You Poor Thing: A Retrospective Autoethnography of Visible Chronic Illness as a Symbolic Vanishing Act

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Abstract

In this autoethnography, I outline a framework for understanding illness as deviance, contextualizing general sociological theory on sick role dynamics to the specific case of chronic conditions that manifest with visible physical differences. I demonstrate two distinct ways in which chronic conditions can foster labeling and stigma. First, I explore how social norms can result in sanctions for showing physical evidence of chronic conditions. I describe sanctions I have experienced for violating conventional ideas about youth and female beauty, and associated behavioral expectations. Second, I explore how double jeopardy can result from failing to meet usual social expectations for sickness. I describe sanctions I have experienced for violating ideas of what abilities a person with a chronic illness should possess, and how they should behave in relation. I conclude by illuminating how normative social discourse can simultaneously sensationalize and efface people with visible chronic diseases.

Keywords

Chronic Conditions, Illness Management, Presentation of Self, Deviance, Autoethnography

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Acknowledgements

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In this autoethnography, I outline a framework for understanding illness as deviance, contextualizing general sociological theory on sick role dynamics to the specific case of chronic conditions that manifest with visible physical differences. I demonstrate two distinct ways in which chronic conditions can foster labeling and stigma. First, I explore how social norms can result in sanctions for showing physical evidence of chronic conditions. I describe sanctions I have experienced for violating conventional ideas about youth and female beauty, and associated behavioral expectations. Second, I explore how double jeopardy can result from failing to meet usual social expectations for sickness. I describe sanctions I have experienced for violating ideas of what abilities a person with a chronic illness should possess, and how they should behave in relation. I conclude by illuminating how normative social discourse can simultaneously sensationalize and efface people with visible chronic diseases. Keywords: Chronic Conditions, Illness Management, Presentation of Self, Deviance, Autoethnography
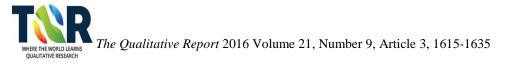
While working on an autoethnography of my psychosocial experiences surrounding drug therapy (Nowakowski, 2016, forthcoming), I included examples of how instrumental resources for illness management can become sign equipment for the social roles associated with chronic disease itself. I wrote about how even though I experience constant pain whenever I need to sit on a hard chair, I refuse to carry an orthopedic cushion because I feel it would fundamentally change the definition of my situation (Goffman, 1959) in the eyes of others by changing how they understand my circumstances and what appropriate ways to respond to those circumstances might be. If my body shows visible evidence of disease but I carry no corresponding sign equipment that tells others I am sick (Goffman, 1959), I control a portion of the narrative people formulate before getting to know me. This guidance occurs via omission rather than commission, but constitutes a form of impression management nonetheless.

As I got deeper into this discussion, I quickly realized that this topic was better suited for an entirely separate autoethnography – one dealing explicitly with how representations of chronic conditions are formed, and how these representations often reproduce structural inequalities. I set about exploring in detail how others perceive me from visual information alone, and how I negotiate those perceptions as a medical sociologist with an intractable chronic disease. I began to delve into the perpetual misperception of me as a frail, ineffectual outsider to the carefree vitality of young adult life. In this paper, I examine these experiences and observations using sociological theories of identity, presentation of self, and role expectations.

Background

Autoethnography is the study of the self as subject through critical analysis of lived experience (Ellis et al., 2011). In the late 1980s, social scientists began embracing autoethnography as a legitimate and valuable method of empirical research (see Riley, 1988; Berger, 1990). The value of autoethnography for interdisciplinary social science stems

primarily from its ability to capture unique dimensions of the social world and interactions within it (Ellis et al., 2011). For these reasons, established scholars have increasingly encouraged their junior peers to conduct reflexive qualitative inquiry in domains of experience to which they feel personally connected (Anderson, 2006). Likewise, autoethnography addresses issues of bias via explicit emphasis on standpoints. Because researchers conducting autoethnography can never fully "withdraw from inclusion" in the phenomena of interest, they must instead critically analyze the meaning and value of their insider status, as well as potential drawbacks introduced by inclusion in their own study populations. Murphy (1987) operationalized this balance between insider status and critical inquiry in research on embodied health.

As a methodological approach, autoethnography indeed offers unique insights into key processes in health and well-being. Rier (2000) speaks to the importance of autoethnography as a means of incorporating diverse perspectives into research on health. Autoethnography can contribute data that would otherwise remain uncaptured because it gives voice to the experiences of patients themselves (Rier, 2000). Liggins et al. (2013) note that autoethnography also offers a means of reconciling multiple perspectives that a single individual's experiences offer if they are both a user of health services and a scholar of same. Although many early autoethnographies of health addressed acute illness experiences, scholars of health have increasingly used autoethnography to critically analyze processes and outcomes in chronic illness (Karnilowicz, 2011). As an interdisciplinary sociomedical science researcher living with persistent autoimmune disease, I count myself among their number.

As a critical medical sociologist interested in the intersectionality of different social locations and how these intersections shape lived experience of chronic illness, I also acknowledge the value of autoethnography for affirming the voices of marginalized populations. Feminist standpoint theorists have long championed the importance of actively giving voice to populations of which scholars are themselves members (Biber & Leavy, 2007). As an academic researcher who is female, genderqueer, and disabled I occupy multiple marginalized social locations, as well as several privileged positions that enable me to establish a voice for myself and others through scholarship. Using autoethnography to achieve this voice provides a valuable tool for analyzing not only my own experiences of privilege and disadvantage, but also the likely social locations of others and how they may shape interactions that I myself experience.

The social context of health and illness stems from multiple intersecting cultural and societal systems that condition responses to differences in appearance and functioning (Conrad & Barker, 2010). In operationalizing both experiences of and responses to chronic illness, sociologists have thus used autoethnography to illustrate both embodied elements of disease processes and symbolic meanings attached to these experiences. Founding symbolic interactionist Goffman (1963) demonstrates how stigma arises in social responses to visible evidence of disease, then becomes internalized as identity over time. Interactionist research on health has since evolved to include autoethnographic inquiry. For example, Wilbers (2015) gives examples of the utility of autoethnography for understanding both components of life with chronic pain, and the role of stigma in connecting the two.

In understanding stigma, multiple scholars have also noted that painful conditions may receive especially strong judgment because of the invisible nature of pain itself (Crooks et al., 2008; Glenton, 2003; Holloway et al., 2007). Likewise, the visibility of the body and its apparent anatomy shape social expectations for behavior from an early age via exposure to norms such as gender performance (Martin, 1998). This includes behavior related to illness management in general (Charmaz, 2000) as well as disability (Crooks et al., 2008) and pain control (Wilbers, 2015) specifically. The intersection of illness behaviors and experiences with multiple social roles, and associated conflicts between the obligations of patients and those of

other identities, have also been emphasized in critical autoethnography of chronic illness (Strunin & Boden, 2004). The visibility or invisibility of particular symptoms often constitutes an important focus in autoethnographic research on chronic disease because it conditions social responses to bodies of people with specific health conditions, and the expectations that people often form about these bodies.

An area that remains relatively unexplored in social science inquiry on chronic illness, however, is the simultaneous hypervisibility and invisibility of *the body itself*. Extant research, autoethnographic and otherwise, often dichotomizes elements of the illness experience into visible ones represented by the body and invisible ones represented by the mind. Yet in an abstract sense, the body itself can become erased by stigmatizing social responses as surely as the emotions contained within it can. Scholars have written extensively on the effacement of identity, of suffering, and of legitimacy that often occurs in the experience of chronic illness. The same core elements of illness stigma that can erode the abstract elements of personhood—judgment, discrediting, mockery, ostracism—can do so not only by conveying that bodily experiences are somehow imagined or fabricated, but also by implying that the body itself is not really there at all. I thus use autoethnography to explore the relationship between hypervisibility and invisibility in the experience of chronic illness via critical analysis of my own life history.

Methods

Type of Inquiry

I used qualitative autoethnography to explore social responses to people with visible chronic illness and their bodies. In using this methodology, I built on a rich tradition of qualitative inquiry in the illness management literature as described by Charmaz (2000). As recommended by Bury (1991), I also incorporated personal biography to capture the unique analytical value of lived experience. To perform critical analysis of my past experiences, I used a narrative approach. Using narrative inquiry conferred three distinct advantages: (1) establishing a unified voice for myself as both scholar and patient; (2) illustrating biographical developments and transitions in the experience of chronic illness; and (3) contextualizing critical interpretations of social interactions as my own perspectives rather than objective truth.

Participant Engagement

This study is fundamentally an "oral history," which means it is purely retrospective and was done through critical reflection on lived experience rather than planned research activity. It was exempt from IRB review for this reason, etc. Because it is not considered human subjects research, the standards for confidentiality in reporting are different from those for many other types of studies. Specifically, there was never a link in the first place between any of the people described in this manuscript and participation in research because this was not considered to fall within the scope of formal research activity. Consequently, it would be impossible to identify any of the individuals described in the manuscript because there are no records of participation. As such, some descriptions of individuals' likely social locations are included here for purposes of contextualization and attention to intersectionality. This approach also increases the theoretical rigor of the manuscript by creating opportunities to incorporate theory from multiple subfields of qualitative sociology, and reduces reliance on firsthand understanding of interactions in favor of evidence-based frameworks for critical inquiry.

Data Collection

Because this study is an oral history, no prospective data collection was conducted and the inquiry was not considered to be human subjects research. Oral history is one of the accepted methodological approaches for conducting autoethnography (Ellis et al., 2011). It is specifically useful for research on the social context of chronic illness because it can capture both the complete scope and the complex nuances of lived health experiences. Like Rier (2000), I compiled my data for this autoethnography through critical reflection. I began by taking written notes on my own life experiences in a relatively inductive manner, focusing on capturing multiple dimensions of my personal biography as opposed to only those experiences speaking to a specific research question. I then began to weave in ideas about how to use interdisciplinary social science theory and empirical evidence from other published studies, and in so doing identified clear lines of inquiry that I could follow in my field notes to develop a research topic. These conceptual questions are articulated in the ensuing section detailing analytic approaches.

Data Analysis

To analyze my field notes, I used a grounded theory approach incorporating content analysis with open coding. As described by Charmaz (2006), this process involves grouping observations into thematic categories based on shared content. While grouping specific content elements from my notes into major themes, I also began to pair each thematic category with notes on key theories and publications that would facilitate critical analysis of case examples in particular groups of observations. These thematic categories formed the central structure for my results section, the presentation of which I detail in the concluding content of this methods review.

To ensure rigor and trustworthiness in my critical analysis of the field notes I compiled from lived experience, I used two complementary approaches. First, I consulted the literature on autoethnography for guidance in framing my interpretations of life events as both enriched by the incorporation of personal perspective and inherently limited by the inclusion of only one person's read on a particular interaction. The literature suggested that I should actively embrace the unique parameters of autoethnography as part and parcel of its distinct value for social science inquiry on health (Murphy, 1987). I also heeded recommendations from Liggins et al. (2013) to reflect explicitly on the different but interrelated contributions my experiences as a patient and scholar might make to my analytic perspective. Second, I solicited critical input from colleagues and other peers in the field who specialize in qualitative research, ethnography, and specifically autoethnography both within and outside of health sciences disciplines. I asked my colleagues to critique my analyses of each interaction detailed in the manuscript, and to contribute their own evidence-based perspectives on how intersecting social locations and norms shaped the dynamics of each case example. Synthesizing these interrelated but distinct perspectives from content experts greatly enriched my analyses, and enabled me to comment meaningfully on potential shortcomings of my biographical perspective.

Presentation of Results

To maintain a rigorous and evidence-based approach to data analysis and reporting, I organized my observations into thematic categories reflecting major concepts in critical interactionist analysis of illness experience. I used seminal publications from symbolic interactionism and medical sociology literatures to ground my framing of key themes and allow my work to contribute to a global body of scholarship on social responses to chronic illness. I

focus extensively on social norms associated with the sick role (Parsons, 1951) and the associated concept of illness as deviance (Twaddle, 1981) as well as how these social constructions of illness contribute to stigma (Goffman, 1963). In the process, I weave in literature from a variety of interdisciplinary sociomedical disciplines to compare and contrast with conclusions from my own case examples. Within each section of the results, I explore how the intersecting social locations of both myself and people with whom I interacted may have shaped each exchange and its consequences. In the process, I note the inherent limitations of reporting a single person's perspective on life events. To minimize the impact of these limitations on the integrity of the research presented, I explicitly focus on reporting only what I saw and perceived—and how my own socialization likely led me to perceive it—rather than attempting to define other people's identities or relay their own biographical narratives.

To this end, I utilize gender neutral pronouns to refer to strangers so as not to make assumptions about their gender identities. In APA style, which is the current standard for publications in TQR, the preferred gender neutral pronoun is "they" and its conjugated forms. In a similar fashion, where possible I refer to appearance (i.e., male-appearing, female-appearing, etc.) rather than seeking to place strangers into identity categories based on my impression of their appearance. These practices both reflect current methodological conventions in autoethnography (Ellis et al., 2011) and affirm the agency of other people (see Biber & Leavy, 2007). As this manuscript deals principally with perceptions of agency and value directed towards people with visible chronic health conditions, employing inclusive language was a core emphasis from the start.

Findings

Social Expectations and Self Presentation

People who have only spoken to me on the telephone generally appear surprised when meeting me for the first time. I talk a lot, and tend to do so with a high level of confidence. Having grown up deeply involved with performing arts, I still treat my world like a stage a lot of the time. I behave gregariously, speak loudly, and rarely feel embarrassed or awkward even if people stare at me. Yet just as the magic of many stage productions shatters if the "fourth wall" (Goffman, 1974) between audience and performers gets broken, so too does my self-assurance quickly shift when my boundaries are breached. Even after 31 years of living with my disease and its pervasive consequences, I still doubt I will ever grow accustomed to having my personal space unapologetically invaded by strangers who treat my body and health as their business.

People frequently express surprise upon meeting me in person because I am not what they expect. The voice they hear on the telephone – by all accounts a convincing incarnation of strength and social dominance – rapidly breeds cognitive dissonance when contrasted with my appearance. Festinger (1957) defines cognitive dissonance as a disconnect between expectations and experiences, and something that commonly occurs when appearances and behaviors seem to conflict with one another. I have no illusions about looking just like everyone else, though I do make some attempts to "pass" (Goffman, 1963) as a healthy person. At 5 feet 4 inches and 85 pounds, this is difficult at best. I do not wear makeup to hide the circles beneath my eyes or the veins visible through my skin. On good days, that skin appears dry and rough; on bad ones, it flakes like snow before cracking into painful fissures. My cheeks sink inward toward reconstructed gums, grafts upon grafts to repair years of damage. My joints are the biggest parts of my limbs; my ribs are visible even through my back. My hands and feet are mottled purple and white with the telltale pattern of Raynaud's syndrome, a condition common

in people with autoimmune diseases that arises from damage to blood vessels and nerves in the hands and feet. My fingers feel cold to the touch on hot Florida days.

Yet still I feel a sense of ownership – this body is mine, my liberator as much as my captor. When I look in the mirror, I do not focus on the visible bones and tendons, the white patches on my hands, or the black circles beneath my eyes. What I see first is a happy and thriving person, a survivor eager to enjoy each day. But these things that seem so ancillary to me are what many others see first, and comment on. Anything different can be read as deviant, and elicit a corresponding response. It often does not take long for people to ascertain that I am ill and produce some variant of the socially accepted response: *you poor thing.* In a moment I am reduced to subordinate status, a fragile paper doll in the hands of a clumsy customer.

So what am I, if not utterly lacking in strength and agency? I have already told you that I live with a chronic inflammatory disease, and I find it hard to imagine that a fragile or weak person would have lasted long in my world. I lived for many years with chronic pelvic pain that became so agonizing I seriously questioned my will to live. I had diarrhea constantly, and with it the constant fear of not being able to make it to a bathroom in time. I watched my life slip away between my fingertips for years, getting piecewise insights about this organ or that as I visited specialist after specialist. After 24 years of struggles and false starts including four hospitalizations and half a dozen exploratory surgeries, I finally got diagnosed with "non-specific mucositis." This is an ornate way of saying that my mucous membranes are always inflamed, for reasons yet unknown, and prone to attacking themselves. I share many symptoms with people who have better-understood inflammatory and autoimmune conditions, such as Crohn's disease and cystic fibrosis. But as a sociologist, I also understand that all labeling is ultimately boundary work, a practice of drawing distinctions between perceived groups and ascribing meaning to these differences (Goffman, 1963) that obscures the tremendous commonality of experience among people with chronic conditions.

My comprehensive diagnosis certainly came as a relief, in part because it helped me to resolve the inchoate feelings that Karp (1996) notes often come with knowing something is wrong but not being able to give it a name. More importantly, diagnosis ostensibly gave me legitimacy as described by Link and Phelan (2013). This legitimacy would have come from claiming the social benefits of the sick role, defined by Parsons (1951) as a specific set of privileges and responsibilities that come from having a medically recognized illness. After years of alternately being chided for not seeking enough medical care and accused of "faking it" for claiming to be sick while continuing to work, I hoped that achieving a conclusive diagnosis that captured all of the specific issues identified by previous physicians would afford me some respite from constantly being expected to prove my condition.

Yet as Glenton (2003) points out, expectations for patient behavior still follow the Parsonian ideal quite closely. Specifically, people with chronic conditions are often expected to perform illness by occupying purely passive and subordinate roles. Those who maintain active professional lives and/or adapt to functional limitations are frequently accused of overplaying their symptoms to receive attention, or even suspected of having mental illnesses. Life after diagnosis would quickly demonstrate the wisdom of Glenton's (2003) insights. Contemporary sociologists have critiqued the sick role concept as a suboptimal model for explaining the behavior of people with chronic conditions both generally (Segall, 1976) and in the context of diverse life circumstances (Cockerham, 2007). Burnham (2012) has spoken of its growing irrelevance and even "death" in the context of current health care landscapes. But my own interactions with intimate partners, work colleagues, casual acquaintances, and even family members suggested otherwise.

Illness as Deviance

My own experiences showed me that while those who study the social construction of health and illness may have moved away from the sick role (Burnham, 2012), people often draw implicitly on these constructs in responding to chronic disease. In a general sense, people frequently respond to the illness itself as a form of social deviance. More specifically, they often respond to specific performances of sickness as either deviant or normative. Merely occupying the sick role does not suffice; one must perform it consistently, precisely, and without objection in order to access its purported benefits. Nearly six years post-diagnosis, I have thus come to understand the notion of illness as deviance in binary context, building on Gerson's (1967) assertion that illness proves problematic in social context because it violates notions of acceptable identities and behaviors. . Interactions with people I have not previously met frequently illustrate the two distinct levels of deviance I occupy as a person with chronic disease. First, I live with an incurable chronic condition that introduces significant functional limitation as well as changes in physical appearance. I thus defy usual social expectations for human beings in general and young people specifically. Second, I challenge stereotypical notions of what people with such conditions are like – how we live, how we behave, how we feel, and how we maintain independence. I thus defy social expectations for people with persistent chronic health conditions, both globally and in specific social locations.

The first level of deviance I negotiate is the overall framing of illness as deviance from the usual social expectations I face, both generally as a member of contemporary American society and specifically as a relatively young person who appears female. I deviate from normative expectations of youth and perhaps even "successful aging" (Rowe & Kahn, 1997). I did recently turn 32, but have welcomed this quantitative evidence of aging as a sign of progress and triumph. It is difficult for me to see 32 as anything but a glorious achievement when at 23 doctors told me I might not live to see another sunrise. This contrasts with norms described by Calasanti and Slevin (2001) that frame aging in females as a process of declining social value. Moreover, the concept of successful aging itself includes elements of ableist bias (Minkler & Fadem, 2002) as well as race and class representations (Dillaway & Byrnes, 2009). While I cannot necessarily do all of the physical tasks that my age peers without functional limitations can, I consider myself to be aging successfully because I enjoy my life on a daily basis, and feel that my body allows me to do those activities that are most important to me.

As a sociologist of health, I simultaneously affirm and analyze my ostensible resistance to ageist concepts of beauty and relevance. On the one hand, I absolutely see age norms as arbitrary, socially constructed, and counterproductive. I echo Holstein and Minkler (2003) in calling for a society in which people can define "successful aging" on their own terms. Proactive coping with the sequelae of chronic disease offers one way to do this (Ouwehand, De Ridder, & Bensing, 2007). I frequently use this strategy by searching for ways in which my own experiences can enrich my academic work and community engagement, and in the process shine a bright light on how my health experiences have aged me inside and out. On the other hand, I can easily pass for much younger ages, and may thus not understand how it feels to be personally subjected to negative messages about growing older. While shopping for housewares at the start of a new academic term, I was asked by a doting cashier, "Oh sweetie, is this your first time in college?" I responded that "actually, this is my second time in grad school." This gave the cashier a good laugh. However, the moment gave me pause because it revealed finer nuances of how others often read my visual appearance, both generally as a young female and specifically with respect to my chronic disease. I am at once rewarded and rebuked for not looking as if the challenges I have weathered have aged my body.

Likewise, the fact that I am young simultaneously refutes and entrenches the notion of myself as a frail invalid. I routinely get told that I do not look my age as if this were a

compliment, illustrating the marginalization of aging females described by Calasanti and Slevin (2001). While I try not to dwell on these moments, I cannot shake the feeling of deep insult they engender. I have worked hard for every minute of these 32 years of life, counted each new day as a victory since that night seven years ago when I almost lost everything. If the youthful appearance of my face empowers me socially, this power is pyrrhic at best because it diminishes both other females and my own accomplishments in illness management.

Even if this empowerment were genuine, it would still be harshly tempered by the infantilization that my appearance from the neck down yields. We live in a society that simultaneously prizes and ridicules extreme thinness, hammering people with morally charged messages about weight loss and control (Bordo, 1993) while framing bony bodies as weak and powerless (Dworkin, 2003). These social narratives and controls manifest firmly along gendered lines: the ideal female or woman is as submissive as she is slender (Starkie, 1995). She graciously accepts the "help" offered by larger and/or male-appearing people, paying no mind to the fact that these actions often reproduce harmful expectations that physically small females cannot take care of themselves or live independently.

I think about this every time I purchase groceries. It is standard procedure in some Florida supermarkets for grocery baggers to ask if shoppers would like assistance loading groceries into their cars. I quickly learned that it is also standard procedure for baggers to harangue shoppers with smaller bodies if they politely refuse this assistance. These experiences are also common for wheelchair users (Cahill & Eggleston, 1995), older individuals (Markle-Reid & Browne, 2003), children (Cahill, 1990), and other people perceived as fragile and lacking in independence. These assumptions frame people with visible chronic conditions as "open persons" (Goffman, 1963) whose bodies are considered public domain for invasive questions and touches as well as unwanted aid. Because my body conveys both frailty and youth, I am infantilized intensely and often aggressively when attempting to complete common activities. In some cases I have had to assert four or five times that I neither require nor desire help. On one particularly memorable occasion, nothing short of me asserting that "no means no" would suffice for the bagger to release my cart.

In such situations, the obvious parallels with rape scenario dynamics described by Kitzinger and Frith (1999) have not necessarily ended with words. In the process of aggressively pushing "help" that would actually be anything but, grocery store employees of multiple genders have taken it upon themselves to touch me physically, as if my thin body either cannot be trusted to carry heavy bags or must be sanctioned because it *can* be trusted to do so. Visibly ill people are often expected to perform their diseases quietly and passively, with a sort of cheerful bravery in accepting their lost agency (Charmaz, 1983). Often the "quiet pride" (Davis & Magilvy, 2000) of surviving chronic illness gives way to something more sinister: the stoical repression of all negative emotion, effacing not only the evidence of disease but also people's autonomy in responding to its indignities.

Recently I was reminded of this dynamic while returning from an academic conference. I connected through a busy metropolitan airport, with limited time to board my next flight. Given that the first priority when I disembark from an airplane is generally finding a bathroom, I set about doing so immediately upon exiting the jetway. My agitated expression and rapid searching of all nearby gates signaled to another deplaning passenger that I was obviously a flummoxed teenager unfamiliar with airports and searching for my next flight, which I had already located. The passenger, a male-appearing person with graying hair, placed a hand on my shoulder. "Miss," they said with an air of syrupy condescension, "just so you know, when you come out of an airplane and need to find your next flight, you'll want to look at the screen right in front of the gate. They always have all the departing flights listed there. You looked like you were confused and not very familiar with airports, so I wanted to make sure I took the time to help you."

Upon learning that I was not completely naïve about travel, but rather desperately seeking a bathroom and distinctly unappreciative of both the patronizing tone and the unwarranted physical contact, the passenger looked at me as if my need of a lavatory were both disgusting and inconvenient to their world view. They did not react to learning that I had a chronic bowel disease by showing either embarrassment over their assumptions or concern for my well-being, but rather by labeling my body as deviant rather than compliant. Link and Phelan (2013) note that this process of labeling often leads to stigmatization. Drossman and colleagues (1988) explored the widespread experience of stigma among people with inflammatory bowel diseases. The fact that 84 percent of people in a recent study (Taft et al., 2009) of the psychosocial impacts of these conditions reported perceived stigma suggests that this problem is no less pervasive today.

I felt acutely aware of this stigma while attempting to negotiate the interaction at the airport. In a single awkward moment, it seemed as though I had gone from a sexualized teenager inviting unnecessary touches and patronizing flirtation to a sexless incubator of disease, not merely undesirable but outright revolting. The slenderness that seconds ago had signaled youth and innocence now communicated the ravages of unchecked illness, and the potential for me to drain the vitality of those with robust health. Stigma did confer a unique advantage in this situation: An unwanted touch was retracted, never to happen again. Cole (1975) describes a general social tendency to desexualize people with chronic, disabling conditions. Such desexualization may have shielded me from further violations of my physical space, because touching me was no longer desirable. But as I settled in at the gate and fished around for my boarding pass, I felt the scorn of several pairs of eyes. This experience illustrated the ways in which the first level of deviance quickly gives way to the second as interactions progress.

Social Closure and Sanctions for Unexpected Behavior

The second level is the framing of any behavior that does not conform to sick role expectations as deviant, and therefore subject to sanctioning. Cole (1975) notes that infantilizing behavior is common in social responses to people with visible diseases and/or disabilities. As an 85-pound adult who appeared to be searching for something in the airport terminal, I was automatically infantilized by people who thought I could not find my connecting flight without help. Even though chronic gastric malabsorption says nothing about my intellectual capacity or practical knowledge of how to navigate airports, the aesthetic consequences of this condition seem to lead people to assume that I have no physical or executive functionality whatsoever. When I violated these expectations – first by explaining that I had already located my departure gate and subsequently by pointing out that the other passenger's behavior was patronizing and inappropriate – people responded with judgment and revulsion to both my deviant status as described by Gerson (1967), then further sanctioned me for my failure to perform this status correctly as described by Scheff (1963).

Of the people who observed the original interaction between me and the other passenger, several proceeded to glare at me and shake their heads. The only person who did not do this – and instead cast a withering look in the direction of the person who had touched me unsolicited – was another person who appeared to be a female of Black heritage. I imagined that this individual probably knew something about being sanctioned for advocating for oneself (Collins, 1998). Given that this passenger had a much more robust frame than my own, I also wondered if they might also be well versed in people attempting to exercise jurisdiction over their body. The largest people and the smallest ones should be natural allies given the amount of liberty others often take in policing and sanctioning bodies considered outside the

mainstream, yet often become entangled in constructed opposition that frames thinness and fatness as fundamentally distinct social problems (Sobal & Maurer, 1999).

I frequently see this dynamic in action when spending time in public with my partner, a bisexual male whose body appears quite different from mine in certain ways. We are probably more similar than we are unique: they and I share an ethnically diverse heritage that includes a variety of White and Native American populations. Perhaps as a result, we have similar hair and eye color as well as skin tone. We are both of fairly average height for our respective sex groups. However, many features beyond mere genital anatomy distinguish our bodies. Though both of us identify as genderqueer and generally invert traditional notions of gender, we also physically embody a number of gender stereotypes. My partner appears physically imposing, sturdy and thick through the trunk region. They have visible evidence of traumatic physical injury – broken teeth, wasted connective tissue, dermal scars. My own scars appear only on the inside, on membranes damaged from years of unchecked allergic reactions. To an uninformed observer my partner looks daunting, whereas I look like an easy mark. People who do not know us well often read my partner as a dominant protector figure for this reason, then act surprised when I interdigitate myself between them and a potential aggressor, or otherwise indicate that I am in control of the situation.

Thinking about my physical differences with my partner sharpens my awareness of how people with smaller bodies are treated as fundamentally different creatures from those with larger ones. Being unusually physically slender because of a chronic disease only intensifies these dynamics. I actually do have a distinct preference for males with fuller figures, but not because I feel the need to be protected from physical threats. Rather, I find sturdier bodies appealing and comforting in a variety of ways. I love the soothing warmth of resting my bony frame against the supple fat and muscle of another person's body. Holding a person whose figure has not been scavenged relentlessly by disease and my own apathy about protecting it feels endlessly comforting, like kneading the dense dough for homemade bread. Other people's muscles are always new to me, burly and steadfast with layers of development on top of the sinews I see on my own frame. Yet even my own thinking reflects years of socialization, including the systemic message that I differ fundamentally from my fellow human beings with more robust bodies.

With this narrative comes the expectation that I will behave differently as a result of my appearance and the illness that sustains it. I have frequently been told that I need to "tone down" my handshake because it is "shocking" and even "scary." Invariably I have gotten this advice from broad-shouldered males in pressed suits – people who only seconds before were eagerly wringing the hands of other males, straining to show dominance by establishing the harder grip. Apparently having a hand squeezed hard by a skinny, visibly ill female means one must question one's own masculinity, rather than merely squeezing back and offering them a business card. Even though a strong handshake often helps females succeed in career pursuits (Wesson, 1992) it can also produce social sanctions, especially if the person delivering it does not appear physically strong. I suspect people's reactions to me in these situations owe equally to my female appearance and the specific ways in which my body shows the hardships it endures.

People occupying the sick role are often conceptualized as frail and perpetually exhausted, unable to muster the energy to lift their heads from a pillow, let alone attend a professional function (Cockerham, 2007). Parsons (1975) even commented on this by explaining that people whose illness completely dominates their every activity are rare. In an update and reframing of the original sick role concepts, Parsons (1975) explains that people with chronic conditions usually retain elements of their previous existence, continuing to function in spaces that accommodate them. As a result, people with chronic conditions often preserve their own self-concepts as engaged members of society rather than pursuing a

"sickness career" (Twaddle, 1981). Their responsibilities may change with diagnosis and entry into the sick role, but are not obliterated by these transitions.

Yet demonstrating the ability to sustain professional activity often earns people with chronic conditions a stern reminder that functioning in the workplace equates to not being genuinely sick. Nuttbrock (1986) points out that people with chronic conditions cannot reap the full range of benefits the sick role ostensibly confers if they do not perform it perfectly at all times. Yet often the individuals who can most benefit from the respite provided by the sick role are those who do continue to lead demanding lives that include multiple responsibilities (Nuttbrock, 1986). Professionals with chronic conditions need access to the sick role to sustain their overall functionality during times of challenge. Paid medical leave is a key resource that promotes resilience, but people may be sanctioned for using medical leave or taking supporting roles on group projects if they do not show sufficient proof of their compromised status.

Variations in Sick Role Norms

This is one area in which my class and race privileges, and the specific privileges afforded to me as a university faculty member, likely shield me from disadvantage I would otherwise experience. Mirowsky and Ross (2003) describe how privilege in some domains of social life can buffer against disadvantage in other domains, helping people cope and offsetting potential negative consequences for mental and physical well-being. . My career affords ample paid medical leave, as well as excellent health insurance for the many occasions when I require health care services. While health insurance is not necessarily a panacea for the symptoms I experience, having a strong coverage plan reduces the anxiety I feel about being able to get services when I need them. Nyman (1999) notes that this is one of the core reasons for which people often purchase health insurance if they cannot get it through their employers. Working for a medical school also ensures that I am surrounded by colleagues who possess at least a basic understanding of chronic disease and how it affects people's daily lives. Rather than sanctioning me for using too much medical leave, my colleagues actually question whether or not I use enough of it. They encourage me to take time to rest, and urge me with gentle good humor not to work myself to death. At times when I do experience particularly extreme symptoms, I also have the ability to work from the comfort of my home. I can work on writing projects or grade papers while resting in bed as easily as I can while sitting in my office.

The nature of my work, and the level of autonomy I enjoy in conducting it, affords me a luxury that few people with chronic conditions enjoy. Historically I have rarely taken advantage of this benefit, exhibiting a high level of "sickness presenteeism" even at times when doing so threatened my long-term health. Aronsson, Gustafsson, and Dallner (2000) define presenteeism as the practice of remaining at work during times of poor health. During a seemingly endless cycle of respiratory infections that unfailingly led to bronchitis and pneumonia, I stubbornly remained at work. Hansen and Andersen (2008) note that personality traits likely play a role in presenteeism, and I suspect this was true for me. Because I enjoy my work deeply and find a deep sense of purpose therein, I feel disjointed and sad when forced to stay away from campus. Hansen and Andersen (2008) also acknowledge the salience of structural pressures (Hansen & Andersen, 2008) in keeping people at work when sick. I see echoes of these influences in my own persistence in remaining at work long after I should have sought medical care. Specifically, staying at work constituted a form of "face work" (Goffman, 1967) framing me as a capable and valuable worker.

This impression management (Goffman, 1959) strategy failed spectacularly: When I developed a rattling cough, my supervisor gently informed me that I was banned from returning to work until I sought medical attention and began to recover. However, the experience did show me the level of social support I could expect from colleagues in academia. Thoits (1995)

notes that such support can play a positive role in promoting and protecting health. Sending me home was my supervisor's way of letting me know that I did not need to do the same kind of face work in the office that I did in other social spaces. My supervisor affirmed, first indirectly and later explicitly when I returned to work, that I could prioritize symptom management over presenteeism without worrying about being viewed as laggardly or expendable. Dew, Keefe, and Small (2005) note that these are common fears contributing to presenteeism.

Eventually, I got vaccinated for bacterial pneumonia so that I would not need to choose between my life's passion and my health, but when the vaccine proved insufficient to protect my lung health I continued to work through chronic bronchitis and bouts of pneumonia. My perceived ability to take time to rest when ill did not improve substantially until I transitioned into a faculty position from my previous staff one. When I got promoted into a position of greater authority and responsibility, I began to feel more comfortable exercising sick role privileges, which often come at greater cost to those in subordinate roles (Dew, Keefe, & Small, 2005). Even then, it took nearly a year before I would cave and take time off work to visit an immunologist in search of effective treatment. This resulted in me being placed on inhaled steroids that finally cleared the infections in my lungs and allowed the tissue to heal, but much damage had been done and I was left with nearly 20 percent of my lung function gone for good. The fact that I retained that much lung function after five years of chronic infections may itself owe in part to social and economic privileges I experienced along the way.

Moreover, the benefits of the sick role extend far beyond the workplace. My class and race privileges have likely also afforded me some protections in more general social situations, although perhaps for objectionable reasons. Specifically, extreme thinness is generally more accepted in higher-SES spaces than it is in lower-SES ones, and likewise more accepted in White communities than it is in Black or Latino ones (Goffman, 1963). In many cases, people in higher-SES and/or white social spaces respond with envy to the sight of a very thin body. While this gives me a certain amount of "thin privilege" that makes certain activities easier for me (Kwan, 2010), it also makes for very awkward conversations when I explain that my diet secret is a chronic disease that makes me defecate and vomit a lot. The fact that I still receive envious comments even after relaying this information illustrates how much higher-SES and White communities prize thinness (Bowen, Tomoyasu, & Cauce, 1992).

When I have spent time with people from lower-SES, Black, and/or Latino backgrounds, I have likewise experienced wholly unsolicited commentary on my weight. However, these comments have generally not reflected the envy that people of higher SES and/or White heritage sometimes express. At a Black History Month celebration several years ago, a Black person with a heavyset, female-appearing body walked up to me and said "You're so skinny, I'm getting sick just looking at you." Even though I had just been insulted, I knew better than to strike back at a heavier person. People of larger sizes often experience tremendous stigma both structurally and interactionally (Farrell, 2011). I wanted neither to intensify that stigma nor to challenge the embracing of sturdier bodies in a space where such characteristics are valued more highly. Instead, I explained that I had a chronic disease and was, essentially, skinny because I was sick. Their response immediately shifted to empathy and concern: "Oh, you poor thing. Are you feeling okay?" This person simultaneously demonstrated caring and infantilized me (Cole, 1975). Both sets of behaviors mirror common social norms about how to interact with people who have visible chronic conditions (Clark, 2007).

On another occasion, a male-appearing person who seemed to have a working-class background and White heritage walked up to me at the supermarket in a low-income community where I lived at the time. They started rambling about how unattractive my body was and how I should eat more, not stopping to think about the fact that food only has nutritional value if you can successfully hold it down and digest it. This individual went so far

as to place several grocery items in my cart before I informed them that calling me ugly would not cure the disease that made me look that way. I knew I had no further recourse in the moment. Visible chronic illness often creates the expectation to control emotions in public in order to gain acceptance (Cahill & Eggleston, 1994). Only when this person did not respond in the socially normative way – by expressing concern rather than further antagonizing me – did I dare point out that calling me ugly would not make them any prettier.

In general, the unsolicited commentary I have received in lower-SES, Black, and/or Latino spaces has taken much kinder forms: offers of home-cooked food, questions about my health, hard chairs swapped out for softer ones. While being extremely thin can present a concern in these social spaces, it is often perceived as normative for people of White heritage even if it is not embraced as an aesthetic ideal for community members of other backgrounds (Rubin, Fitts, & Becker, 2003). I have generally received more curious questions about my weight from individuals in these spaces, but also more compassion about its origins. I have also perceived fewer efforts to expose me as a fraud for having a job and going to work every day. Twaddle (1981) notes that people with chronic conditions often experience a kind of double jeopardy in being perceived as having little value if they do not work, and having little legitimacy if they do. I have found that marginalized spaces are often the safest ones of all, perhaps in part because stigmatized persons are more likely to understand the perpetual "face work" (Goffman, 1967) required to achieve acceptance from dominant groups. Schwalbe and colleagues (2000) describe a diverse array of "generic processes" that reproduce inequality across multiple social contexts. My own experiences suggest that the policing of the bodies and lives of people with chronic conditions may be one such process.

These processes necessarily invoke intersectional factors. I experience the social consequences of chronic illness in ways related not only to my disease itself, but also to the various social positions I occupy. McCall (2003) notes that complex interplay between social locations is often as impactful as individual forms of privilege and marginalization themselves.. This concept builds on Dannefer's (2003) assertion that advantage and disadvantage are not mutually exclusive, but rather coexisting in nuanced ways. My experience of chronic mucositis stems not only from the genes that created the condition, but also from the simultaneous advantage and disadvantage that I experience in everyday life. I experience my condition as a person who is female appearing, cissexed, genderqueer, attracted to people who look male, highly educated, relatively affluent, mostly White, a native speaker of English, donor conceived, and many other things. The "body privilege" I may or may not experience in specific social spaces illustrates these dynamics, as it depends strongly on a complex array of contextual factors (van Amsterdam, 2013).

Preconceptions concerning visibly ill bodies and food consumption have frequently illustrated the inherent ironies of common social responses to chronic disease. Proffered food comes with multiple social expectations of its own; sanctions invariably follow if I violate any of those. Not accepting food because I was not hungry has often led people to make a spectacle of my health issues, paralleling the sensationalization of bodies whose appearance results primarily from anorexia nervosa (Warin, 2004) and opioid addiction (Hickman, 2002). Not accepting food because I was not interested in eating a particular item has often signaled people to keep pressuring me as if I were a "fussy" child unwilling to try new foods. Not accepting food because I was allergic to one of the ingredients has often spurred people to call me "weird" or accuse me of being a hypochondriac – a common occurrence according to Coulson and Knibb (2007).

Actually accepting food brings challenges as well. I frequently receive scrutiny for what I choose to eat, how much, and at what pace. If I place a small amount of food on my plate, people often pressure me to take more and accuse me of not taking care of myself. These behaviors echo the idea that people in the sick role must make every effort to "recover"

(Parsons, 1951). These specific pressures related to my thinness seem to supersede classed and racialized attitudes about weight, focusing the message more on my perceived poor health. Thompson (1992) suggests that people often respond negatively to thinner bodies because they do not want to think about the fragility of their own health. (Thompson 1992). Just as messages concerning fatter bodies often encourage people to think that larger people eat constantly, so too do stereotypes about thinner people never eating.

Negotiating Deviant Roles and Seeking Acceptance

I have developed strategies for negotiating the stigma of visible chronic disease by adapting my eating behavior in public spaces. Over time I have learned that if I take more food than I can actually consume – thereby "passing" (Goffman, 1963) as a person without chronic gastrointestinal issues – people usually leave me alone. However, even this method is not foolproof. Sometimes employing this strategy merely results in people openly mocking me, suggesting that I am incapable of eating anything at all because I weigh so little. Pointing out that I would not be alive if I did not eat regularly rarely helps matters, especially in discourse with people whose cultural backgrounds encourage them to view thinner people as weak and/or childlike. In these instances, displaying assertive or aggressive behavior often leads to stronger sanctions due to increased cognitive dissonance (Gluck & Geliebter, 2002).

Consistent with Cole's (1975) observations, I am often mocked and infantilized more intensively on days when my physical disability is particularly apparent. On bad days my hands tremble and spasm constantly, shot through with sharp pain. Holding and maneuvering eating utensils becomes difficult, and carrying dishes often results in accidents. I negotiate these challenges by moving slowly and exercising patience with myself. One of the ways I engage in "proactive coping" (Ouwehand, de Ridder, & Bensing, 2007) is to use adaptive techniques, described by Stephanidis (2001) as specific strategies for completing tasks that minimize the impact of functional limitations. However, my ability to do this becomes limited when I need to devote cognitive resources to fending off people who attempt to "help" (Cahill & Eggleston, 1995) me by interfering, in some cases attempting to take objects away without my consent. These moments catalyze reflection on the difference between "being helpful" and providing true social support – the latter only occurs when the action taken is perceived as supportive by its recipient. Genuinely supportive action can not only affirm people as agentic, but also reduce stress and even improve adaptation to the condition itself (Thoits, 1995).

I believe I have adapted well to the demands of living with chronic mucositis. While I still experience feelings of anger, loss, and frustration at times, I view these as normal and healthy aspects of experiencing chronic illness. Charmaz (2000) describes this sense of normalcy as an important part of illness management, which can protect the mental health of people with chronic conditions to some degree. Focusing my career intensively on the study of chronic conditions in biopsychosocial context has enabled me to achieve a sense of meaning and coherence surrounding my own disease. Disclosing my own experiences of illness has allowed me to form and nurture a positive self-concept framing my condition as a unique and valuable tool for effective scholarship. Charmaz (2002) notes that improvements in self-concept and sense of control are common consequences of sharing one's story with others. Likewise, I have created stability and "order" instrumentally through proactive self-management of my physical symptoms as well as their psychosocial sequelae. Indeed, my strategies and practices for self-management illustrate many of the misperceptions that I encounter when interacting with others.

It is certainly accurate to assume that I deal with unpleasant symptoms on a regular basis: pain in various places, tremors, rigidity of fingers and toes, dry mouth, nausea, itching and burning in the mucosa, feeling cold all the time, diarrhea, vomiting, trouble swallowing,

dizziness, and the occasional fluttering sensation in my chest. Yet for me, these experiences have become normal (Charmaz, 2000) and thus no longer cause cognitive dissonance (Festinger, 1957). When I experience these events, I adapt my activities accordingly. Using adaptive techniques (Stephanidis, 2001) makes my world accessible and prevents me from feeling disabled, even though I remain conscious of my functional limitations. Learning what techniques work best – and communicating them to others who wish to provide support – has empowered me tremendously. It has done so instrumentally by facilitating my achievement of key professional goals, and also psychologically by affirming my sense of control.

This strong sense of personal control – common in higher SES individuals, and probably of great importance to me in part because of my class background (Mirowsky & Ross, 2003) – leads me to engage in health promotion activities in addition to symptom adaptation ones. I cultivate a "health lifestyle" that helps to prevent flare-ups and nurture general well-being. Cockerham (2005) defines health lifestyles as sets of behaviors that promote and protect health in multiple domains. I engage in regular physical activity such as walking, strength training, and swimming. While spending time at home, I rarely sit down, instead pacing around constantly and dancing to music. I prepare most of my meals from scratch using whole food ingredients. My diet consists mainly of fresh fruits and vegetables, and omits known symptom triggers such as coffee and eggs. I maintain an allergy-friendly home environment through frequent dusting and vacuuming, avoidance of scented products, and cultivation of houseplants. I try to get at least six hours of sleep nightly to promote healing and prevent fatigue.

Structural factors, most notably my relatively high SES and the resources I can access as a result, certainly enhance my ability to succeed in managing my condition using these methods. Likewise, actively cultivating a helpful health lifestyle both demonstrates and affirms the agency (Cockerham, 2005) that I am often presumed to lack. My physical appearance has sometimes led people to assume that I feel exhausted all the time and have difficulty opening doors, when in fact I maintain a relatively active lifestyle and generally do not require assistance with physical tasks. I have learned this because when people do learn more about my lifestyle and how I manage my condition, they often express surprise at the kinds of activities I am able to do. When this happens, I am reminded of the questions a coworker asked many years ago about what it is like to live in my body. "What is it like to be that thin?" they asked, genuinely curious. "Are you able to sit on anything without it hurting? Do you feel freezing cold all the time? How do you find clothes that fit?" Although wholly understandable, these questions highlighted the frequent assumption that visible chronic conditions foster pervasive victimization and a complete lack of normalcy.

This conversation took place several years prior to my final hospitalization and the comprehensive diagnosis that followed. But I had already lived with my gastrointestinal issues for so long that even though I was still struggling to maintain my weight, I found it difficult to imagine living in any other body. I explained to my coworker that being "that thin" just felt like being myself because I had grown so accustomed to my disease and its consequences. "You poor thing," they said, head swaying sadly back and forth, "There's nothing left of you." My coworker likely intended to convey sympathy and affirm my strength in dealing with some very challenging symptoms. These actions are often framed as appropriate responses to people living with chronic illness (Clark, 2007). However, sympathy often carries patronizing connotations that subordinate recipients (Clark, 2007). My coworker's comment thus illustrated the paradox of social responses to chronic conditions that limit physical size: a simultaneous process of sensationalization and effacement.

Conclusions

I have frequently found myself caught in a harsh spotlight that draws relentless and often cruel attention to the physical signs of my condition. I have been bombarded with the notion that there is nothing left of me, but not because I had actually been reduced to dust and air. Rather, I have received the message that nothing remains of the things that once made me human: agency, sovereignty, independence, wisdom, strength. I have lost myself both within and beyond the realm of personal identity because I have been reminded incessantly of my transgressions against others for the challenges I have endured and how I have changed as a result, then robbed of my last shreds of selfhood upon demonstrating that I am still whole. If there is nothing left of me, it is because what I do have left is repeatedly stolen, and I am often chastised for reclaiming it.

This structural marginalization, like many other forms of it, seems to be born of willful ignorance and sustained by materialistic apathy. I have learned that people with chronic conditions can become things in a literal sense, objectified and ultimately discarded. The lot of the *poor thing* is that of passive gratitude, of pitying glances from those who save us from the rigors of a world we clearly cannot handle. People have helped themselves to me like a doll on a shop shelf – handled at first with tender consideration, then with increasing disregard as I ceased to amuse. Living with visible chronic illness has often made me feel like secondhand goods, bounded by constant reminders of who I can and cannot be. These microaggressions strip away the accomplishment of surviving, render offensive many of the qualities and actions that can make life rewarding. Perhaps these struggles frighten others because they serve as reminders of how fragile health really is – and how strong one must be to endure when it falls away.

Of course, in responding to and attempting to navigate the responses of people without visible chronic conditions to my own body and symptoms, I have met and communicated with many people who understand these experiences intuitively because of comparable health trajectories in their own lives. Brown and colleagues (2004) describe how people with similar health experiences often bond over their shared history, a phenomenon they refer to as "embodied health." Josefsson (2005) provides a detailed example of how embodied health can help people connect and cope with persistent illness with her research on patients' online communities. Her work echoes seminal research from Thoits (1995) and other scholars who demonstrate the potential of social support and empathy – and the focused intersection of the two – can transform daily experience and overarching quality of life for people living with chronic conditions. Support and empathy flow from constructed communities united by common experiences in health (Josefsson, 2005). These may include, but are certainly not limited to: chronic pain, functional impairment, early mortality, communication difficulties, sexual changes, social isolation, and persistent uncertainty.

In my own life, I have seen these principles in action, and experienced their transformative potential. Indeed, the desire to seek opportunities for action and make positive impacts on the lives of others have motivated me at every stage of developing my own career in interdisciplinary sociomedical scholarship and outreach. Whether teaching in the classroom, exchanging manuscript drafts with colleagues, sharing stories with people in the community, etc. I always seem to find people who understand my journey because they are on a similar one themselves. Being able to offer – and also receive – social support in those moments feels like the greatest possible affirmation. I experience this with my life partner, a fellow traveler on the road of chronicity, on a daily basis. At the same time, there is something incredibly powerful about connecting with a complete stranger over shared experiences of illness, and knowing that they truly *see* me.

Just as interactions with people who do not have visible conditions often lead to feelings of effacement and alienation, so too do these embodied health experiences inspire feelings of happiness and gratitude. Though our experiences and the evidence they leave behind may render us symbolically invisible to many in our world, the history we share through embodied health makes us gloriously visible in very impactful ways. We see how we look through the eyes of others who know our struggles and frustrations, our deeply rooted fears and the hopes we cling to (see Nowakowski, 2016) in spite of everything. The community we find in disclosing our stories and opening ourselves to social support becomes a mirror in which we always appear, even at times when the rest of the world fades us into faint shadows. If I have learned one thing on this journey, it is that visible chronic illness can be a vanishing *act* because all life is a performance (Goffman, 1959). In sharing our stories with kindred others, we go backstage to explore the elements of stagecraft hidden from the audience's view, and remind ourselves that the masks we wear are real.

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