



Rare vs. Rarely Diagnosed: Counterstory and Coalition Building in Online Patient Advocacy Communities

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Abstract: This article demonstrates how online health communities use intersectional practices of counterstory and coalition building to advocate for awareness of their illnesses within the greater medical community. This study analyzes 320 online postings, 84 published narratives, 30 written reflections, and 10 interviews in an online health community for Asherman syndrome, a rare illness that develops after reproductive surgery. The findings of this study highlight how patients pose an important counterstory of Asherman syndrome as a “rarely diagnosed” condition to increase awareness of the illness among medical professionals. Additionally, individuals use their own unique positions with coalitions to create TPC that leads to changes in healthcare outcomes. This article argues that TPC researchers can amplify this patient-created TPC to help intervene in healthcare concerns.

Keywords: patient advocacy, online health communication, reproductive health, counterstory, coalition building

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Introduction

It is estimated that approximately 30 million Americans are currently living with a rare disease, or roughly 1 out of every 10 Americans (NIH, 2017). While instances of each particular illness may be rare, collectively rare diseases represent a large healthcare problem in the United States, with a similar number of patients as those currently diagnosed with diabetes (CDC, 2020; Halley et al., 2023). Research with patients who have experienced rare diseases and their families have shown many communication problems in healthcare. For example, most rare illnesses have few treatments, and many have no treatments at all (NIH, 2017). Additionally, patients report challenges in obtaining an accurate and timely diagnosis and locating effective therapies, as well as a lack of knowledgeable providers and established patient communities for support (Halley et al., 2023). Cumulatively, these problems can lead to patients feeling isolated and stigmatized from healthcare providers and their social support networks. Furthermore, adults with rare illnesses report lower health-related quality of life compared to the general population, including adults living with chronic disease (Bogart et al., 2022; Halley et al., 2023).

Rare illness research demonstrates the importance of social justice and advocacy for individuals navigating increasingly complex health systems; patients with rare illnesses often need to extensively self-advocate to access adequate care, manage insurance issues, and avoid medical errors (Halley et al., 2023; von der Lippe et al., 2017). Additionally, patients with rare illnesses are often referred to patient advocacy groups to gather and share resources to advocate for their illness on a wider scale. This need for self and community advocacy can contribute to increased levels in health disparities, especially as advocacy in healthcare can become more difficult when other barriers to care — such as insurance status, rural location, limited English proficiency, or structural inequities in healthcare — are present (Halley et al., 2023). To better understand health disparities and create technical and professional communication that helps individuals make health decisions and improve their lives, it is imperative for TPC researchers to understand how patient advocacy groups gather, organize, and advocate for themselves.

This article attends to these concerns by focusing on patient advocacy efforts in an online community for Asherman syndrome (AS), a rare illness that develops after reproductive surgery, most commonly after dilation & curettage (D&C) procedures. A D&C is a common medical procedure that removes tissue from inside the uterus after miscarriage, abortion, or childbirth. Asherman syndrome is an iatrogenic response to the D&C, where the body forms internal scar tissue that produces symptoms such as chronic pain, infertility, future pregnancy complications, and other disorders such as endometriosis (Hooker et al., 2014). Additionally, because many AS patients struggle with infertility and repeat miscarriages due to scarring, those who can conceive have increased risks of obstetric complications, such as preterm labor, low birth weight, and placental complications that lead to severe bleeding during childbirth (such as retained placenta and placenta accreta). If undetected before childbirth, these conditions can lead to hemorrhaging and the need for emergency lifesaving preventions.

Due to these complications, individuals with Asherman syndrome advocate for increased awareness of AS, complications of the condition, and greater attention to the risks of D&Cs during the informed consent process. In an influential and systematic review of 18 studies and 2,682 patients from 1966 to 2013, researchers found that the incidence of Asherman syndrome

can be as high as 20–40% (with an average of 19.1%) after D&C procedures (Hooker et al., 2014). However, because healthcare providers believe that AS occurs rarely, these incidence rates are often not conveyed to patients before surgery (Hooker et al., 2014; Vancaillie et al., 2020). In contrast, waiting to miscarry naturally or miscarrying using medication is considered 95% effective with no harmful side effects; however, D&Cs are still conducted in at least 50% of miscarriages, and they are considered one of the most common medical procedures in the U.S. (Lohmann-Bigelow et al., 2007). What’s more, once patients start experiencing symptoms of AS, the perceived rare nature of the illness often leads to long delays in diagnosis and treatment (Vancaillie et al., 2020). Additionally, although research has shown that, on average, more than 80% of patients can achieve a successful pregnancy after proper treatment, many patients with Asherman syndrome are incorrectly diagnosed as infertile and are recommended expensive and unnecessary treatment options, such as IVF or surrogacy (March, 2011; Vancaillie et al., 2020).

Because Asherman syndrome is often missed or misdiagnosed by healthcare providers (March, 2011; Vancaillie, 2020), patients must advocate for themselves to receive a timely diagnosis and treatment. Individuals begin these advocacy efforts by gathering and sharing their stories in online health communities, such as the International Asherman’s Association and Asherman Syndrome Australia and New Zealand. By gathering information and knowledge online and comparing this information with medical research *and* knowledge of their bodies, patients in these online communities are using what White-Farnham, Finer, and Molloy (2020) call “rhetorical ingenuity — the practice of creating one’s own rhetorical means in highly charged, often technical, yet extremely personal, rhetorical situations” (p. 2). Rhetorical ingenuity differs from rhetorical invention because patients with AS often do not already have access to the available means of persuasion; instead, they are recognizing the medical information they’re lacking and gathering lived experiences to answer their questions and advocate for themselves. Likewise, patients with Asherman syndrome are often acutely aware of the types of medical research they need but does not yet exist, and they often make up for a lack of medical information by gathering and sharing their own lived experiences online.

This article focuses explicitly on how patients gather and share their experiences online to advocate for themselves with healthcare providers and the greater medical community. To gather these experiences, I analyzed 320 online discussion posts, 30 surveys and written reflections, 84 published narratives, and 10 semi-structured interviews, as part of a larger autoethnographic study of my experiences as both a patient and researcher with Asherman syndrome (IRB #597). In particular, I found the combined methodological frameworks of counterstory and coalition building especially helpful to unpack how patients worked together to raise awareness and meet their health goals. Digital spaces are complex and nuanced, and they contain useful information, misinformation, empowering narratives, and disempowering narratives all at once (Nish, 2022). Therefore, when I began working with the Asherman online communities for this project, I wanted to select methodologies that would help me describe the important work that patients were completing, while also looking for ways that online communities could still be harmful or marginalizing to members. Additionally, I wanted to use a methodology that would help me interrogate my own embodied positionality as a cisgender white woman who is not only a researcher, but also a patient living with Asherman syndrome. In particular, I found that the intersectional practices of counterstory and coalition building helped me better understand how patients with Asherman syndrome collaborate across differences to advocate for themselves and

their illnesses, while also helping me carefully listen to the participants of this project to avoid telling singular narratives of lived experience.

I begin this article by describing my own embodied experiences with Asherman syndrome to illustrate the importance of advocacy within community-based research projects in TPC and RHM, echoing the calls of scholars who have encouraged researchers to not only study the lived and embodied experiences of vulnerable communities, but also to amplify their concerns and intervene in the problems they face. Next, I demonstrate how the intersectional practices of counterstory and coalition building helped me better understand how patients with Asherman syndrome work collectively to advocate for themselves within the medical community. I end this article with a discussion of the future advocacy work that still needs to be completed when working with patient communities.

Asherman Syndrome

As a patient who was first diagnosed with Asherman syndrome after a D&C in 2013, I've experienced firsthand the difficulty in advocating for myself with healthcare professionals. The first time I experienced this difficulty was during the diagnosis and treatment process. Even though research has shown that AS should be suspected in any individual with a history of D&C presenting with pelvic pain, infertility, and/or reduced or absent menstruation (Vancaillie et al., 2020), I had to undergo months of testing through multiple healthcare professionals before receiving a diagnosis. After receiving a diagnosis, I was told by multiple doctors that I was permanently infertile and would be unable to have children without adoption or surrogacy. Because these options were unavailable to me, due to their high costs, I began seeking out different answers. I found the Asherman online community my first night of searching online; with the advice of patients from the group, I found an Asherman specialist who was able to treat my scarring. Within three months of my appointment with the AS specialist, I was pregnant with my first child, who is now 10 years old.

The second time I had to advocate for myself was at the end of this pregnancy. During my appointment with the Asherman specialist, he explained that a common complication of Asherman syndrome is placenta accreta, where the placenta attaches too deeply to the wall of the uterus (Mayo Clinic, 2025). Placenta accreta is a serious issue that can lead to hemorrhaging during childbirth, and this AS specialist recommended that my OBGYN request an MRI during my third trimester to check the placenta. However, when I requested the MRI during this period, my OBGYN refused. She explained that there was no need to conduct an MRI during a healthy pregnancy: my most recent ultrasound hadn't shown anything out of the ordinary. When I cited the Asherman specialist's recommendation, she remarked that my concerns were the unwarranted anxiety of a first-time parent. After my doctor's admonishment, I abandoned my request. I would later come to regret my response: during my delivery, the attending OBGYN — a different provider than the one who dismissed my concerns — found placenta accreta. I started losing blood quickly, and because I have a rare blood type, there wasn't blood immediately available for a transfusion. After the procedure, the doctor told me it had been difficult to stop the blood loss and that I was lucky to be alive. Unfortunately, to stop the bleeding, she had to perform another D&C, and my Asherman syndrome returned.

Less than three years later, I was at a hospital advocating for myself again. This time, I was six weeks pregnant and on a family vacation when I woke up in extreme pain. My family drove me to the hospital in the middle of the night, where I waited more than five hours for an ultrasound. While I explained that the pain in my abdomen was worse than contractions during childbirth, I was told that it was “probably a urinary tract infection” by the emergency physician on call. However, my ultrasound showed an ectopic pregnancy, and I was then rushed into an emergency surgery. The ectopic pregnancy had ruptured, and the pain I was feeling was caused by internal bleeding. The surgeon needed to remove the fallopian tube and discovered that my other fallopian tube was scarred shut due to my Asherman syndrome. After this procedure, multiple healthcare providers told me that I wouldn’t be able to conceive naturally again. Due to the physical and mental trauma I had endured throughout each of my pregnancies, I decided not to pursue IVF or other reproductive technologies. The material and physical costs had become too high.

While my experience is personal and embodied, these types of stories are common within the Asherman online community. Individuals describe the difficult process of convincing healthcare providers of their diagnosis, often needing to switch healthcare providers or find a specialist to receive a correct diagnosis of Asherman syndrome. What’s more, individuals with AS who can’t receive a correct diagnosis may have multiple miscarriages or multiple rounds of IVF before treatment. Because IVF is often unsuccessful unless AS is treated first, these failed rounds lead to lost time and income, as well as immense grief for patients (Vancaillie et al., 2020). Even when patients achieve a correct diagnosis and successful treatment, the advocacy work doesn’t end there; patients often need to convince healthcare providers of pregnancy complications, secure a safe childbirth for themselves, and prevent future fertility loss.

These types of advocacy work show the clear need for TPC interventions. Because of the rare nature of the illness, individuals with AS have often never met anyone offline with the condition, and they often report limited success advocating for themselves individually with healthcare providers. In order to persuade the medical community to listen to their concerns, patients often need to work collectively to meet their health goals. However, the difficulty in any type of collective work becomes telling stories that do not become singular narratives of empowerment, progress, or success; patient stories are complex, messy, and embodied, and the complexities of these narratives help patients see that there are choices in ways to move forward. For example, there are different treatment options available to treat Asherman syndrome, and the choice in treatment is an embodied one. Other patients may choose to discontinue treatment altogether due to the trauma and grief of multiple surgical procedures or multiple losses. Perhaps most importantly, patient narratives should not equate treatment with success: as my story shows, these singular narratives may overly simplify the long and painful treatment process by emphasizing medical progress. Therefore, when researching patient stories, I have found it is imperative to prioritize research methodologies that center patient experience and have the explanatory power to show how individuals work collectively while still emphasizing embodied differences.

Counterstory and Coalition Building as Intersectional Research Practices

To address similar concerns, researchers in TPC continue to interrogate and update research methods and methodologies to better incorporate social justice and build theory from the lived experiences of marginalized communities (Agboka, 2013; Alexander & Edenfield, 2020; Frost et al., 2021; Haas & Eble, 2018; Harper, 2021; Jones, 2016; Walton et al., 2019). For example, Jones (2016) insists that technical communicators not only see themselves as authors, but also as advocates who have the opportunity to work toward positive social change: “At this point in history, scholars concerned with the social, economic, and political implications of their work must now consider ways to critique, intervene in, and create communicative practices and texts that positively impact the mediated experiences of individuals” (p. 344). Jones’ (2016) scholarship signifies an important “turn” in TPC scholarship from a focus on ethics, which may imply individual characteristics, to social justice, which by nature tends to be more collective and focused on action (Jones et al., 2016). Additionally, social justice scholarship seeks a more deliberately intersectional approach, one that recognizes that race, gender, class, sexuality, identity, and ability are intertwined and function together to co-construct realities. Finally, a social justice perspective indicates that researchers are not only responsible for describing the experiences of individuals but are also responsible for working to improve the lives of these individuals to help them meet their goals.

These calls for action and social justice demonstrate the importance of conducting research that is ethical and inclusive of diverse patient experiences, especially when considering which stories to prioritize and amplify and which actions to facilitate to work for change in medicine. In this regard, counterstory is a useful research approach that rejects notions of objective methods and builds theory directly from lived experience: “Counterstory functions as both methodology and method for minoritized people to intervene in research methods that would form ‘master narratives’ based on ignorance and assumptions about minoritized people” (Martinez, 2019, p. 21). While counterstory is similar to other narrative methods, it differs from these methods in a few critical ways. First, counterstory requires researchers to recognize the rich, complex, and multiple histories of communities and view these histories — whether written or oral — not as a representation of lived experience, but instead as active and “powerful forms of resistance which are repeated and shared” (Smith, 1999, p. 2). Second, counterstory demonstrates a commitment to social justice outcomes. As Martinez (2019) states: “While there are many stories, and while many data are narrativized, counterstory is distinguished from other forms of storytelling by its transparent commitment to a ‘liberatory and transformative response to racial, gender and class oppression’” (p. 17). Therefore, counterstory is an important methodology for TPC and RHM researchers to utilize, as it disrupts Western ways of doing research that have often been prioritized within medical and academic settings. By centering the lived experiences of patients who have been the most marginalized and prioritizing the multiplicity of embodied histories, researchers can better understand how these histories inform practices that can lead to change.

As a central methodology within critical race theory (CRT), counterstory emphasizes several of CRT’s major tenets, such as the permanence of racism, the centrality of experiential knowledge, the challenging of dominant ideologies, intersectionality and antiessentialism, interdisciplinarity, and a commitment to social justice (Martinez, 2019). When implementing counterstory as a methodology in health communication research, we must acknowledge that racism is a deep and structural problem in the United States, one that operates as a constant, cumulative, and compounding form of oppression in healthcare, along with other social oppressions.

Additionally, we must center the lived experiences of participants, especially those participants who may experience multiple forms of marginalization. When listening to these stories, we can prioritize multiplicities and differences to show that while members may create solidarities to meet specific goals, their experiences are complex and nuanced and do not reflect a singular narrative of shared experience. Finally, as researchers, we can listen carefully for participant stories that challenge dominant narratives and top-down approaches to medicine, while amplifying participants' own problem-solving strategies as they attempt to navigate oppressive structures to access better care for themselves.

While counterstory is an important method to prioritize the lived experiences of individuals, social justice outcomes often require collective interventions. Therefore, the theoretical framework of coalition building (Walton et al., 2019) can be a helpful, complementary lens that can work alongside counterstory to help researchers demonstrate how individuals collaborate across differences to meet a variety of objectives. Citing Young (2000), the authors elaborate,

An account of someone's life circumstances contains many strands of difficulty or difference from others that, taken one by one, can appear to be the result of decision, preferences, or accidents. When considered together, however, and when compared with the life story of others, they reveal a net of restricting and reinforcing relationships. (p. 51)

Because oppressions are structural and institutionalized, the authors show how individual actions alone are often not sufficient to engender social change. Therefore, because "social justice is collective and active," a framework of coalition building works toward this goal by "taking collective action against oppression in ways that preserve and account for difference while consciously, intentionally centralizing marginalized perspectives" (Walton et al., 2019, p. 21). This requires not only recognizing and critiquing oppressive structures but highlighting those perspectives that are most marginalized and working actively to change those structures in ways that group members value.

To help researchers implement the active work involved in changing oppressive structures, the authors present the 4Rs — recognize, reveal, reject, and replace — as an "intentional heuristic for action" when utilizing a framework of coalition building (Walton et al., 2019, p. 148). The first step, recognition, requires listening, trusting, and believing that an injustice has occurred when it is described. It includes affirming the experiences of those who are marginalized, even when those experiences are different from what we would expect. The next step, revealing, requires us to speak this injustice and oppression to others. This requires an evaluation of risk, and asking ourselves, "What can I, given my positionality in this moment, organization, or institution, do to address this problem?" (Walton et al., 2019, p. 140). This may include revealing the injustice to those in power, or it may include revealing the injustice to an ally to strategize and move forward. The third step is the rejection of the oppressive behavior, policy, or structure. This is where the importance of a coalition comes in, as "individuals can rarely reject, let alone replace, unjust practices alone, and recognition on one person's part is often prompted by another's revealing" (Walton et al., 2019, p. 142). The final step is to replace the oppressive behavior or structure. Sometimes replacing can be a small, personal change, but it often means "shoring up additional resources, challenging power relations or meaningful personal

relationships, and restructuring organizations through new policies and procedures” (Walton et al., 2019, p. 142). By working through the 4R’s, individuals can recognize and reveal injustices, recruit allies within a coalition, and begin working for change.

Counterstory and coalition building are important research frameworks to the study of Asherman syndrome because they document collective action while attending to the multiplicity and multiple realities present in the lived experiences of patients. To gather these lived experiences, I collected data in a two-part process. In the first phase of research, I conducted a qualitative content analysis of 320 posts collected from the most popular thread in the Asherman online community. This analysis helped me gather themes regarding why participants join the group and the rhetorical strategies they used to advocate for themselves, as well as the effects of these strategies on healthcare outcomes. In line with feminist research methods, data from this phase was used to understand overall trends within the group, but patient writing was not collected or quoted, as patients may not have wished to have their posts used outside of their original context. In the second phase of the project, participants were recruited directly from Asherman online communities on Facebook, Instagram, and Reddit to participate in a 14-question survey and written reflection about their experiences participating in the Asherman online communities. At the end of the written reflection, patients could choose to elaborate on their responses in a semi-structured interview. In total, 30 participants completed the survey and written reflection, and 10 individuals completed a semi-structured phone interview. As a further step, I also gathered 84 published patient narratives from a patient-authored publication, *The Silent Syndrome*, and the Asherman Australia and New Zealand advocacy website. I believe these written reflections, interviews, and published narratives provide a rich pool of data about the rhetorical strategies patients use to advocate for themselves within and beyond medical settings.

In what follows, I describe how an attention to the methodology of counterstory helped me notice a critical difference described by patients in this research project: Asherman syndrome is not a rare condition, but rather a rarely diagnosed one. This counterstory challenged my own assumptions as a researcher, as I incorrectly anticipated that patients would create solidarity under the shared experience of navigating a rare illness. Instead, patients highlighted how the categorization of “rare” by healthcare providers and medical organizations instead served as a dominant and oppressive narrative that worked insidiously to keep patient from receiving an accurate diagnosis and treatment. Next, I interrogate how members of the Asherman online communities actively build coalitions using the 4Rs to recognize, reveal, reject, and replace this oppressive narrative that silences their lived experiences. Before moving to the next section, it is important to note here that all names have been either removed or changed (even in the case of published narratives), to provide an extra layer of anonymity for patients who have chosen to share their experiences. Additionally, many individuals experience infertility (and thus AS), including cisgender women, transgender men, and nonbinary people. While I intentionally use the terms “individuals,” “people,” and “patients” in this article, some participants use gendered language in their writing, and the original language has been retained in quotations throughout this article.

Counterstory and Asherman Syndrome: A Rare vs. A “Rarely Diagnosed” Disorder

The published narratives, written reflections, and interviews gathered in this project all indicate the complex issues facing patients with Asherman syndrome. As one individual demonstrated in an online narrative:

I was nineteen years old when I had a D&C procedure, due to retained placenta after the birth of my first child. I was not aware of the risk of Asherman's syndrome. I didn't get a menstrual period for a year after having my first child and that prompted me to see a doctor and find out what was going on with my body. It took a year to diagnose that I had Asherman's syndrome. It took a further seven years for my partner and I to have another baby, all the while unsure if we would ever be able to see this come to fruition. We suffered five miscarriages (some I needed to be admitted to the hospital for) and the premature loss of our daughter at eighteen weeks gestation. In addition to all the loss we faced, I had ten surgeries over that time, all linked to Asherman's syndrome. These were repeated hysteroscopy and laparoscopy surgeries. I also suffered two secondary hemorrhages after the birth of our daughter (deceased) and of our son (living). Altogether my partner and I have spent over \$100,000 out of our own pockets. Because of Asherman's I have had to sacrifice financially, emotionally, and physically. The effects have caused so much hurt for myself and my family. (Asherman Australia and New Zealand)

This story reflects the time-consuming diagnosis and treatment process for Asherman syndrome and the emotional toll it can take. As another patient explains, "For many women with Asherman's, the psychological pain is triple-fold: first, the devastating loss of a single pregnancy, then the incomprehensible threat of losing the chance at future pregnancies, and finally the almost complete devaluation of their experiences by their doctors" (*The Silent Syndrome*, p. 37). As patients have expressed throughout this project, it is difficult to advocate for themselves and make healthcare decisions related to Asherman syndrome, especially when so few healthcare providers are knowledgeable about the condition themselves.

In this regard, the online Asherman communities present useful information that members often can't find anywhere else. As Vanessa describes in her written reflection for this project: "90% of what I learned was through the online communities, not the health care system or medical professionals." However, while the Asherman online communities can provide information about the symptoms of Asherman syndrome and different options available for treatment, this information is typically only circulated within the communities, that is, to patients already diagnosed with Asherman syndrome. As Tara describes in her written reflection, "I hope that my experience can help other women, but unfortunately if they come to the group, they are already suffering from Asherman's and the devastation that comes with infertility." Additionally, many of the recommendations put forward by group members, such as traveling to see an Asherman specialist, are only available to the patients with sufficient material resources to follow these recommendations. Therefore, many patients wish for their stories to reach beyond the online Asherman communities to medical providers and healthcare institutions. As Vanessa states in her interview, "Awareness and knowledge sharing from these online communities needs to bubble up and put pressure on our medical system to do better for women." Ideally, patients with advocacy goals hope to prevent future cases of Asherman syndrome by reaching individuals who haven't had a D&C yet but may be recommended one by healthcare providers in the future.

In order to effect change on a larger scale, patients emphatically presented an important counterstory of Asherman syndrome that centers lived experience, challenges dominant medical narratives, and fosters social justice outcomes: Asherman syndrome is not a rare condition but is instead a “rarely diagnosed” condition. While the language change may seem minor, the impacts to patients are significant. As the Asherman Syndrome Australia and New Zealand organization notes in a letter crafted to the Royal Australian and New Zealand College of Obstetricians and Gynecologists (RANZCOG):

We feel that it would be worth considering a change in classification of Asherman Syndrome from being a ‘rare’ condition, to a ‘rarely diagnosed’ condition. Many women cited a lack of awareness of Asherman Syndrome by their General Practitioner (GP), or that their concerns were dismissed because Asherman Syndrome is viewed as ‘rare’. This was in spite of presenting to their doctor with a history of uterine surgery and common symptoms of Asherman Syndrome. For many women, this resulted in lengthy delays to diagnosis. Many women had to fight hard for correct assessment procedures, and often sought second and third opinions in response to their concerns being dismissed. Often, women paid significant out of pocket costs to enable this care.

These comments align with the findings from this research project, where participants noted the difficulty in achieving a diagnosis, with providers insisting that patients can’t possibly have Asherman syndrome, because it’s “too rare.” Additionally, the perceived rare nature of the condition often keeps medical providers and hospital staff from including Asherman syndrome as a clear risk of D&C procedures during the informed consent process. This omission has drastic consequences for patients, as many patients surveyed and interviewed for this project felt they were not clearly informed of the risk of Asherman syndrome when choosing to have a D&C. This not only causes significant emotional and physical trauma to patients but also leads to a breakdown of trust between patients and healthcare providers.

Even when patients conduct additional research on Asherman syndrome and D&C procedures outside of the informed consent process, the dominant narrative of the rare nature of the condition is prominently displayed in most online medical literature. For example, the National Institute of Health states that “Asherman syndrome is a rare condition. In most cases, it occurs in women who have had several dilation and curettage (D&C) procedures” (para. 2). During interviews, patients often discussed the problems with medical websites minimizing the risk of D&C procedures. As one patient describes in a published narrative:

I believe that the information about the risks associated with Asherman’s Syndrome should really emphasize that the possibility of scarring is much greater than previously assumed. The implication that scarring typically happens after repeat procedures, and not a single D&C, provides a false sense of security to women like me, for whom Asherman’s can be exceedingly tragic when it occurs following a first unsuccessful pregnancy, endangering all future chances of conceiving. (*The Silent Syndrome*, p. 212)

Similarly, patients treated for miscarriage or missed miscarriage who are recommended D&C procedures may perform online searches to obtain information about the overall safety and risks

associated with the procedure. Again, the language used on medical websites is often vague and emphasizes the rare nature of complications. For example, when outlining the risks of D&C procedures, the American College of Obstetricians and Gynecologists (ACOG) website states:

Complications are rare. When they do occur, they include bleeding, infection, or perforation of the uterus...In rare cases, after a D&C has been performed for miscarriage or abortion, bands of scar tissue called adhesions may form inside the uterus. These adhesions may cause infertility and amenorrhea. This is called Asherman syndrome. Asherman syndrome can often be treated successfully with surgery. Call your health care professional if your period has not returned within 3 months after a D&C. (para. 12–13)

Again, the messaging provided from medical websites indicates that D&C procedures are generally safe, with minimal risks involved. However, when studies have demonstrated that, on average, 19.1% of patients develop Asherman syndrome after D&C, with increased risks after missed miscarriage, repeat D&Cs, or the removal of retained placenta, these websites may not be adequately representing the real risks involved with the procedure (Hooker et al., 2014). Additionally, while it is true that Asherman syndrome can often be treated successfully with surgery, the writing in this excerpt downplays the often long — and traumatic — journey patients with Asherman syndrome must endure to find and receive adequate treatment and elides the greater problem that many individuals without the resources to fund this care may never be able to receive treatment. Indeed, multiple patients in this project noted that if they had been told they had a 19.1% chance of developing Asherman syndrome after the D&C, they would have selected another treatment option, such as medical management of their miscarriage.

Most importantly, the counterstory of “rarely diagnosed” highlights how the description of a “rare” illness can be extremely harmful to many patients, as this perception keeps patients from receiving an accurate diagnosis and treatment. Additionally, while many members participating in this project reported experiencing some form of oppression from healthcare providers, such as dismissals of symptoms and inaccurate diagnoses, structural inequities in healthcare cause multiple and compounding oppressions for individuals due to race, class, identity, sexual orientation, and ability (Alexander & Edenfield, 2021; Harper, 2021; Yam, 2020). For example, studies have shown that “racial and ethnic minorities, including Black and Hispanic women, experience infertility significantly more than their Caucasian counterparts” (Siegel et al., 2021, p. 347); however, “even in states with comprehensive infertility mandates, infertility care still is used disproportionately by non-Hispanic white women of high socioeconomic and educational status” (ASRM, p. 56). While socioeconomic factors are certainly part of this problem, structural racism also accounts for this disparity. As the American Society for Reproductive Medicine (2021) notes, “Women of color, for example, have reported that some physicians brush off their fertility concerns, assume they can get pregnant easily, emphasize birth control over procreation, and may dissuade them from having children” (p. 57). Additionally, past state insurance laws have relied on a definition of infertility that requires “6–12 months of unprotected heterosexual intercourse,” which excludes many LGBTQ+ couples and single individuals from infertility coverage (ASRM, p. 57).

Even for patients who successfully receive treatment for Asherman syndrome and are able to conceive, the dominant medical narrative of Asherman syndrome as a rare illness may make it

even more likely for individuals to experience dismissals of pregnancy and childbirth complications. In a healthcare system where BIPOC are already 2 to 3 times more likely to die in childbirth than white individuals (CDC, 2019), any increased risk is alarming and unacceptable. As one patient describes in their interview, “I know about the higher maternal mortality rates among Black women, and it all starts with dismissing symptoms. Discrimination is exhausting and infertility is exhausting and the place where they intersect is heartbreaking. It is on every one of us in the infertility community to continue to amplify the voices of Black women in particular on this topic and demand a system that is equitable and safe for BIPOC.” As this participant shows, positive change in standards for care cannot happen without closely examining the ways that dismissals of patient experience are closely intertwined with structural inequities in healthcare. An intentional focus on counterstory amplifies how the repetition of dominant medical narratives, like continuing to view an illness as “rare,” even when it affects almost 1 in 5 individuals who receive D&C procedures, helps perpetuate and compound the dismissal of symptoms that disproportionately affects those patients who are already the most likely to have their symptoms dismissed.

While the counterstory of Asherman syndrome as a rarely diagnosed condition is compelling, powerful, and backed by research, patients with Asherman syndrome must find ways to spread this counterstory outside of their own patient networks to reach healthcare providers and future patients. Therefore, patients must combine the methods of counterstory with the benefits of coalition building in order to meet their advocacy goals.

Coalition Building in Patient Communities

While the Asherman online communities offer informational support for patients by sharing symptoms, treatment best practices, and recommendations for healthcare specialists, this support is ultimately the most helpful for those individuals who already have access to the material resources to travel and pay for treatment. As the Asherman Australia and New Zealand organization elaborates on their website:

To secure the highest quality of treatment (surgery by a specialist in Asherman syndrome), many women have had to find the resources to go to Sydney for surgery. This has put many of us under significant strain. Some of us have gone into debt, and many women are not in a financial or social position to fly interstate for surgery. Some women who have had local surgery by someone who is not specialized in Asherman syndrome have had their condition drastically worsened and as a result are unlikely to ever be able to fall pregnant. This is a devastating outcome for these women and their families.

The level of perseverance and resources required by many of us to get proper diagnosis and treatment has left us wondering how many women are out there with undiagnosed and/or inadequately treated Asherman syndrome. We are particularly concerned about women in regional/country areas given that the vast majority of us have needed to seek diagnosis and treatment services in capital cities.

In the Asherman online communities, the most marginalized patients are those individuals who are not able to achieve a diagnosis or treatment due to cost, geographic barriers, or structural

inequities within the healthcare system. In order to support the community's greater health goals of AS prevention, members must center and prioritize these differences when building coalitions for change. Additionally, they must actively utilize the 4Rs to recognize, reveal, reject, and replace the dominant narrative of Asherman syndrome as a "rare illness" by supplanting this narrative with their own embodied stories.

Most participants in this project complete the first 2Rs by recognizing the problem of dismissing patient symptoms and rejecting the dominant narrative of "rare illness," replacing it with the counterstory of "rarely diagnosed" illness. However, for their advocacy efforts to be successful, patients must work to reveal the counterstory of Asherman syndrome as a "rarely diagnosed" condition in a way medical providers and the general public will recognize, reject, and replace as well. This coalition building most often occurred by writing letters to healthcare providers and hospitals; creating blogs, podcasts, and other social media outreach; and crafting petitions to medical professional organizations. The most common form of advocacy that members reported after their diagnosis of Asherman syndrome was to write a letter to the healthcare provider or hospital that had performed their D&C procedure. Participants in this project describe how writing these letters provided a sense of therapeutic relief, where they could voice the hardships of living with Asherman syndrome while also demonstrating to medical institutions that D&C procedures can and do cause lasting harm to patients. While patients benefit from the process of letter writing itself, they report mixed results in terms of the reception of their letters. For example, a patient living in Australia who requested a meeting with hospital staff was promptly rejected:

After having unsuccessful treatment for Asherman syndrome and being told I would not be able to have any further children, I wrote to the private Perth hospital where my D&C had occurred, requesting to meet with the obstetrician and hospital staff to explain the impact of Asherman's on my life. In writing, they declined my request to meet with them. It was a huge slap in the face. (Asherman Australia and New Zealand)

However, other patients described successful responses and meetings with healthcare providers and administrators, with some hospitals offering to change their informed consent processes to include Asherman syndrome. As another patient describes in an online narrative:

I wrote to the public Perth hospital where my D&C had occurred and informed them about my Asherman syndrome diagnosis (two years post-surgery). The head of the Obstetrics Department met with me and thanked me for alerting them to my situation. He discussed changes they would make to protocols around D&Cs and consent processes. I feel proud to have in some small way been a part of changing this situation and hopefully preventing other women from experiencing the pain that I have endured.

Although letter writing to reveal the problems with D&C procedures may encounter limited success within medical settings, successful letters arguably have dramatic consequences for the many future patients who will visit these institutions. Additionally, while some institutions may originally reject letters to change policies, they may be more amenable in the future if they continue to receive letters from concerned patients. For example, Owens (2009) describes how continued resistance from individuals regarding pubic shaving and enemas, once considered

routine aspects of childbirth, eventually led to additional medical research and the removal of these practices. In an Asherman-specific case, one clinic in Vancouver BC received six reports of Asherman syndrome in an 18-month period; these reports led to a practice audit at the clinic and changes in informed consent processes and patient information materials (Gilman Barber et al., 2014). Therefore, while these letters may not be immediately successful, over time they may begin a trend that eventually leads to better outcomes for patients by revealing to medical providers that Asherman syndrome is not as rare as they once believed.

While patients often attempt to effect change in medicine through writing letters directly to medical professionals, individuals with larger professional or social networks use their unique positions within this coalition to leverage these networks to reveal this counterstory to the public. For example, multiple members related their stories with Asherman syndrome on individual blogs and Instagram, using hashtags such as #ashermans and #infertility to increase their reach to a wider public audience. Additionally, one member used her training as a journalist to write an article in a popular health publication, another started an infertility podcast, and a third member posted her Asherman story as a blog post on her business website, a maternity clothing retailer. As this individual states in a written reflection for this project, “I felt like sharing candid stories of me talking about my current journey with Asherman’s would help women out there who may be unknowingly going through the same thing.” This may help some patients who have yet to be diagnosed with Asherman syndrome, due to the perception of the illness as a rare condition. Additionally, other patients describe sharing various treatment options online, with the hope that this information could help someone else. As Cara relates in a written reflection for this project:

I joined the Asherman online community because there wasn't a lot of information out there when I was going through my diagnosis (2013). I had consults with doctors all over the country. I did every treatment suggested and even some not suggested. I did it all. But even googling Asherman's there was so little known. Therefore, every time I did a treatment, received advice, I did my best to relay that on my blog so that maybe, one of those treatments WOULD work for someone that came across the information I had.

This ethos of sharing — sharing vulnerable lived experiences and complex treatment decisions — is evident throughout the online discussion posts, published narratives, surveys, and interviews. Indeed, 60% of survey participants in this project indicated that they shared their unique experiences with Asherman syndrome in the hopes that it would help other patients. Although most of these patients describe never meeting anyone offline with Asherman syndrome, many are more than willing to share their stories with the hope that it will help someone else.

In order to create change and awareness on a larger scale, patients have also started petitions for various medical professional organizations, such as ACOG and RANZCOG. This effort began after a member received a diagnosis for AS and recognized that most doctors were performing “blind” D&Cs (no visualization via ultrasound) without full recognition of the implications of these procedures. As this member shares in her written reflection for this project:

Angered and motivated to help prevent more women from suffering, I inquired on the forum whether women might support a comment letter/petition to ACOG asking them to

update their guidelines [on D&Cs]. Many were excited and said yes. With some members helping by sharing medical studies or offering to line-edit my copy, I drafted an extensive foot-noted letter, bolstered by many scientific studies. I invited women to share their stories and a few volunteered. I helped them shorten and polish them. I wanted doctors to read first-hand accounts and not just scientific studies. At first, I wanted to keep the signatures to US patients but so many international folks were interested that I expanded it and decided to CC all of the relevant ACOG-equivalent colleges in Canada, the UK, and Australia, as well as two NIH officials.

The international letter, titled “Request for an urgent review of clinical guidelines to prevent the formation of intrauterine adhesions following a dilation and curettage,” was submitted in June 2021. As of the writing of this article in June 2025, there has been no official response from the medical organizations addressed in the letter.

Through the relationships developed working on the international petition, participants in Australia and New Zealand decided to draft a follow-up letter, which they submitted to RANZCOG in September 2021. This letter contained 16 citations to current medical research on Asherman syndrome and included researched-backed recommendations for best practices in the treatment of AS. The letter states,

We, as an alliance of Australian and New Zealander women with Asherman Syndrome, are sending you this follow-up letter expressing our keen desire to work alongside RANZCOG to raise greater awareness and promote improved treatment of Asherman syndrome. We have integrated our collective experiences with current medical research – and do so with full acknowledgement that we are not medical professionals. We hope you can read this letter from a place of understanding that our primary aim is to prevent other women from experiencing the levels of pain and distress that we have.

This alliance then created their own website, the Asherman Syndrome Australia and New Zealand, where they posted the letter and recommendations, along with the embodied stories of ten patients and an interview with the leading Asherman specialist in Australia. In 2024, the incoming president of RANZCOG agreed to a meeting with representatives from Asherman Australia and New Zealand and has promised to review the guidelines on the management of miscarriage. While these guidelines have not been changed as of the writing of this article, by creating these documents, and making them publicly available on their website, this group of patients will undoubtedly help many more individuals who come to the website searching for information on Asherman syndrome. They have successfully revealed the problem to medical institutions, and their efforts have been recognized. In time, patients hope that RANZCOG will complete the 4Rs by rejecting current D&C practices and replacing them — with better informed consent procedures with the true risks of AS and treatment options that have been proven to be safer for patients, such as miscarriage using medication and ultrasound-guided D&Cs (Freedman & Schlaff, 2021).

As these patient narratives demonstrate, intersectional frameworks such as counterstory can reveal the underlying stories that can oppress patients and keep them from receiving care. Additionally, theories such as coalition building can demonstrate how individuals use their own

positionalities within communities to effect change on a larger scale. Patients in the Asherman online communities recognize the injustice that occurs when individuals are not adequately informed of the risks of D&C procedures during the informed consent process, and they attempt to reveal this injustice to others by composing letters, emails, articles, social media posts, blogs, podcasts, and petitions. Additionally, they reject the view that Asherman syndrome is a rare condition and expertly weave together patient narrative and current medical literature to replace this outdated information with their own patient-created TPC. While these texts have yet to be fully validated by the medical community, it still shows the power and potential of patients working collaboratively to actively create large-scale change in medicine.

Implications for Future Research

In the rhetoric of health and medicine specifically, scholars have also increasingly encouraged researchers to consider how their work can improve medical outcomes by helping patients meet their health objectives. In “The Rhetorician [of Health and Medicine] as Agent of Social Change,” Finer draws on Cushman’s (1996) work to implore researchers to “take social responsibility for the people from whom we come to understand a topic” (p. 207). As Finer discusses, social responsibility includes amplifying the self-advocacy work of patients and also advocating for them through our writing: “When it comes to healthcare, self-advocacy requires an empowered voice *backed by* literate practices and rhetorical strategies” (pp. 207–208, italics in original). For example, Cushman (1996) describes writing documents such as “resumes, job applications, college applications...recommendations to landlords, potential employers, admissions counselors, and DSS [Department of Social Services] representatives” to help advocate for the participants in her dissertation project (p. 13). Similarly, Finer reflects on the literate and rhetorical practices necessary for self-advocacy in healthcare settings, including finding medical resources, evaluating the credibility of those sources, and understanding a variety of stakeholder agendas. As Finer compellingly argues, when it comes to health and medicine, “reading and writing are necessary for literal survival” (p. 208). Because rhetoricians are trained and capable in these areas, Finer implores scholars to reflect on the ways we can use these specific skills to facilitate action and intervention within the communities we work with.

Ultimately, I have found that intersectional frameworks, such as counterstory and coalition building, can help center the lived experiences of patients throughout the research process, especially in an attention to the ethical elements of research and eschewing cohesive and singular narratives. A combined focus on counterstory and coalition building is also helpful for researchers due to an intentional and persistent focus on action, accessibility, and improved outcomes for participants. These priorities can serve as a helpful reminder to researchers that we must also diligently work outside of academic research and publication to help community members meet their specific goals. As other researchers in RHM have demonstrated, one helpful step in this direction may include publishing our work in open access journals or sharing our de-identified data directly with participants (De Hertogh, 2018; McKinley, 2020). However, as Cushman (2006) and Finer (2020) have noted, researchers interested in advocacy work may also need to help write a variety of other technical communication. Importantly, intersectional feminist practices help demonstrate how researchers can center patients’ healthcare concerns and amplify the important TPC that patients have already created. As Harper (2020) describes, “the genres of written communication used by activists (websites, press releases, social media posts,

memos, and position statements) aim to redress oppression, while the written communication strategies of government establishments (regulatory writing) help maintain systems of inequity” (p. 231). By amplifying these activists’ own written genres, researchers in TPC and RHM can work to help patients intervene in these systems of inequity.

By listening to members of the Asherman online communities, I found many aspects of TPC that could be improved to help patients receive better care. First, people who are recommended D&C procedures need updated information on the prevalence of Asherman syndrome in patient education materials. Secondly, Asherman syndrome should be added as a specific concern within informed consent documents presented to patients before the D&C procedure. In these materials, rather than citing Asherman syndrome as a “rare” condition, it is exponentially more helpful to include current percentages, as many individuals would not consider 19.1% (almost 1 in 5 patients) a “rare” complication (Hooker et al., 2014). Third, patients would like to see the options for medical management of miscarriage to be presented equally in patient-provider communication. Throughout this project, patients often felt that doctors prioritized D&Cs over medical management, because D&Cs are considered safe and more efficient than miscarriage through medication. However, current research in Asherman syndrome has shown that because medical management is as effective as D&C procedures and less risky, this option should be prioritized, or at the very least, presented as an equal solution to surgery (Freedman & Schlaff, 2021). This point becomes even more important as the current medications used for miscarriage management, misoprostol and mifepristone, may be limited due to abortion restrictions in many states. In these instances, patients dealing with pregnancy loss will have to rely on D&Cs, and the rate of Asherman syndrome will surely increase.

While this research project focuses on one illness, I believe the findings show how TPC researchers can work with patients to research and improve informed consent documents and patient-education materials on a wider scale to help more patients achieve better care. Ultimately, this study finds that TPC that prevents Asherman syndrome is ultimately the most pressing and helpful communication to help patients meet their goals. Once patients have symptoms of Asherman syndrome, treatment is costly and not always covered by insurance. There are many geographic barriers to receiving treatment from an Asherman specialist, and patients may have their symptoms dismissed due to the cumulative factors of a perceived rare illness along with structural inequities in healthcare. However, researchers and practitioners in TPC can also help patients in other ways. For example, TPC practitioners can help patients by synthesizing current medical research for inclusion on advocacy websites. They can use this research to help write letters to healthcare providers requesting different options for treatment or improved informed consent processes. They can help amplify patients’ concerns by signing or writing petitions to larger medical organizations. They can write letters to state representatives asking for state-mandated infertility insurance and greater equity in infertility care. While these types of documents are not prioritized in academic research, they are imperative to help patients achieve better care.

Finally, teachers of TPC can help include the activist work of patients within the classroom in order to show the value of advocacy in technical and professional communication. In my own teaching experience, I have found that including patient TPC in the classroom helps alter students’ perspectives on the stakes of the writing they can and will be responsible for after

graduation. What's more, it helps students begin to think of the ways they will need to advocate for themselves and one another outside of academic settings. For example, in my PhD program, a mentor taught me to tell future medical providers, "I would like you to write in my medical chart that I asked for that test and you refused," and I often pass this advice down to my own students. As a class example, I have found that these types of conversations can help students unpack the ways that TPC can help intervene in other, larger institutional systems they would like to change, and they also help us start discussions about how simple acts, such as deeply listening to someone's story of grief and loss, can be a foundational act of coalition building and solidarity. Because health, illness, loss, and advocacy are concepts that will ultimately affect us all at some point, these conversations can be useful starting points for larger discussions on the complex relationship between users and TPC to challenge notions of "objective" or "apolitical" writing in the field (Walton et al., 2019). Additionally, this strategy helps students interrogate how "TPC as a field should tend to its practices of knowledge legitimization, particularly by acknowledging, inviting, and accepting the different ways that knowledge is made" (Walton et al., 2019, p. 153). Including patient narratives in the writing classroom can help students think critically about how knowledge is produced not only from the top-down, but from the bottom-up, and how that knowledge can be amplified through coalitions to create change.

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