systematic Review and Meta-Analysis." *BJOG: An International Journal of Obstetrics & Gynaecology* 126 (9): 1104–15. https://doi.org/10.1111/1471-0528.15692.

Boyce, Kate. 2020. Interview.

Branley, Dawn B., and Judith Covey. 2017. "Pro-Ana versus Pro-Recovery: A Content Analytic Comparison of Social Media Users' Communication about Eating Disorders on Twitter and Tumblr." *Frontiers in Psychology* 8 (August). https://doi.org/10.3389/fpsyg.2017.01356.

brown, adrienne maree. 2017. *Emergent Strategy: Shaping Change, Changing Worlds*. Illustrated edition. Chico, CA: AK Press.

Brown, Julie, and Cynthia Farquhar. 2015. "An Overview of Treatments for Endometriosis." *JAMA* 313 (3): 296–97. https://doi.org/10.1001/jama.2014.17119.

Bruns, Axel. 2008. *Blogs, Wikipedia, Second Life, and Beyond: From Production to Produsage*. New York City: Peter Lang.

Brydges, Laura. 2021. “Hidden Disability Symbol: Canada Movement.” Disabled World. August 15, 2021. https://www.disabled-world.com/disability/awareness/hidden-disability-symbol.php.

Bujnowska-Fedak, Maria M., Joanna Waligóra, and Agnieszka Mastalerz-Migas. 2019. “The Internet as a Source of Health Information and Services.” In *Advancements and Innovations in Health Sciences*, edited by Mieczyslaw Pokorski, 1–16. Advances in Experimental Medicine and Biology. Cham: Springer International Publishing. https://doi.org/10.1007/5584_2019_396.

Bullo, Stella. 2018. “Exploring Disempowerment in Women’s Accounts of Endometriosis Experiences.” *Discourse & Communication* 12 (6): 569–86. https://doi.org/10.1177/1750481318771430.

Bullo, Stella, and Jasmine Heath Hearn. 2020. “Parallel Worlds and Personified Pain: A Mixed-Methods Analysis of Pain Metaphor Use by Women with Endometriosis.” *British Journal of Health Psychology* 26 (2). https://doi.org/10.1111/bjhp.12472.

Bullo, Stella, and Annalise Weckesser. 2021. “Addressing Challenges in Endometriosis Pain Communication Between Patients and Doctors: The Role of Language.” *Frontiers in Global Women’s Health* 2: 88. https://doi.org/10.3389/fgwh.2021.764693.

Bunde, Mali, Jerry Suls, René Martin, and Katherine Barnett. 2006. “Hystersisters Online: Social Support and Social Comparison among Hysterectomy Patients on the Internet.” *Annals of Behavioral Medicine: A Publication of the Society of Behavioral Medicine* 31 (3): 271–78. https://doi.org/10.1207/s15324796abm3103_9.

Burla, Laurin, Dimitrios Rafail Kalaitzopoulos, Julian Matthias Metzler, David Scheiner, and Patrick Imesch. 2021. “Popularity of Endocrine Endometriosis Drugs and Limited Alternatives in the Present and Forseeable Future: A Survey among 1420 Affected Women.” *European Journal of Obstetrics & Gynecology and Reproductive Biology*, no. 262: 232–38.

Bury, Michael. 1982. “Chronic Illness as Biographical Disruption.” *Sociology of Health & Illness* 4 (2).

Bush, Deborah, Emily Brick, Michael C. East, and Neil Johnson. 2017. “Endometriosis Education in Schools: A New Zealand Model Examining the Impact of an Education Program in Schools on Early Recognition of Symptoms Suggesting Endometriosis.” *Australian and New Zealand Journal of Obstetrics and Gynaecology* 57 (4): 452–57. https://doi.org/10.1111/ajo.12614.

Bushnell, M. Catherine, Marta čeko, and Lucie A. Low. 2013. “Cognitive and Emotional Control of Pain and Its Disruption in Chronic Pain.” *Nat. Rev. Neurosci.* 14 (7): 502–11. https://doi.org/10.1038/nrn3516.

Butler, Judith. 2004. *Precarious Life: The Powers of Mourning and Violence*. Brooklyn: Verso Books.

———. 2005. *Giving an Account of Onself*. New York: Fordham UP.

Callard, Felicity, and Elisa Perego. 2021. “How and Why Patients Made Long Covid.” *Social Science & Medicine (1982)* 268 (January). https://doi.org/10.1016/j.socscimed.2020.113426.

Canguilhem, Georges. 1991. *The Normal and the Pathological*. Princeton: Princeton UP.

Carneiro, Márcia Mendonça, Barbara Lopes Farace, Luisa Silva de Carvalho Ribeiro, Raphaela Cristina Conrado C Silverio, Thais Moreira, Agnaldo Lopes da Silva Filho, Ana Luiza Lunardi Rocha Baroni, and Márcia Cristina França Ferreira. 2020. “Using

Social Media to Educate Women and Healthcare Providers on Endometriosis: Preliminary Results." *JBRA Assisted Reproduction* 24 (1): 9–12. https://doi.org/10.5935/1518-0557.20190048.

Carpan, Carolyn. 2003. "Representations of Endometriosis in the Popular Press: 'The Career Woman's Disease.'" *Atlantis: Critical Studies in Gender, Culture & Social Justice* 27 (2): 32–40.

Carter, Angela M. 2015. "Teaching with Trauma: Disability Pedagogy, Feminism, and the Trigger Warnings Debate." *Disability Studies Quarterly* 35 (2). https://doi.org/10.18061/dsq.v35i2.4652.

Chapman, Elizabeth N., Anna Kaatz, and Molly Carnes. 2013. "Physicians and Implicit Bias: How Doctors May Unwittingly Perpetuate Health Care Disparities." *Journal of General Internal Medicine* 28 (11): 1504–10. https://doi.org/10.1007/s11606-013-2441-1.

Charon, Rita. 2016. *The Principles and Practice of Narrative Medicine*. Oxford: Oxford UP.

Charon, Rita, Sayantani DasGupta, Nellie Hermann, Craig Irvine, and Eric R. Marcus. 2017. *The Principle and Practices of Narrative Medicine*. New York: Oxford UP.

Chun, Wendy Hui Kyong. 2016. *Updating to Remain the Same: Habitual New Media*. Cambridge: MIT Press.

Clare, Eli. 2017. *Brilliant Imperfection: Grappling with Cure*. Durham: Duke UP.

Clark, Michelle. 2012. "Experiences of Women with Endometriosis: An Interpretative Phenomenological Analysis." Thesis, Edinburgh: Queen Margaret University. https://eresearch.qmu.ac.uk/handle/20.500.12289/7722.

Cofield, Laura, and Lucy Robinson. 2016. "'The Opposite of the Band': Fangrrrling, Feminism and Sexual Dissidence." *Textual Practice* 30 (6): 1071–88. https://doi.org/10.1080/0950236X.2016.1209946.

Cohn, Shannon. 2020. Interview.

Cole, Jennifer M., Sarah Grogan, and Emma Turley. 2021. "'The Most Lonely Condition I Can Imagine': Psychosocial Impacts of Endometriosis on Women's Identity." *Feminism & Psychology* 31 (2). https://journals.sagepub.com/doi/full/10.1177/0959353520930602.

Cook, A., and E. Hopton. 2017. "Endometriosis Presenting in a Transgender Male." *Journal of Minimally Invasive Gynecology* 24 (7): S126. https://doi.org/10.1016/j.jmig.2017.08.297.

Couldry, Nick. 2008. "Mediatization or Mediation? Alternative Understandings of the Emergent Space of Digital Storytelling." *New Media & Society* 10 (3): 373–91. https://doi.org/10.1177/1461444808089414.

Couser, G. Thomas. 2009. *Signifying Bodies: Disability in Contemporary Life Writing*. Ann Arbor: The University of Michigan Press.

Cox, Helen, Lorraine Henderson, Natalie Andersen, Glenda Cagliarini, and Chantal Ski. 2003. "Focus Group Study of Endometriosis: Struggle, Loss and the Medical Merry-Go-Round." *International Journal of Nursing Practice* 9 (1): 2–9. https://doi.org/10.1046/j.1440-172x.2003.00396.x.

Craig, Kenneth D. 2015. "Social Communication Model of Pain." *PAIN* 156 (7): 1198–99. https://doi.org/10.1097/j.pain.0000000000000185.

Culley, Lorraine, Caroline Law, Nicky Hudson, Elaine Denny, Helene Mitchell, Miriam Baumgarten, and Nick Raine-Fenning. 2013. "The Social and Psychological Impact of

Endometriosis on Women's Lives: A Critical Narrative Review." *Human Reproduction Update* 19 (6): 625–39. https://doi.org/10.1093/humupd/dmt027.

Cvetkovich, Ann. 2012. *Depression: A Public Feeling*. Durham: Duke UP.

Dagrosa, Alysia. 2020. Interview.

De Lauretis, Teresa. 1984. "Semiotics and Experience." In *Alice Doesn't: Feminism, Semiotics, Cinema*. New York: Macmillan.

De Ruddere, Lies, and Kenneth Craig. 2016. "Understanding Stigma and Chronic Pain: A State-of-the-Art Review." *Pain* 157: 1607–10.

De Ruddere, Lies, Liesbet Goubert, Ken Martin Prkachin, Michael André Louis Stevens, Dimitri Marcel Leon Van Ryckeghem, and Geert Crombez. 2011. "When You Dislike Patients, Pain Is Taken Less Seriously." *Pain* 152 (10): 2342–47. https://doi.org/10.1016/j.pain.2011.06.028.

Dean, Jodi. 2010. "Affective Networks." *Mediatropes* 2 (2): 19–44.

Dencik, Lina. 2015. "Social Media and the 'new Authenticity' of Protest." In , edited by Lina Dencik and Oliver Leistert, 203–18. London: Rowman & Littlefield International. https://orca.cardiff.ac.uk/75026/.

Denny, E. 2011. "The Experience of Living with Endometriosis." In *Deep Pelvic Endometriosis: A Multidisciplinary Approach*, edited by Paola De Nardi and Stefano Ferrari, 79–92. Milano: Springer Milan. https://doi.org/10.1007/978-88-470-1866-2_4.

Denny, Elaine. 2009. "I Never Know from One Day to Another How I Will Feel: Pain and Uncertainty in Women with Endometriosis." *Qualitative Health Research* 19 (7): 985–95. https://doi.org/10.1177/1049732309338725.

Denny, Elaine, and Christopher H. Mann. 2007. "Endometriosis-Associated Dyspareunia: The Impact on Women's Lives." *BMJ Sexual & Reproductive Health* 33 (3): 189–93. https://doi.org/10.1783/147118907781004831.

Didion, Joan. 1979. *The White Album*. Manhattan: Simon & Schuster.

Dijck, José van. 2013. *The Culture of Connectivity: A Critical History of Social Media*. 1 online resource (ix, 228 pages) vols. Oxford ; Oxford University Press. http://site.ebrary.com/id/10686674.

Dizon, Don S., David Graham, Michael A. Thompson, Lisa J. Johnson, Claire Johnston, Michael J. Fisch, and Robert Miller. 2012. "Practical Guidance: The Use of Social Media in Oncology Practice." *Journal of Oncology Practice* 8 (5): 114–24. https://doi.org/10.1200/JOP.2012.000610.

Dobson, Amy Shields. 2015. *Postfeminist Digital Cultures: Femininity, Social Media, and Self-Representation*. New York: Palgrave Macmillan.

Dokumaci, Arseli. 2017. "Performing Pain and Inflammation: Rendering the Invisible Visible." *AMA Journal of Ethics* 19 (8): 834–38. https://doi.org/10.1001/journalofethics.2017.19.8.imhl1-1708.

———. 2018. "Disability as Method: Interventions in the Habitus of Ableism through Media Creation." *Disability Studies Quarterly* 38 (3).

———. 2023. *Activist Affordances: How Disabled People Improvise More Habitable Worlds*. Durham: Duke University Press Books.

Dolmage, Jay Timothy. 2014. *Disability Rhetoric*. Syracuse: Syracuse UP.

Dowd, Michelle M., and Julie A. Eckerle, eds. 2007. *Genre and Women's Life Writing in Early Modern England*. Abingdon: Routledge.

Drummond, Jessica, Dr. 2021. *Outsmart Endometriosis: Relieve Your Symptoms and Get Your Career Back on Track*. Las Vegas: Lifestyle Entrepreneurs Press.

Duffy, Brooke Erin. 2017. *(Not) Getting Paid to Do What You Love*. New Haven: Yale UP.

Duffy, Brooke Erin, and Elizabeth Wissinger. 2017. "Mythologies of Creative Work in the Social Media Age: Fun, Free, and 'Just Being Me.'" *International Journal of Communication* 11 (0): 20.

Duguay, Stefanie. 2019. "'Running the Numbers': Modes of Microcelebrity Labor in Queer Women's Self-Representation on Instagram and Vine." *Social Media + Society* 5 (4): 2056305119894002. https://doi.org/10.1177/2056305119894002.

Dumaresque, Renee. 2020. "Vulvodynia, It's in My Head: Mad Methods Toward Crip Coalition." *Journal of Feminist Scholarship* 17 (17): 81–105. https://doi.org/10.23860/jfs.2020.17.06.

Dumit, Joseph. 2006. "Illnesses You Have to Fight to Get: Facts as Forces in Uncertain, Emergent Illnesses." *Social Science & Medicine (1982)* 62 (3): 577–90. https://doi.org/10.1016/j.socscimed.2005.06.018.

Durham Peters, John. 1999. *Speaking into the Air: A History of the Idea of Communication*. Chicago: The University of Chicago Press.

Dusenbery, Maya. 2017. *Doing Harm: The Truth about How Bad Medicine and Lazy Science Leave Women Dismissed, Misdiagnosed, and Sick*. New York: HarperOne.

Edwards, Robert R., Claudia Campbell, Robert N. Jamison, and Katja Wiech. 2009. "The Neurobiological Underpinnings of Coping With Pain." *Current Directions in Psychological Science* 18 (4): 237–41. https://doi.org/10.1111/j.1467-8721.2009.01643.x.

Emma. 2020. Interview.

"Endometriosis: An Assessment of Elagolix for Endometriosis." 2018. Institute for Clinical and Economic Review. 2018. https://icer.org/assessment/endometriosis-2018/.

Endometriosis Association. n.d. "Time to Raise Our Voices! (Joe with Endo)." *Endometriosis Association* (blog). Accessed January 8, 2021. https://endometriosisassn.org/joe-with-endo.

Epstein, Julia. 1994. *Altered Conditions: Disease, Medicine, and Storytelling*. Abingdon: Routledge.

Estes, Stephanie J, Carrie E Huisingh, Stephanie E Chiuve, Natalia Petruski-Ivleva, and Stacey A Missmer. 2020. "Depression, Anxiety, and Self-Directed Violence in Women With Endometriosis: A Retrospective Matched-Cohort Study." *American Journal of Epidemiology*, November. https://doi.org/10.1093/aje/kwaa249.

Facchin, Federica, Giussy Barbara, Emanuela Saita, Paola Mosconi, Anna Roberto, Luigi Fedele, and Paolo Vercellini. 2015. "Impact of Endometriosis on Quality of Life and Mental Health: Pelvic Pain Makes the Difference." *Journal of Psychosomatic Obstetrics and Gynaecology* 36 (4): 135–41. https://doi.org/10.3109/0167482X.2015.1074173.

Faulkner, Alison, and Phil Thomas. 2002. "User-Led Research and Evidence-Based Medicine." *The British Journal of Psychiatry* 180 (1): 1–3. https://doi.org/10.1192/bjp.180.1.1.

Fiesler, Casey, and Nicholas Proferes. 2018. "'Participant' Perceptions of Twitter Research Ethics." *Social Media + Society* 4 (1): 2056305118763366. https://doi.org/10.1177/2056305118763366.

Finney Rutten, Lila J., Kelly D. Blake, Alexandra J. Greenberg-Worisek, Summer V. Allen, Richard P. Moser, and Bradford W. Hesse. 2019. "Online Health Information Seeking Among US Adults: Measuring Progress Toward a Healthy People 2020 Objective." *Public Health Reports* 134 (6): 617–25. https://doi.org/10.1177/0033354919874074.

Ford, Anne Rochon, and Diane Saibil, eds. 2010. *The Push to Prescribe: Women and Canadian Drug Policy*. Toronto: Women's Press.

Foster, D. C., J. L. Stern, J. Buscema, J. A. Rock, and J. D. Woodruff. 1981. "Pleural and Parenchymal Pulmonary Endometriosis." *Obstetrics & Gynecology* 58 (5): 552–56.

Foucault, Michel. 1972. *The Archaology of Knowledge*. London: Tavistock Publications.

———. 1988. "Technologies of the Self: Lectures at University of Vermont in October 1982." In *Technologies of the Self*, 16–49. Amherst: University of Massachusets Press. https://foucault.info/documents/foucault.technologiesOfSelf.en/.

———. 1997. "The Ethics of the Concern of the Self as a Practice of Freedom." In *Ethics: Subjectivity and Truth*, 281–301. New York: The New Press.

Fournier, Lauren. 2018. "Sick Women, Sad Girls, and Selfie Theory: Autotheory as Contemporary Feminist Practice." *A/b: Auto/Biography Studies* 33 (3): 643–62. https://doi.org/10.1080/08989575.2018.1499495.

Frances. 2020. Interview.

Frank, Arthur W. 1997. *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago: The University of Chicago Press.

franzke, aline shakti, Anja Bechmann, Michael Zimmer, Charles Ess, and The Association of Internet Researchers. 2020. "Internet Research: Ethical Guidelines 3.0." https://aoir.org/reports/ethics3.pdf.

Freedman, Sylvia. 2016. "With Endometriosis, Shouldn't 'Let's Get You Well' Come before 'Let's Get You Pregnant'?" The Guardian. February 19, 2016. http://www.theguardian.com/commentisfree/2016/feb/19/with-endometriosis-shouldnt-lets-get-you-well-come-before-lets-get-you-pregnant.

Friedman, May, and Silvia Schultermandl. 2018. "Introduction: Autobiography 2.0 and Quick Media Life Writing." *Interactions: Studies in Communication & Culture* 9 (2): 143–54. https://doi.org/10.1386/iscc.9.2.143_2.

Fritsch, Kelly. 2016. "Blood Functions: Biosociality, and the Facts of the Body." *Journal of Literary & Cultural Disability Studies* 10 (3): 341–56.

Fuchs, Christian. 2018. "'Dear Mr. Neo-Nazi, Can You Please Give Me Your Informed Consent so That I Can Quote Your Fascist Tweet?': Questions of Social Media Research Ethics in Online Ideology Critique." In *The Routledge Companion To Media And Activism*. Routledge.

Gagliardi, Anna R., Bryanna B. Nyhof, Sheila Dunn, Sherry L. Grace, Courtney Green, Donna E. Stewart, and Frances C. Wright. 2019. "How Is Patient-Centred Care Conceptualized in Women's Health: A Scoping Review." *BMC Women's Health* 19 (1): 156. https://doi.org/10.1186/s12905-019-0852-9.

Garland-Thomson, Rosemarie. 2005. "Feminist Disability Studies." *Signs* 30 (2): 1557–87.

Gatchel, Robert J., Donald D. McGeary, Cindy A. McGeary, and Ben Lippe. 2014. "Interdisciplinary Chronic Pain Management: Past, Present, and Future." *The American Psychologist* 69 (2): 119–30. https://doi.org/10.1037/a0035514.

Gay, Roxane. 2014. *Bad Feminist*. New York: Harper Perennial.

Gelder, Ken, and Sarah Thornton, eds. 1997. *The Subcultures Reader*. New York: Routledge.

Gerbaudo, Paolo. 2012. *Tweets and the Streets : Social Media and Contemporary Activism*. Pluto Press.

Gilmore, Leigh. 2012. "Agency Without Mastery: Chronic Pain and Posthuman Life Writing." *Biography* 35 (1): 83–98.

———. 2017. *Tainted Witness: Why We Doubt WHat Women Say About Their Lives*. New York: Columbia UP.

Gitelman, Lisa. 2006. *Always Already New: Media, History, and the Data of Culture*. https://doi.org/10.7551/mitpress/1208.001.0001.

Gonzalez-Polledo, Elena. 2016. "Chronic Media Worlds: Social Media and the Problem of Pain Communication on Tumblr." *Social Media + Society* 2 (1). https://doi.org/10.1177/2056305116628887.

Grace. 2020. Interview.

Grandi, Giovanni, Fabio Barra, Simone Ferrero, Filomena Giulia Sileo, Emma Bertucci, Antonella Napolitano, and Fabio Facchinetti. 2019. "Hormonal Contraception in Women with Endometriosis: A Systematic Review." *The European Journal of Contraception & Reproductive Health Care* 24 (1): 61–70. https://doi.org/10.1080/13625187.2018.1550576.

Gravel-Patry, Fanny. 2021. "'Instagram Therapy' and How Women Use Social Media for Mental Health Support, Solidarity." The Conversation. 2021. http://theconversation.com/instagram-therapy-and-how-women-use-social-media-for-mental-health-support-solidarity-164448.

Greene, Sarah M, Leah Tuzzio, and Dan Cherkin. 2012. "A Framework for Making Patient-Centered Care Front and Center." *The Permanente Journal* 16 (3): 49–53.

Gregg, Melissa, and Gregory J. Seigworth. 2010. *Affect Theory Reader*. Durham: Duke UP.

Guidone, Heather C. 2020a. "The Womb Wanders Not: Enhancing Endometriosis Education in a Culture of Menstrual Misinformation." In *The Palgrave Handbook of Critical Menstruation Studies*, edited by Chris Bobel, Inga T. Winkler, Breanne Fahs, Katie Ann Hasson, Elizabeth Arveda Kissling, and Tomi-Ann Roberts. Singapore: Palgrave Macmillan. http://www.ncbi.nlm.nih.gov/books/NBK565622/.

———. 2020b. Interview.

Guidry, Jeanine P. D., and Eric G. Benotsch. 2019. "Pinning to Cope: Using Pinterest for Chronic Pain Management." *Health Education & Behavior* 46 (4): 700–709. https://doi.org/10.1177/1090198118824399.

Haas, Stephen M., Meghan E. Irr, Nancy A. Jennings, and Lisa M. Wagner. 2011. "Communicating Thin: A Grounded Model of Online Negative Enabling Support Groups in the pro-Anorexia Movement." *New Media & Society* 13 (1): 40–57. https://doi.org/10.1177/1461444810363910.

Hadfield, R., H. Mardon, D. Barlow, and S. Kennedy. 1996. "Delay in the Diagnosis of Endometriosis: A Survey of Women from the USA and the UK." *Human Reproduction (Oxford, England)* 11 (4): 878–80. https://doi.org/10.1093/oxfordjournals.humrep.a019270.

Hadjistavropoulos, T., K. D. Craig, S. Duck, A. Cano, L. Goubert, P.L. Jackson, J.S. Mogil, et al. 2002. "A Biopsychosocial Formulation of Pain Communication." *Psychological Bulletin* 137 (6): 910–39.

Hall, Stuart. 1973. *Encoding and Decoding in the Television Discourse*. Birmingham: Centre for Contemporary Cultural Studies.

Hamraie, Aimi, and Kelly Fritsch. 2019. "Crip Technoscience Manifesto." *Catalyst: Feminism, Theory, Technoscience* 5 (1): 1–34.

Hand, Martin. 2018. "Visuality in Social Media: Research Images, Circulations and Practices." In *The SAGE Handbook of Social Media Research Methods*. Thousand Oaks: Sage Publications.

Hankinson Nelson, Lynn. 1993. "Epistemological Communities." In *Feminist Epistemologies*. New York: Routledge.

Haraway, Donna J. 2016. *Staying with the Trouble: Making Kin in the Chthulucene*. Illustrated edition. Durham: Duke University Press.

Harrison, Faye V. 1995. "Auto-Ethnographic Reflections on Hierarchies in Anthropology." *Practicing Anthropology* 17 (1/2): 48–50.

Hawk, Brandon W. 2020. "Stella Immanuel's Theories about the Relationship between Demons, Illness and Sex Have a Long History." The Conversation. 2020. http://theconversation.com/stella-immanuels-theories-about-the-relationship-between-demons-illness-and-sex-have-a-long-history-143587.

Healey, Martin, Claudia Cheng, and Harvinder Kaur. 2014. "To Excise or Ablate Endometriosis? A Prospective Randomized Double-Blinded Trial After 5-Year Follow-Up." *Journal of Minimally Invasive Gynecology* 21 (6): 999–1004. https://doi.org/10.1016/j.jmig.2014.04.002.

Hedva, Johanna. 2016. "Sick Woman Theory." *Mask Magazine*, 2016.

Henderson, Les. 2020. Interview.

Hill, Sarah. 2017. "Exploring Disabled Girls' Self-Representational Practices Online." *Girlhood Studies* 10 (2): 114–30. https://doi.org/10.3167/ghs.2017.100209.

Hirsch, Martin, Shivani Aggarwal, Claire Barker, Colin J. Davis, and James M. N. Duffy. 2017. "Googling Endometriosis: A Systematic Review of Information Available on the Internet." *American Journal of Obstetrics and Gynecology* 216 (5): 451–58. https://doi.org/10.1016/j.ajog.2016.11.1007.

Hirsch, Michele Lent. 2018. *Invisible: How Young Women with Serious Health Issues Navigate Work, Relationships, and the Pressure to Seem Just Fine*. Boston: Beacon Press.

Hoffman, Kelly M., Sophie Trawalter, Jordan R. Axt, and M. Norman Oliver. 2016. "Racial Bias in Pain Assessment and Treatment Recommendations, and False Beliefs about Biological Differences between Blacks and Whites." *Proceedings of the National Academy of Sciences* 113 (16): 4296–4301. https://doi.org/10.1073/pnas.1516047113.

Holowka, Eileen Mary. 2018. "Between Artifice and Emotion: The 'Sad Girls' of Instagram." In *Leadership, Popular Culture, and Social Change*. Northampton: Edward Elgar.

———. 2022. "Mediating Pain: Navigating Endometriosis on Social Media." *Frontiers in Pain Research* 3 (889990). https://doi.org/10.3390/fpain.2022.889990.

Househ, Mowafa. 2013. "The Use of Social Media in Healthcare: Organizational, Clinical, and Patient Perspectives." *Studies in Health Technology and Informatics* 183: 244–48.

Howard, Jacqueline. 2018. "10 Top Questions You Had for Dr. Google in 2018." CNN. December 21, 2018. https://www.cnn.com/2018/12/21/health/health-questions-2018-google-explainer/index.html.

Hsu, Albert L, Izabella Khachikyan, and Pamela Stratton. 2010. “Invasive and Non-Invasive Methods for the Diagnosis of Endometriosis.” *Clinical Obstetrics and Gynecology* 53 (2): 413–19. https://doi.org/10.1097/GRF.0b013e3181db7ce8.

Humphreys, Lee. 2018. *The Qualified Self: Social Media and the Accounting of Everyday Life*. Cambridge: MIT Press.

Huntington, Annette, and Jean A. Gilmour. 2005. “A Life Shaped by Pain: Women and Endometriosis.” *Journal of Clinical Nursing* 14 (9): 1124–32. https://doi.org/10.1111/j.1365-2702.2005.01231.x.

Hustwaite, Bridget. 2021. *How To Endo: A Guide to Surviving and Thriving with Endometriosis*. Sydney: Allen & Unwin.

Jabr, Fadi I., and Venk Mani. 2014. “An Unusual Cause of Abdominal Pain in a Male Patient: Endometriosis.” *Avicenna Journal of Medicine* 4 (4): 99–101. https://doi.org/10.4103/2231-0770.140660.

Jackson, Gabrielle. 2019. *Pain and Prejudice: A Call to Arms for Women and Their Bodies*. Vancouver: Greystone Books.

Jackson, Jean E. 2011. “Pain: Pain and Bodies.” In *A Companion to the Anthropology of the Body and Embodiment*. Hoboken: Wiley-Blackwell.

Jenkins, Henry, Mizuko Ito, and danah boyd. 2015. *Participatory Culture in a Networked Era: A Conversation on Youth, Learning, Commerce, and Politics*. 1st edition. Cambridge, UK ; Malden, MA: Polity.

Jenkins, Todd R. 2009. “Endometriosis: The Case for Surgical Excision - Skin & Allergy News.” *The Cutting Edge: The Female Patient* 34. https://www.yumpu.com/en/document/read/37376957/endometriosis-the-case-for-surgical-excision-skin-allergy-news.

Jeon-Miranda, Kyung. 2020. Interview.

Johnson, Neil P., Lone Hummelshoj, for the World Endometriosis Society Montpellier Consortium, M.S. Abrao, G.D. Adamson, C. Allaire, V. Amelung, et al. 2013. “Consensus on Current Management of Endometriosis.” *Human Reproduction* 28 (6): 1552–68. https://doi.org/10.1093/humrep/det050.

Jones, Cara E. 2015. “Wandering Wombs and ‘Female Troubles’: The Hysterical Origins, Symptoms, and Treatments of Endometriosis.” *Women’s Studies*, no. 44: 1083–1113.

———. 2016. “The Pain of Endo Existence: Toward a Feminist Disability Studies Reading of Endometriosis.” *Hypatia* 31 (3): 554–71. https://doi.org/10.1111/hypa.12248.

Jones, Georgina, Crispin Jenkinson, and Stephen Kennedy. 2004. “The Impact of Endometriosis upon Quality of Life: A Qualitative Analysis.” *Journal of Psychosomatic Obstetrics and Gynaecology* 25 (2): 123–33. https://doi.org/10.1080/01674820400002279.

Jubanyik, K. J., and F. Comite. 1997. “Extrapelvic Endometriosis.” *Obstetrics and Gynecology Clinics of North America* 24 (2): 411–40. https://doi.org/10.1016/s0889-8545(05)70311-9.

Kafer, Alison. 2013. *Feminist, Queer, Crip*. Bloomington: Indiana UP.

Käll, Lisa Folmarson. 2012. *Dimensions of Pain: Humanities and Social Science Perspectives*. London: Routledge.

Kasana, Mehreen. 2014. “Feminisms and the Social Media Sphere.” *WSQ: Women’s Studies Quarterly* 42 (3): 236–49. https://doi.org/10.1353/wsq.2014.0065.

Keller, Jessalynn. 2014. "Making Activism Accessible: Exploring Girls' Blogs as Sites of Contemporary Feminist Activism." In *The Politics of Place: Contemporary Paradigms for Research in Girlhood Studies*. Oxford: Berghahn Books.

Kenagy, Gretchen P. 2005. "Transgender Health: Findings from Two Needs Assessment Studies in Philadelphia." *Health & Social Work* 30 (1): 19–26. https://doi.org/10.1093/hsw/30.1.19.

Kennedy, Umit, and Emma Maguire. 2018. "The Texts and Subjects of Automediality." *M/C Journal* 21 (2).

Kim, Heewon. 2014. "Enacted Social Support on Social Media and Subjective Well-Being." *International Journal of Communication* 8 (0): 21.

King, Kathleen. 2019. "To What Extent Does the Information Found on the Internet Help with the Diagnosis and Treatment Process of Endometriosis." Master's Thesis, The University of Sheffield.

———. 2020. Interview.

Kirmayer, Laurence J. 2012. "Cultural Competence and Evidence-Based Practice in Mental Health: Epistemic Communities and the Politics of Pluralism." *Social Science & Medicine* 75 (2): 249–56. https://doi.org/10.1016/j.socscimed.2012.03.018.

Kirschner, Paul A. 2017. "Stop Propagating the Learning Styles Myth." *Computers & Education* 106 (March): 166–71. https://doi.org/10.1016/j.compedu.2016.12.006.

Kirschning, Silke, and Ernst von Kardorff. 2008. "The Use of the Internet by Women with Breast Cancer and Men with Prostate Cancer-Results of Online Research." *Journal of Public Health* 16 (2): 133–43. https://doi.org/10.1007/s10389-007-0134-0.

Kleinman, Arthur. 1988. *The Illness Narratives: Suffering, Healing, and the Human Condition*. Ann Arbor: The University of Michigan Press.

Konrad, Annika. 2021. "Access Fatigue: The Rhetorical Work of Disability in Everyday Life" 83 (3).

Krebs, Erin E., Timothy S. Carey, and Morris Weinberger. 2007. "Accuracy of the Pain Numeric Rating Scale as a Screening Test in Primary Care." *Journal of General Internal Medicine* 22 (10): 1453–58. https://doi.org/10.1007/s11606-007-0321-2.

Krsmanovic, Ana, and Marleah Dean. 2021. "How Women Suffering from Endometriosis Disclose about Their Disorder at Work." *Health Communication* 0 (0): 1–12. https://doi.org/10.1080/10410236.2021.1880053.

Kuller, Alex. 2020. Interview.

Lakshmi Piepzna-Samarasinha, Leah. 2018. *Care Work: Dreaming Disability Justice*. Vancouver: Arsenal Pulp Press.

Landzelius, Kyra. 2006. "Introduction: Patient Organization Movements and New Metamorphoses in Patienthood." *Social Science & Medicine (1982)* 62 (3): 529–37. https://doi.org/10.1016/j.socscimed.2005.06.023.

Latour, Bruno. 2005. *Reassembling the Social: An Introduction to Actor-Network-Theory*. New York: Oxford UP.

"Lawsuits." n.d. Lupron Victims Hub. Accessed January 6, 2021. https://www.lupronvictimshub.com/lawsuits.html.

Lecompte-Van Poucke, Margo. 2022. "'You Got This!': A Critical Discourse Analysis of Toxic Positivity as a Discursive Construct on Facebook." *Applied Corpus Linguistics* 2 (1). https://doi.org/10.1016/j.acorp.2022.100015.

Lenzer, Jeanne. 2013. “Why We Can’t Trust Clinical Guidelines.” *BMJ: British Medical Journal* 346 (7913): 20–22.

Leonardi, Mathew, Andrew W Horne, Katy Vincent, Justin Sinclair, Kerry A Sherman, Donna Ciccia, George Condous, Neil P Johnson, and Mike Armour. 2020. “Self-Management Strategies to Consider to Combat Endometriosis Symptoms during the COVID-19 Pandemic.” *Human Reproduction Open* 2020 (2). https://doi.org/10.1093/hropen/hoaa028.

Levina, Marina. 2017. “Network.” In *Keywords for Media Studies*. New York: New York UP.

Levy, Adrian R., Katherine M. Osenenko, Greta Lozano-Ortega, Robert Sambrook, Mark Jeddi, Serge Bélisle, and Robert L. Reid. 2011. “Economic Burden of Surgically Confirmed Endometriosis in Canada.” *Journal of Obstetrics and Gynaecology Canada: JOGC = Journal d’obstetrique et Gynecologie Du Canada: JOGC* 33 (8): 830–37. https://doi.org/10.1016/S1701-2163(16)34986-6.

Li, Rui, Donna A. Kreher, Ashley L. Gubbels, and Amy R. Benjamin. 2021. “Prevalence and Time of Diagnosis of Endometriosis across Racial and Ethnic Groups in the US.” medRxiv. https://doi.org/10.1101/2021.07.28.21261303.

Loh, Seung-Hee, Bark-Lynn Lew, and Woo-Young Sim. 2017. “Primary Cutaneous Endometriosis of Umbilicus.” *Annals of Dermatology* 29 (5): 621–25. https://doi.org/10.5021/ad.2017.29.5.621.

Lomoro, Pascal, Igino Simonetti, Annalisa Nanni, Rosario Cassone, Francesco Di Pietto, Giorgia Vinci, Maria Sole Prevedoni, Stefania Romano, and Luigi Sammarchi. 2019. “Extrapelvic Sciatic Nerve Endometriosis, the Role of Magnetic Resonance Imaging: Case Report and Systematic Review.” *Journal of Computer Assisted Tomography* 43 (6): 976–80. https://doi.org/10.1097/RCT.0000000000000916.

Lorde, Audre, and Tracy K. Smith. 2020. *The Cancer Journals*. Penguin Classics. New York City: Penguin Books.

LP. 2020. Interview.

Luka, Mary Elizabeth, and Mélanie Millette. 2018. “(Re)Framing Big Data: Activating Situated Knowledges and a Feminist Ethics of Care in Social Media Research.” *Social Media + Society* 4 (2): 205630511876829. https://doi.org/10.1177/2056305118768297.

Lupton, Deborah. 2012. *Medicine as Culture: Illness, Disease and the Body*. 3rd ed. London. https://doi.org/10.4135/9781446254530.

Lupton, Deborah, and Sarah Maslen. 2019. “How Women Use Digital Technologies for Health: Qualitative Interview and Focus Group Study.” *Journal of Medical Internet Research* 21 (1): e11481. https://doi.org/10.2196/11481.

Maguire, Emma. 2018. *Girls, Autobiography, Media: Gender and Self-Mediation in Digital Economies*. London: Palgrave Macmillan.

Mairs, Nancy. 1997. *Waist-High in the World: A Life Among the Nondisabled*. 1st edition. Boston: Beacon Press.

Malatino, Hil. 2020. *Trans Care*. Minneapolis: The University of Minnesota Press.

Malik, Sumaira H., and Neil S. Coulson. 2008. “Computer-Mediated Infertility Support Groups: An Exploratory Study of Online Experiences.” *Patient Education and Counseling* 73 (1): 105–13. https://doi.org/10.1016/j.pec.2008.05.024.

Mantel, Hilary. 2004. *Giving Up The Ghost*. London: UK General Books.

Marchant, Jo. 2016. *Cure: A Journey into the Science of Mind Over Body*. New York: Crown Publishing.

Marinho, Manuela C. P., Thais F. Magalhaes, Luiz Flavio C. Fernandes, Kathiane L. Augusto, Aline V. M. Brilhante, and Leonardo R. P. S. Bezerra. 2018. "Quality of Life in Women with Endometriosis: An Integrative Review." *Journal of Women's Health (2002)* 27 (3): 399–408. https://doi.org/10.1089/jwh.2017.6397.

Markovic, Milica, Lenore Manderson, and Narelle Warren. 2008. "Endurance and Contest: Women's Narratives of Endometriosis." *Health (London, England: 1997)* 12 (3): 349–67. https://doi.org/10.1177/1363459308090053.

McCosker, Anthony. 2012. "Pain Sense: Nociception, Affect and the Visual Encounter." *Transformations*, no. 22.

McLuhan, Marshall. 1994. *Understanding Media: The Extensions of Man*. Massachusetts: MIT Press.

McSheffrey, Elizabeth. 2022. "Endometriosis: Why Canadian Women Are Flocking to a Clinic in Bucharest for Surgery | Globalnews.Ca." Global News. 2022. https://globalnews.ca/news/9182656/endometriosis-care-canada-bucharest-romania/.

Meggyesy, Michael, Michael Friese, Joachim Gottschalk, and Uwe Kehler. 2020. "Case Report of Cerebellar Endometriosis." *Journal of Neurological Surgery. Part A, Central European Neurosurgery* 81 (4): 372–76. https://doi.org/10.1055/s-0040-1701622.

Meghani, Salimah H., Eeeseung Byun, and Rollin M. Gallagher. 2012. "Time to Take Stock: A Meta-Analysis and Systematic Review of Analgesic Treatment Disparities for Pain in the United States." *Pain Medicine* 13 (2): 150–74. https://doi.org/10.1111/j.1526-4637.2011.01310.x.

Melzack, R. 2001. "Pain and the Neuromatrix in the Brain." *Journal of Dental Education* 65 (12): 1378–82.

Mendes, Kaitlynn, Jessica Ringrose, and Jessalynn Keller. 2019. *Digital Feminist Activism: Girls and Women Fight Back Against Rape Culture*. Oxford: Oxford UP.

Mingus, Mia. 2015. "Medical Industrial Complex Visual." *Leaving Evidence* (blog). 2015. https://leavingevidence.wordpress.com/2015/02/06/medical-industrial-complex-visual/.

Mitroi, Gabriel. 2020. Interview.

Mohanty, Chandra. 1995. "Feminist Encounters: Locating the Politics of Experience." In *Social Postmodernism: Beyond Identity Politics*. New York: Cambridge UP.

Mol, Annemarie. 2002. *The Body Multiple: Ontology in Medical Practice*. Durham: Duke UP.

Mollow, Anna. 2014. "Criphystemologies: What Disability Theory Needs to Know about Hysteria." *Journal of Literary & Cultural Disability Studies* 8 (2): 185–201.

Moradi, Maryam, Melissa Parker, Anne Sneddon, Violeta Lopez, and David Ellwood. 2014. "Impact of Endometriosis on Women's Lives: A Qualitative Study." *BMC Women's Health* 14 (1): 123. https://doi.org/10.1186/1472-6874-14-123.

Morneault, Madelyn. 2020a. "It's My Pu**y and I'll Touch It If I Want To." Medium. June 16, 2020. https://medium.com/@miss.misdiagnosis/its-my-pu-y-and-i-ll-touch-it-if-i-want-to-3708bab4636d.

———. 2020b. Interview.

Morozov, Evgeny. 2012. *The Net Delusion: The Dark Side of Internet Freedom*. Reprint edition. New York: PublicAffairs.

Mousa, Mira, Moamar Al-Jefout, Habiba Alsafar, Christian M. Becker, Krina T. Zondervan, and Nilufer Rahmioglu. 2021. "Impact of Endometriosis in Women of Arab Ancestry on: Health-Related Quality of Life, Work Productivity, and Diagnostic Delay." *Frontiers in Global Women's Health* 2: 66. https://doi.org/10.3389/fgwh.2021.708410.

Nakamura, Lisa. 2015. "Blaming, Shaming, and the Feminization of Social Media." In *Feminist Surveillance Studies*. Durham: Duke UP.

Neal, Diane M, and Pamela J McKenzie. 2011. "Putting the Pieces Together: Endometriosis Blogs, Cognitive Authority, and Collaborative Information Behavior." *Journal of the Medical Library Association : JMLA* 99 (2): 127–34. https://doi.org/10.3163/1536-5050.99.2.004.

Newman-Toker, David E., Ernest Moy, Ernest Valente, Rosanna Coffey, and Anika L. Hines. 2014. "Missed Diagnosis of Stroke in the Emergency Department: A Cross-Sectional Analysis of a Large Population-Based Sample." *Diagnosis (Berlin, Germany)* 1 (2): 155–66. https://doi.org/10.1515/dx-2013-0038.

Nezhat, Camran, Farr Nezhat, and Ceana Nezhat. 2012. "Endometriosis: Ancient Disease, Ancient Treatments." *Fertility and Sterility* 98 (6): S1–62. https://doi.org/10.1016/j.fertnstert.2012.08.001.

Ng, Nicole, Kate Wahl, Natasha L. Orr, Heather Noga, Christina Williams, Catherine Allaire, Mohamed A. Bedaiwy, and Paul J. Yong. 2020. "Endometriosis and Negative Perception of the Medical Profession." *Journal of Obstetrics and Gynaecology Canada: JOGC = Journal d'obstetrique et Gynecologie Du Canada: JOGC* 42 (3): 248–55. https://doi.org/10.1016/j.jogc.2019.08.034.

NIH Report. n.d. "Research Portfolio Online Reporting Tools." Accessed January 5, 2021. https://report.nih.gov/funding/categorical-spending#/.

Nkosi, Nomagugu Chantelle. 2020. Interview.

Nnoaham, Kelechi E., Lone Hummelshoj, Premila Webster, Thomas d'Hooghe, Fiorenzo de Cicco Nardone, Carlo de Cicco Nardone, Crispin Jenkinson, Stephen H. Kennedy, and Krina T. Zondervan. 2011. "Impact of Endometriosis on Quality of Life and Work Productivity: A Multicenter Study across Ten Countries." *Fertility and Sterility* 96 (2): 366–73. https://doi.org/10.1016/j.fertnstert.2011.05.090.

Olszanowski, Magdalena. 2014. "Feminist Self-Imaging and Instagram: Tactics of Circumventing Sensorship." *Visual Communication Quarterly* 21 (2): 83–95. https://doi.org/10.1080/15551393.2014.928154.

"OOC Excision Fund." n.d. Accessed February 23, 2021. https://sites.google.com/view/oocexcisionfund/.

Osuch, Janet R., Kami Silk, Carole Price, Janice Barlow, Karen Miller, Ann Hernick, and Ann Fonfa. 2012. "A Historical Perspective on Breast Cancer Activism in the United States: From Education and Support to Partnership in Scientific Research." *Journal of Women's Health* 21 (3): 355–62. https://doi.org/10.1089/jwh.2011.2862.

Owens, Dierdre Cooper. 2017. "Introduction: American Gynecology and Black Lives." In *Medical Bondage*, 1–14. Race, Gender, and the Origins of American Gynecology. University of Georgia Press. https://doi.org/10.2307/j.ctt1pwt69x.5.

Ozorio, Julianna. 2020. Interview.

Ozyurek, E. S., T. Yoldemir, and U. Kalkan. 2018. "Surgical Challenges in the Treatment of Perimenopausal and Postmenopausal Endometriosis." *Climacteric: The Journal of the*

International Menopause Society 21 (4): 385–90. https://doi.org/10.1080/13697137.2018.1439913.

Papacharissi, Zizi. 2011. *A Networked Self: Identity, Community and Culture on Social Network Sites*. New York: Routledge.

———. 2015. *Affective Publics: Sentiment, Technology, and Politics*. New York: Oxford UP.

Parker, Charlie, Sam Scott, and Alistair Geddes. 2019. *Snowball Sampling*. SAGE Publications Ltd. https://doi.org/10.4135/9781526421036831710.

Parker, Lara. 2020. *Vagina Problems: Endometriosis, Painful Sex, and Other Taboo Topics*. New York: St. Martin's Press.

Parsons, Caroline S. 2019. "Hystersisters: Messages of Social Support in an Online Health Support Group for Women." *Journal of Communication in Healthcare* 12 (2): 121–33. https://doi.org/10.1080/17538068.2019.1612211.

Patel, Rajesh, Tammy Chang, S. Ryan Greysen, and Vineet Chopra. 2015. "Social Media Use in Chronic Disease: A Systematic Review and Novel Taxonomy." *The American Journal of Medicine* 128 (12): 1335–50. https://doi.org/10.1016/j.amjmed.2015.06.015.

Patsavas, Alyson. 2014. "Recovering a Cripistemology of Pain: Leaky Bodies, Connective Tissue, and Feeling Discourse." *Journal of Literary & Cultural Disability Studies* 8 (2): 203–18.

Pelletier, Roxanne, Karin H. Humphries, Avi Shimony, Simon L. Bacon, Kim L. Lavoie, Doreen Rabi, Igor Karp, Meytal Avgil Tsadok, and Louise Pilote. 2014. "Sex-Related Differences in Access to Care among Patients with Premature Acute Coronary Syndrome." *CMAJ : Canadian Medical Association Journal* 186 (7): 497–504. https://doi.org/10.1503/cmaj.131450.

Petersen, Nancy. 2020a. Interview.

———. 2020b. "Endometriosis: Its Emotional Impact and Causative Factors." NancysNookEndo. October 1, 2020. https://nancysnookendo.com/endometriosis-its-emotional-impact-and-causative-factors/.

Poletti, Anna. 2017. "What's Next? Mediation." *A/b: Auto/Biography Studies* 32 (2): 263–66. https://doi.org/10.1080/08989575.2017.1288033.

———. 2020. *Stories of the Self*. New York: NYU Press.

Poletti, Anna, and Julie Rak. 2014. *Identity Technologies: Constructions of the Self Online*. Madison: University of Wisconsin Press.

Pols, Jeannette. 2014. "Knowing Patients: Turning Patient Knowledge into Science." *Science, Technology, & Human Values* 39 (1): 73–97. https://doi.org/10.1177/0162243913504306.

Price, Margaret. 2015. "The Bodymind Problem and the Possibilities of Pain." *Hypatia* 30 (1): 268–84. https://doi.org/10.1111/hypa.12127.

Price, Margaret, and Stephanie L. Kerschbaum. 2016. "Stories of Methodology: Interviewing Sideways, Crooked and Crip." *Canadian Journal of Disability Studies* 5 (3): 18–56. https://doi.org/10.15353/cjds.v5i3.295.

Puar, Jasbir. 2017. *The Right to Maim: Debility, Capacity, Disability*. Durham: Duke UP.

Pybus, Jennifer. 2015. "Accumulating Affect: Social Networks and Their Archives of Feelings." *Networked Affect*, February, 234–49.

Radin, Patricia. 2006. "'To Me, It's My Life': Medical Communication, Trust, and Activism in Cyberspace." *Social Science & Medicine (1982)* 62 (3): 591–601. https://doi.org/10.1016/j.socscimed.2005.06.022.

Rafique, Saima, and Alan H DeCherney. 2017. "MEDICAL MANAGEMENT OF ENDOMETRIOSIS." *Clinical Obstetrics and Gynecology* 60 (3): 485–96. https://doi.org/10.1097/GRF.0000000000000292.

Rains, Stephen. 2018. *Coping with Illness Digitally*. Cambridge: MIT Press.

Rak, Julie. 2015. "Life Writing Versus Automedia: The Sims 3 Game as Life Lab." *Biography* 38 (2): 155–80.

Redwine, David. 2003. "Management of Endometriosis After Hysterectomy and Bilateral Salpingo-Oophorectomy." In *Endometriosis: Advances and Controversies*. New York: Marcel Dekker Inc.

Redwine, David B. 2009. "Expert Report of Dr. David B. Redwine Re: Karin Klein v. TAP Pharmaceuticals, Inc." https://www.lupronvictimshub.com/home/RedwineExpertReport001.pdf.

———. 2012. *Googling Endometriosis: The Lost Centuries*. CreateSpace Independent Publishing Platform.

Ren, Jie, Viju Raghupathi, and Wullianallur Raghupathi. 2020. "Understanding the Dimensions of Medical Crowdfunding: A Visual Analytics Approach." *Journal of Medical Internet Research* 22 (7): e18813. https://doi.org/10.2196/18813.

Rentschler, Carrie. 2017. "Affect." In *Keywords for Media Studies*, edited by Jonathan Gray and Laurie Ouelette, 12–14. New York: New York UP.

Rishe, Jenneh. 2020. Interview.

———. 2022. *Part of You, Not All of You: Shared Wisdom and Guided Journaling for Life with Chronic Illness*. Mascot Books.

Roesch-Dietlen, Federico, Alejandra Jiménez-García, Alfonso Pérez-Morales, Peter Grube-Pagola, Karen Lizzette Ramírez-Cervantes, and José Maria Remes-Troche. 2011. "Hepatic Endometriosis." *Annals of Hepatology* 10 (3): 347–48.

Rogers, Peter A. W., Thomas M. D'Hooghe, Asgerally Fazleabas, Caroline E. Gargett, Linda C. Giudice, Grant W. Montgomery, Luk Rombauts, Lois A. Salamonsen, and Krina T. Zondervan. 2009. "Priorities for Endometriosis Research." *Reproductive Sciences* 16 (4): 335–46. https://doi.org/10.1177/1933719108330568.

Rolla, Edgardo. 2019. "Endometriosis: Advances and Controversies in Classification, Pathogenesis, Diagnosis, and Treatment." *F1000Research* 8 (April). https://doi.org/10.12688/f1000research.14817.1.

Roullier, Chloé, Sophie Sanguin, Camille Parent, Mélyne Lombart, Fabrice Sergent, and Arthur Foulon. 2021. "General Practitioners and Endometriosis: Level of Knowledge and the Impact of Training." *Journal of Gynecology Obstetrics and Human Reproduction* 50 (10). https://doi.org/10.1016/j.jogoh.2021.102227.

Safer, Joshua D., Eli Coleman, Jamie Feldman, Robert Garofalo, Wylie Hembree, Asa Radix, and Jae Sevelius. 2016. "Barriers to Health Care for Transgender Individuals." *Current Opinion in Endocrinology, Diabetes, and Obesity* 23 (2): 168–71. https://doi.org/10.1097/MED.0000000000000227.

Sandahl, Carrie. 2003. "Queering the Crip or Cripping the Queer?" *GLQ: A Journal of Lesbian and Gay Studies* 9 (1–2): 25–56. https://doi.org/10.1215/10642684-9-1-2-25.

Sanmiguel, Lisa Michelle. 2000. “From ‘Career Woman’s’ Disease to ‘An Epidemic Ignored’: Endometriosis in United States Culture Since 1948.” Dissertation, Urbana: University of Illinois. http://hdl.handle.net/2142/86621.

Sarıdoğan, Ertan. 2015. “Endometriosis in Teenagers.” *Women’s Health (London, England)* 11 (5): 705–9. https://doi.org/10.2217/whe.15.58.

Sarmast, Hossein, Ahmad Takriti, and Z. Sepehrmanesh. 2019. “Cardiac Involvement Resulting from Thoracic Endometriosis.” *Cardiovasc. Surg. Int.* 1 (1).

Sarrel, Sallie. 2020. Interview.

Sbaffi, Laura, and Kathleen King. 2020. “Living with Endometriosis: The Role of the Internet in Suporting the Diagnosis and Treatment Process.” *Journal of Consumer Health on the Internet* 24 (4): 370–90.

Scarry, Elaine. 1985. *The Body in Pain: The Making and Unmaking of the World*. New York: Oxford UP.

Schuster, Meike, and Dhanya A. Mackeen. 2015. “Fetal Endometriosis: A Case Report.” *Fertility and Sterility* 103 (1): 160–62. https://doi.org/10.1016/j.fertnstert.2014.09.045.

Scott, Joan W. 1991. “The Evidence of Experience.” *The University of Chicago Press* 14 (4): 733–97.

Seear, Kate. 2014. *The Makings of a Modern Epidemic: Endometriosis, Gender and Politics*. Burlington: Ashgate Publishing Limited.

———. 2021. “Pinning Endometriosis Down: The Need for Ontopolitically-Oriented Research.” Presented at the EndoSRN International Membership Meeting.

Sendra, Anna, and J. Farré. 2020. “Communicating the Experience of Chronic Pain through Social Media: Patients’ Narrative Practices on Instagram.” *Journal of Communication in Healthcare* 13 (1): 46–54. https://doi.org/10.1080/17538068.2020.1752982.

Senft, Theresa M., and Nancy K. Baym. 2015. “Selfies Introduction ~ What Does the Selfie Say? Investigating a Global Phenomenon.” *International Journal of Communication* 9 (0): 19.

Shadbolt, Naomi A., Melissa A. Parker, and Lindy A. Orthia. 2013. “Communicating Endometriosis with Young Women to Decrease Diagnosis Time.” *Health Promotion Journal of Australia: Official Journal of Australian Association of Health Promotion Professionals* 24 (2): 151–54. https://doi.org/10.1071/HE12915.

Shah, Divya K., Molly B. Moravek, Anjel Vahratian, Vanessa K. Dalton, and Dan I. Lebovic. 2010. “Public Perceptions of Endometriosis: Perspectives from Both Genders.” *Acta Obstetricia Et Gynecologica Scandinavica* 89 (5): 646–50. https://doi.org/10.3109/00016341003657900.

Shim, Jessica Y., Marc R. Laufer, and Frances W. Grimstad. 2020. “Dysmenorrhea and Endometriosis in Transgender Adolescents.” *Journal of Pediatric and Adolescent Gynecology* 33 (5): 524–28. https://doi.org/10.1016/j.jpag.2020.06.001.

Shoebotham, Amie, and Neil S. Coulson. 2016. “Therapeutic Affordances of Online Support Group Use in Women With Endometriosis.” *Journal of Medical Internet Research* 18 (5): e109. https://doi.org/10.2196/jmir.5548.

Shohat, Ella. 1992. “Lasers for Ladies: Endo Discourse and the Inscriptions of Science.” *Camera Obscura: Feminism, Culture, and Media Studies* 10 (2): 57–90.

Siebers, Tobin. 2013. “Disability, Pain, and the Politics of Minority Identity.” In *Foundations of Disability Studies*, edited by Matthew Wappett and Katrina Arndt, 17–28. New York: Palgrave Macmillan US. https://doi.org/10.1057/9781137363787_2.

Signorile, Pietro G, Feliciano Baldi, Rossana Bussani, Mariarosaria D’Armiento, Maria De Falco, and Alfonso Baldi. 2009. “Ectopic Endometrium in Human Foetuses Is a Common Event and Sustains the Theory of Müllerianosis in the Pathogenesis of Endometriosis, a Disease That Predisposes to Cancer.” *Journal of Experimental & Clinical Cancer Research* 28 (1): 49. https://doi.org/10.1186/1756-9966-28-49.

Simoens, Steven, Gerard Dunselman, Carmen Dirksen, Lone Hummelshoj, Attila Bokor, Iris Brandes, Valentin Brodszky, et al. 2012. “The Burden of Endometriosis: Costs and Quality of Life of Women with Endometriosis and Treated in Referral Centres.” *Human Reproduction (Oxford, England)* 27 (5): 1292–99. https://doi.org/10.1093/humrep/des073.

Sinaii, N., S. D. Cleary, M. L. Ballweg, L. K. Nieman, and P. Stratton. 2002. “High Rates of Autoimmune and Endocrine Disorders, Fibromyalgia, Chronic Fatigue Syndrome and Atopic Diseases among Women with Endometriosis: A Survey Analysis.” *Human Reproduction (Oxford, England)* 17 (10): 2715–24. https://doi.org/10.1093/humrep/17.10.2715.

Singhal, Astha, Yu-Yu Tien, and Renee Y. Hsia. 2016. “Racial-Ethnic Disparities in Opioid Prescriptions at Emergency Department Visits for Conditions Commonly Associated with Prescription Drug Abuse.” *PLOS ONE* 11 (8). https://doi.org/10.1371/journal.pone.0159224.

Skovlund, Charlotte Wessel, Lina Steinrud Mørch, Lars Vedel Kessing, and Øjvind Lidegaard. 2016. “Association of Hormonal Contraception With Depression.” *JAMA Psychiatry* 73 (11): 1154. https://doi.org/10.1001/jamapsychiatry.2016.2387.

Smith, Sidonie, and Julia Watson. 2010. *Reading Autobiography: A Guide for Interpreting Life Narratives*. 2nd ed. Minneapolis: University of Minnesota Press.

Snelgrove, John W., Amanda M. Jasudavisius, Bradley W. Rowe, Evan M. Head, and Greta R. Bauer. 2012. “‘Completely out-at-Sea’ with ‘Two-Gender Medicine’: A Qualitative Analysis of Physician-Side Barriers to Providing Healthcare for Transgender Patients.” *BMC Health Services Research* 12 (1): 110. https://doi.org/10.1186/1472-6963-12-110.

Snyder, Sharon L., Brenda Jo Brueggemann, and Rosemarie Garland-Thomson, eds. 2002. *Disability Studies: Enabling the Humanities*. New York: Modern Language Association of America.

Sosnowy, Collette. 2014. “Practicing Patienthood Online: Social Media, Chronic Illness, and Lay Expertise.” *Societies* 4 (2). https://doi.org/10.3390/soc4020316.

Spratt, Vicky. 2022. “The Danger Of Instagram Therapists (& What Real Therapists Think Of Them).” 2022. https://www.refinery29.com/en-gb/2021/01/10237732/mental-health-therapy-instagram-accounts.

Steck, A., and B. Steck. 2015. *Brain and Mind: Subjective Experience and Scientific Objectivity*. New York City: Springer.

Stewart, Elizabeth A., Wanda K. Nicholson, Linda Bradley, and Bijan J. Borah. 2013. “The Burden of Uterine Fibroids for African-American Women: Results of a National Survey.” *Journal of Women’s Health* 22 (10): 807–16. https://doi.org/10.1089/jwh.2013.4334.

Stewart, Kathleen. 2007. *Ordinary Affects*. Durham: Duke UP.

Stovicek, Alexandra. 2018. "He Is 1 in 10: A Trans Man Shares What Life Is Like With Endometriosis." Endometriosis : Causes - Symptoms - Diagnosis - and Treatment. June 4, 2018. https://www.endofound.org/he-is-1-in-10-a-trans-man-shares-what-life-is-like-with-endometriosis.

Tan, Sharon Swee-Lin, and Nadee Goonawardene. 2017. "Internet Health Information Seeking and the Patient-Physician Relationship: A Systematic Review." *Journal of Medical Internet Research* 19 (1). https://doi.org/10.2196/jmir.5729.

Tapp, Hazel, Shay E. Phillips, Dael Waxman, Matthew Alexander, Rhett Brown, and Mary Hall. 2012. "Multidisciplinary Team Approach to Improved Chronic Care Management for Diabetic Patients in an Urban Safety Net Ambulatory Care Clinic." *The Journal of the American Board of Family Medicine* 25 (2): 245–46. https://doi.org/10.3122/jabfm.2012.02.110243.

Thernstrom, Melanie. 2010. *The Pain Chronicles: Cures, Myths, Mysteries, Prayers, Diaries, Brain Scans, Healing, and the Science of Suffering*. New York: Farrar, Straus, and Giroux.

Thiel, Peter, Matthew Burke, Philippa Bridge-Cook, and Mathew Leonardi. 2021a. "The Placebo and Nocebo Effects in the Treatment of Endometriosis: A Commentary." Preprint. Preprints. https://doi.org/10.22541/au.161382562.23379706/v1.

Thiel, Peter, Matthew J Burke, Philippa Bridge-Cook, and Mathew Leonardi. 2021b. "Nocebo Effects in the Treatment of Endometriosis." *Reproduction & Fertility* 2 (4): C35–38. https://doi.org/10.1530/RAF-21-0040.

Titchkosky, Tanya. 2007. *Reading and Writing Disability Differently: The Textured Life of Embodiment*. Toronto: University of Toronto Press.

@tomis_endo. 2020. Interview.

Ugwumadu, Lilian, Rima Chakrabarti, Elaine Williams-Brown, John Rendle, Ian Swift, Babbin John, Heather Allen-Coward, and Emmanuel Ofuasia. 2017. "The Role of the Multidisciplinary Team in the Management of Deep Infiltrating Endometriosis." *Gynecological Surgery* 14 (1): 15. https://doi.org/10.1186/s10397-017-1018-0.

Unger, Cécile A. 2015. "Care of the Transgender Patient: A Survey of Gynecologists' Current Knowledge and Practice." *Journal of Women's Health (2002)* 24 (2): 114–18. https://doi.org/10.1089/jwh.2014.4918.

Vicari, Stefania. 2022. *Digital Media and Participatory Cultures of Health and Illness*. Routledge, Taylor & Francis Group.

Wahl, Kate J., Shermeen Imtiaz, Michelle Lisonek, K. S. Joseph, Kelly B. Smith, Paul J. Yong, and Susan M. Cox. 2021. "Dyspareunia in Their Own Words: A Qualitative Description of Endometriosis-Associated Sexual Pain." *Sexual Medicine* 9 (1): 100274. https://doi.org/10.1016/j.esxm.2020.10.002.

Wahl, Kate J., Paul J. Yong, Philippa Bridge-Cook, and Catherine Allaire. 2021. "Endometriosis in Canada: It Is Time for Collaboration to Advance Patient-Oriented, Evidence-Based Policy, Care, and Research." *Journal of Obstetrics and Gynaecology Canada* 43 (1): 88–90. https://doi.org/10.1016/j.jogc.2020.05.009.

Warzecha, Damian, Iwona Szymusik, Miroslaw Wielgos, and Bronislawa Pietrzak. 2020. "The Impact of Endometriosis on the Quality of Life and the Incidence of Depression—A Cohort Study." *International Journal of Environmental Research and Public Health* 17 (10). https://doi.org/10.3390/ijerph17103641.

Welch, Ashley. 2018. "Google's Top Trending Health Questions of 2018." 2018. https://www.cbsnews.com/news/top-10-google-trending-health-questions-of-2018/.

Wendell, Susan. 2001. "Unhealthy Disabled: Treating Chronic Illnesses as Disabilities." *Hypatia* 16 (4,): 17–33.

———. 2996. *The Rejected Body: Feminist Philosophical Reflections on Disability*. 1st edition. New York: Routledge.

Werner, Anne, Lise Widding Isaksen, and Kirsti Malterud. 2004. "'I Am Not the Kind of Woman Who Complains of Everything': Illness Stories on Self and Shame in Women with Chronic Pain." *Social Science & Medicine (1982)* 59 (5): 1035–45. https://doi.org/10.1016/j.socscimed.2003.12.001.

Werner, Anne, and Kirsti Malterud. 2003. "It Is Hard Work Behaving as a Credible Patient: Encounters between Women with Chronic Pain and Their Doctors." *Social Science & Medicine (1982)* 57 (8): 1409–19. https://doi.org/10.1016/s0277-9536(02)00520-8.

Wetherell, Margaret Wetherell Margaret. 2012. *Affect And Emotion*. Los Angeles: Sage Publications.

Whelan, Emma. 2007. "'No One Agrees except for Those of Us Who Have It': Endometriosis Patients as an Epistemological Community." *Sociology of Health & Illness* 29 (7): 957–82. https://doi.org/10.1111/j.1467-9566.2007.01024.x.

———. 2009. "Negotiating Science and Experience in Medical Knowledge: Gynaecologists on Endometriosis." *Social Science & Medicine (1982)* 68 (8): 1489–97. https://doi.org/10.1016/j.socscimed.2009.01.032.

Williams, Raymond. 1962. *Communications*. London: Penguin.

———. 2015. *Structures of Feeling*. *Structures of Feeling*. Berlin: De Gruyter. https://doi.org/10.1515/9783110365481.20.

Woolf, Virginia. 1993. "On Being Ill." *Family Business Review* 6 (2): 199–201. https://doi.org/10.1111/j.1741-6248.1993.00199.x.

Yazdanian, Deliar, Lucia Manganaro, Serena Resta, Adele Ticino, Eliana Fuggetta, Antonella Guarino, Marco Monti, Pierluigi Benedetti Panici, and Maria Grazia Porpora. 2014. "Frequently Misdiagnosed Extrapelvic Endometriosis Lesions: Case Reports and Review of the Literature." *Journal of Endometriosis* 4 (May): 67–78. https://doi.org/10.5301/je.5000188.

Young, Kate, Jane Fisher, and Maggie Kirkman. 2019. "'Do Mad People Get Endo or Does Endo Make You Mad?': Clinicians' Discursive Constructions of Medicine and Women with Endometriosis." *Feminism & Psychology* 29 (3): 337–56. https://doi.org/10.1177/0959353518815704.

Zale, Madalene, Emily Lambert, Marianna D LaNoue, and Amy E Leader. 2020. "Shedding Light on Endometriosis: Patient and Provider Perspectives on a Challenging Disease." *Journal of Endometriosis and Pelvic Pain Disorders* 12 (2): 69–76. https://doi.org/10.1177/2284026520905239.

Zarbo, Cristina, Agostino Brugnera, Luigi Frigerio, Chiara Malandrino, Massimo Rabboni, Emi Bondi, and Angelo Compare. 2018. "Behavioral, Cognitive, and Emotional Coping Strategies of Women with Endometriosis: A Critical Narrative Review." *Archives of Women's Mental Health* 21 (1): 1–13. https://doi.org/10.1007/s00737-017-0779-9.

Zheng, Ping, Wen Zhang, Jinhua Leng, and Jinghe Lang. 2019. “Research on Central Sensitization of Endometriosis-Associated Pain: A Systematic Review of the Literature.” *Journal of Pain Research* 12 (May): 1447–56. https://doi.org/10.2147/JPR.S197667.

Zoffmann, Vibeke, Ingegerd Harder, and Marit Kirkevold. 2008. “A Person-Centered Communication and Reflection Model: Sharing Decision-Making in Chronic Care.” *Qualitative Health Research* 18 (5): 670–85. https://doi.org/10.1177/1049732307311008.