When a Global Pandemic Makes Life More Accessible to Those with Invisible Disabilities

Gretchen Peterson¹

1 University of Memphis, Memphis, TN, USA, gpterson@memphis.edu

Abstract

The Covid-19 pandemic brought social distancing into our vocabulary and made working from home normative for many people. While much of the news has focused on the isolation that social distancing exacerbated and on the adverse effects of the pandemic for individuals with certain disabling chronic illnesses, the move to virtual engagement with work and school made such spaces more accessible. As someone who had Ulcerative Colitis for many years and had surgery during the height of the pandemic in summer 2020, the ability to engage virtually allowed me to continue working despite dealing with illness and then recovering from surgery. This paper takes an autoethnographic approach using autobiographical experiences coupled with existing literature to illustrate how the need for social distancing during the pandemic created greater access to spaces for people with invisible disabilities. In addition, connecting virtually alleviated some of the anxiety from trying to physically be present in public spaces with an illness that can be very stigmatizing. As we look ahead to the inevitable invisible disabilities that will mark those who experienced covid-19, this lesson about how virtual connection can be used to make spaces and events accessible will become increasingly important.

Keywords: Chronic illness, Invisible disability; Accessibility, Stigma, Microaggressions

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Introduction

With the spread of the Covid-19 pandemic in early 2020, people who were not essential workers moved to work from home as businesses closed their doors to slow the spread of the virus. Schools shut their doors, and families had to navigate work and school from home. I was already teaching fully online classes, so I was spared from the dramatic teaching U-turn that so many faculty experienced. However, I served as department chair, so I found myself being called to more meetings as the crisis evolved. While the need to attend so many meetings would have been a source of anxiety previously, the move to virtual meetings made my involvement so much easier. The source of my anxiety about meetings was my ongoing battle with Ulcerative Colitis, a chronic inflammatory illness. I had long experienced the ups and downs of not knowing when my illness might flare, causing me to cancel meetings or events. That cycle had worsened as my illness spiraled and I experienced multiple hospitalizations in recent years. Moving to virtual meetings meant I no longer had to worry about whether I could easily access a restroom during an event since I could now attend from my home with an available restroom always just a few feet away. If I felt particularly weak, I could simply stay in bed while attending a meeting. The move to remote work freed me to be more involved by taking away the pressure to be physically present. My experiences illustrate how providing virtual access to workplaces can facilitate the inclusion of persons with disabling illnesses.

This paper uses an autoethnographic approach that couples autobiographical experiences with extant literature to illustrate the lessons learned as a person with an invisible disability living through a pandemic that required people to work remotely whenever possible. It thus presents an autoethnography in the form of a personal narrative using stories from my own experience in conjunction with analysis using

scholarly literature (Ellis, Adams, and Bochner 2011). This has the advantage of imbuing more emotional content as I grapple with and give voice to my own experience, which seems particularly relevant in discussions of health and illness (Ellis and Bochner 1999). While many in popular media (for example, articles in the New York Times and The Atlantic) expressed concern about the negative mental health consequences of the isolation that came from social distancing, for people with disabilities or disabling illnesses, virtual events enabled greater access to events from which they otherwise would have been excluded.

I use the terms "disability" and "disabling illness" interchangeably throughout this paper. In reflecting on these terminological choices, I recognize it reflects my struggle with defining myself as a person with a disability. There are both identity and legal implications with claiming a disability identity. While I long ago accepted the status of a chronically ill person, it was not until recently that I understood this as an invisible disability. In my view, I was a person with a chronic, disabling illness, but I did not claim the status of a person with a disability in any of my workplaces or other settings. Thus, using the terms "disability" and "disabling illness" better reflects my sense of self as a person with a chronic illness that regularly flared and was at times disabling. I also hope that using both terms enables more readers to connect with the experiences I describe.

Considerable research has examined the impacts of invisible disabilities on the lives of those afflicted. Invisible disabilities include "conditions, illnesses, and structural or biomedical anomalies that are lifelimiting but not readily discernible to others" (Davis 2005: 153). Even though one's illness may not be apparent to others, its impact on life activities is still significant. For example, studies have demonstrated that self-disclosure of an invisible disability results in applicants being viewed less favorably (Guskin 1982). However, more recent research has shown no difference in ratings of candidates with invisible physical disabilities compared to job candidates with no disability (Dolgin and Bellini 2008). In addition, research has shown that such illnesses contribute to career barriers even when considering chronic illness more broadly (not just disability). For example, Beatty (2012) found that others perceive an afflicted person as unable to handle challenging work or likely to exit the workforce, thus demonstrating the biases facing those with chronic illnesses and invisible disabilities.

Theoretical & Empirical Framework

What is Ulcerative Colitis?

Ulcerative Colitis and Crohn's disease are types of inflammatory bowel disease. They are autoimmune disorders where the body attacks the lining of the intestines, causing inflammation and ulceration. Crohn's disease is distinct from Ulcerative Colitis in that Crohn's affects the small intestine or the entirety of the digestive tract. In contrast, Ulcerative Colitis is limited to the large intestine (colon). The inflammation in these diseases causes patients to suffer from bouts of diarrhea, abdominal pain, and gastrointestinal bleeding (Conrad, Roggenbuck, and Laass 2014). According to research published by the Centers for Disease Control, approximately 1.3% (3.1 million) of U.S. adults reported a diagnosis of inflammatory bowel disease (either Ulcerative Colitis or Crohn's disease) (Dahlhamer, Zammitti, Ward, Wheaton, and Croft 2016). While this diagnosis is challenging for anyone, women have reported lower health-related quality of life and more negative emotions with their illness experience (Hauser, Tkalcic, Stimac, Milic, and Sincic Additionally, women with Inflammatory Bowel Disease have indicated concern about feeling alone due to their illness. Thus, the emotional consequences of living with this chronic illness appear to be connected to feelings of isolation.

As a gastrointestinal illness that is largely invisible to others, Ulcerative Colitis presents a challenge to its sufferers in managing their flares and talking about their bathroom needs. Saunders (2014) found that young adults had to navigate the experience of stigma with Inflammatory Bowel Disease because of taboos connected with discussing their particular symptoms. In addition, a diagnosis of Ulcerative Colitis has been associated with life limitations as studies have shown between 13-18% of individuals with UC experienced long-term work disability (Busch, Sonnenberg, and Bansback 2014). Thus, for many patients, Ulcerative Colitis is a chronic, disabling illness that they actively work to "cover" due to its stigmatizing nature. Given the occurrence of symptoms, sufferers cannot wholly conceal their illness, but they will work to downplay the problems that come with illness flares to engage in "covering," as described in Goffman (1963).

My Experience with Ulcerative Colitis

I was first diagnosed with Ulcerative Colitis (UC) in my early 30's and managed reasonably well for about a decade with daily medication. Although, my gastroenterologist at this time referred to my illness as "simmering." Even when I was doing well, my condition always seemed to be present in the

background, ready to flare. I never seemed to achieve a state of remission at any point since my diagnosis. It can be difficult to assess remission in Ulcerative Colitis, and researchers investigating the efficacy of various therapeutic interventions may use different standards to describe remission (Travis and colleagues 2011). But I learned to adapt and still managed daily life activities quite well over the years even while I continued to experience symptoms of my illness (generally significant urgency and high frequency of bowel movements). It never even occurred to me that I had a disability. However, this changed during the two years preceding the Covid-19 pandemic as I was hospitalized eight times.

In December of 2017, I remember getting the flu. Even though I had my annual flu shot, illness hit me hard that year, and I lost about 10 pounds in a couple of weeks. As I struggled with the flu, I also struggled with a significant flare-up of my illness. Since I was still pretty new to working with this doctor, I didn't realize how to get a hold of him. It did not occur to me until much later in my illness that it was essential to emphasize the severity of any symptoms to get a timely appointment (the hidden curriculum of navigating health care). Doctors' offices will sometimes hold appointment slots early in the morning or during lunch to squeeze in patients with urgent needs. Since I did not know how important it was to be blunt with the scheduler about how ill I was, several more weeks passed before I could get an appointment. While the concept of "hidden curriculum" is most often used for formal educational settings (for example, in medical education as described by Hafferty and O'Donnell 2015), I am referring to how we are informally taught to navigate accessing appropriate healthcare. Advocating for ourselves means that it is not enough just to say you need an appointment; you must provide the supportive details of how ill you feel to be seen quickly when you need to be.

By the time of my appointment, I was in the throes of a flare that was not controlled and needed steroids to bring my illness back under control. But despite being given steroids (a strong medication reserved for significant inflammation), I just still was not feeling well and was spending a lot of time in bed. With a flare-up of Ulcerative Colitis, one of the challenges is to remain hydrated, so I kept drinking fluids, trying to regain some energy. I was still going to work and meeting my obligations, but then returning home and going back to bed. I eventually felt pain, like a muscle pull in my right glute muscle.

I had often experienced muscle pulls over the years as an athlete, so I thought nothing of it. Even though I had not been doing a lot of physical activity, I just told myself that I must have slept wrong. Finally,

I got to the point where I was having trouble even keeping liquids down and told my husband I was too dehydrated and needed to go to the hospital. But, going to the emergency room (ER) at the height of flu season is a challenge. I checked in and then moved to some chairs to wait with my husband. By this point, sitting was extremely painful, so waiting in those chairs was too much to bear. After more than an hour in the waiting room with no real movement of people into the ER, I told my husband I couldn't take waiting anymore, and I just wanted to go home. I signed a form saying I was leaving and went home. That was a Thursday night. I went home and went back to bed and largely stayed there for the next several days. Finally, the pain was horrible by Sunday, and I still was not getting enough fluids, so I told my husband he had to take me back to the ER.

By this time, I had learned that you could see ER wait times online. I discovered this as I was looking online to see the locations of other Emergency Rooms in the area when I happened to notice an ER wait time posted at the top of one hospital web page. So, rather than returning to the very busy ER, we had gone to just a few days before, we went farther out into the suburbs to an ER in the same hospital system, but with no wait time. It was a good choice because I had barely finished signing in, and they were bringing me back to be seen. Of course, it may be that I simply looked that sick by that point. They ran tests, and I had a computerized tomography (CT) scan, and they found that while I had a UC flare, I had also developed an abscess and a pocket of infection inside my right glute area. I was scheduled for surgery the next day.

After my surgery, the general surgeon came to talk to me about my UC. In cleaning out the infection, he saw how damaged my large intestine was and suggested I consult with the colorectal surgeon. It was then that I first heard about the possibility of removing my large intestine. I only had two questions about the surgery: would I be able to play softball afterward, and would I be able to go snorkeling? The surgical resident knew that I would be able to return to softball and then made sure to find out about whether I could snorkel (it turns out, you can). I was directed to follow up with my gastroenterologist, and I had an appointment with him two weeks after leaving the hospital. While I was still thinking about what the surgeons had told me, my gastroenterologist became very animated when he found out I had consulted with the surgeon, and he seemed upset about it. He thought it was premature for me to consider removing my intestine as there were medications for UC that we had not tried. His concern for me was evident in his tone of voice, and he spent a lot of time with me at that appointment, talking through non-surgical options.

Over the next two-plus years, I developed a pattern of trying a new medication, thinking it was working, and then starting to flare and developing an infection. With each new medication, I had renewed hope that this one would be the one that would work for me. My gastroenterologist explained his strategy of trying promising medications that used different mechanisms for treating Ulcerative Colitis. Each time I would get so sick and feel dehydrated, I would need to go to the hospital, where they would diagnose me with an infection and put me on IV antibiotics along with high doses of steroids. Throughout this time, my body was constantly being ravaged not only by the flares and infections but then additionally by the steroids and antibiotics. After being hospitalized in March of 2020 and again in May of 2020, I decided to have surgery to remove my large intestine, thus ending my battle with Ulcerative Colitis in July of 2020. I then spent much of the pandemic recovering from this major surgery.

The Stigma of Gastrointestinal Illness

Some challenges come with dealing with a chronic intestinal illness. When you try to explain that you are not feeling well, you do not feel free to say what is wrong. Bathroom habits are just not considered appropriate for polite conversation. The stigmatizing nature of a gastrointestinal illness forces one to engage in "covering." As described by Goffman (1963), covering is intended to move attention away from a stigma to facilitate further interaction. In my efforts to cover, I generally referred to my problem as an issue with my stomach rather than more accurately referring to a problem with my colon. I couldn't hide that I was feeling ill, but I could make it less stigmatizing by referring to my illness as a stomach problem. My experience with Ulcerative Colitis is echoed in the autoethnographic account of dealing with an acute UC flare-up presented by Moore (2012). In particular, Moore's account highlights the efforts made to "cover" one's invisible disability and the challenges that came with claiming an illness identity when one's disabling illness is not visibly apparent. These same themes are echoed in Defenbaugh's (2013) account of Inflammatory Bowel Disease disclosure.

Ulcerative Colitis (UC) is very much an invisible disability. It wasn't until I had the surgery and finally felt recovered that I realized the toll the constant illness had taken on me. I thought I had times when I felt "fine" between the hospitalizations but feeling "fine" is relative. Before surgery, feeling fine was still not having much energy. However, after surgery, I felt a rush of real energy both from surgery and from being free of medications.

Despite my newfound feeling of health, I still find myself covering when it comes to the aftermath of surgery. As I was preparing for surgery, I made arrangements for a colleague to cover as department chair for when I was expected to be in the hospital. While my colleague was incredibly supportive and willing to assist as long as needed, I felt some pressure to return to work as soon as I was out of the hospital and even while recovering in the hospital. I had been encouraged to consider taking medical leave, but I knew I did not have enough sick days accumulated to continue to be paid during such a leave. Returning to work so soon came about partly because of the need to prove I did not require a medical leave that would have created a financial hardship for my family. I also felt the need to prove that surgery was the best decision and that I felt better even while still being treated in the hospital. So even when undergoing major surgery designed to cure my chronic illness, I was still "covering" so as not to betray the extent of my illness.

Invisible Disability & Microaggressions

Microaggressions are defined as "the brief and commonplace daily verbal, behavioral, environmental indignities, whether intentional or unintentional, that communicate hostile, derogatory, or negative racial, gender, and sexual orientation, and religious slights and insults to the target person or group" (Sue 2010:5). Studies of microaggressions have focused most often on race, gender, and sexuality as the identities of individuals who experience microaggressions, and several studies have looked at intersectional identities and microaggressions. Still, very few studies have included disability as one of the intersecting identities (Olkin, Hayward, Abbene, and VanHeel 2019). Many studies on these other identities identified categories or themes microaggressions with some variability in both the number and content of themes depending on the identity being examined (Sue and colleagues 2007, Shelton and Delgado-Romero 2011, and Capodilupo and colleagues 2010).

In terms of microaggressions against persons with disabilities, Olkin and colleagues (2012) found support for twelve domains of microaggressions. This work supported the ten domains previously identified by Keller and Galgay (2010) and added two new dimensions. Of these twelve domains microaggressions, the ones most relevant to my experiences are that someone downplays the effect of disability on your life and that disability is discounted by others based on looking healthy or young. These domains capture the invisibility of chronic illness and the covering that goes with it. In particular, many study participants described experiences with others

who did not understand fluctuations in disabling conditions. For example, a person might walk fine one day and need an assistive device on another day (Olkin and colleagues 2019). For someone with an invisible chronic illness such as Ulcerative Colitis, the fluctuations often meant being active and fully present at some events on some days and being unable to leave the house on other days due to gastrointestinal issues flaring.

Workplaces are generally not well suited to the needs of an individual with a chronic gastrointestinal illness who might need to access a restroom quickly and frequently. My own experiences often involved trying to promptly locate a bathroom empty of others so that I could try and have some semblance of privacy when my illness flared (again, an attempt at covering). Other times, I had to pause a lecture or leave a meeting abruptly to use the nearest facilities. While many colleagues over the years were very supportive and understanding, others questioned the extent of my illness. For example, a colleague pressured me years ago to change a doctor's appointment with a gastroenterologist to hold a committee meeting. The colleague did not believe my doctor's appointment was necessary enough to keep the committee from meeting at that particular time, even though I provided plenty of other available times for the meeting. Having such experiences at work led to anxiety over how others might perceive my need to reschedule meetings or step out of meetings due to flares.

Anxiety is expected when battling a stigmatizing chronic illness that affects your gastrointestinal system. It isn't easy to make plans and, especially, to keep plans. You never know when you might start flaring or when you might urgently need a bathroom. Schneider and Fletcher (2008) found that anxiety was a common reaction among young women with inflammatory bowel disease or irritable bowel syndrome. Taft and colleagues (2011) further demonstrate that perceived stigma is connected to anxiety in persons with Inflammatory Bowel Disease. Thus, managing stigma and anxiety is vital to the chronically ill's lived experiences.

Positive Side of Virtual Access

Even before I had the surgery, the pandemic brought about a newfound freedom. With the move to working from home, all of the issues I previously had with using a public restroom faded away as I could attend meetings and offer my classes without the anxiety of navigating stigmatizing gastrointestinal matters in public spaces. Given the downward slide of my illness over several years, not surprisingly, I was in the hospital at the time when the pandemic started to spread in the United States. I had been hospitalized

with yet another flare and infection. I was in the same hospital as the first hospitalized covid case in the local area in March 2020. All of the patients were reassured that the covid patient was being housed in a space with negative pressurization, so there would be no spread to other areas of the hospital. After about five days, I was able to go home. As the pandemic grew in scope and places began to close, I found that I was being called to even more meetings, all now being held virtually. It didn't matter how I felt that day with a virtual meeting. I could be at work while still in bed. I could turn my camera off and use the restroom as needed, and no one would be the wiser. I could more fully participate in meetings that I previously struggled to attend.

As life moved into virtual spaces, one of the realizations that I had was that virtual access made events accessible. At universities, we often plan events to be in person and assume attendees will be there. Sometimes an event is recorded, but the norm is the expectation of in-person attendance. With the pandemic, the expectation changed to virtual attendance, and we found that we could connect with others even when not physically in the same space. We found ways still to hold events through zoom and other online platforms. In doing so, we found ways to include people who previously missed the event due to challenges in coming to a physical location at a particular time.

In terms of my experience, had my illness spiraled downward at a point in time where people were not forced into virtual engagement, I likely would have been required to take extensive medical leave. I would have been excluded from many events. While my illness was neither caused by nor even exacerbated by the pandemic, the experience of living with an invisible. chronic, disabling condition unfortunately, resonate for long-haul Covid sufferers or even those who have seemingly recovered from Covid. We are now beginning to recognize the extent of the impact Covid may have on the incidence of disabling conditions in the larger population in the pandemic's aftermath.

Initial studies examining the long-term effects highlight the potential for many chronic conditions that could result in some level of disability for impacted individuals (Higgins, Sohaei, Diamandis, and Prasses 2021; Leaung and colleagues 2020). By looking at long-term outcomes from other coronaviruses coupled with early data on health outcomes with covid-19, these studies find potential long-term effects in many body systems, including respiratory, cardiovascular, immunological, gastrointestinal, and others. Thus, there is the potential for a significant increase in the number of individuals managing chronic, disabling illnesses in the wake of the Covid-19 pandemic. While this paper focused on experience with Ulcerative Colitis during the pandemic, there are implications for research on invisible disabilities and living with a disability more generally. In particular, stigma can be reduced for the chronically ill and disabled by providing access to events outside of just face-to-face attendance in a physical space.

One of the lessons that can be learned is that we can manage a combination of virtual and real-world engagement in ways that would allow the full participation of those with disabilities. Even as inperson events return, we can still retain the virtual engagement that would allow the full participation of those who face challenges in being physically present in a space. Dichotomizing events as face-to-face or virtual fails to recognize the possibilities for greater engagement of individuals with disabilities in spaces and events by combining physical and virtual access. For those individuals living with disability and those whose ability to participate in events is impacted by the long-term effects of Covid-19, providing virtual events in conjunction with face-to-face events will offer greater accessibility while alleviating the pressure to cover or disclose one's illness. While there will be challenges in planning events to include both in-person and virtual access, the benefits of expanding accessibility are significant. Once providing virtual access becomes normalized, it will no longer feel like an added burden with planning an event but an expected part of the process and one that would be welcomed by people with disabilities and disabling conditions.

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Author Biography

Gretchen Peterson is a Professor and Chair of Sociology at the University of Memphis specializing in social psychology, the sociology of emotions, and the sociology of sport. Her work has appeared in the *Handbook of the Sociology of Emotions*, *Sociology Compass*, and *PLoS ONE*. She has been a lifelong athlete having played softball for 40 years. For the past 15 years, she has managed both work and leisure while living with an invisible chronic illness. Her current research utilizes her own autobiography to understand how intersecting identities impact experiences with chronic illness.