

Reframing health and illness: a collaborative autoethnography on the experience of health and illness transformations in the life course

Alexandra C. H. Nowakowski¹ and J. E. Sumerau²

¹Department of Geriatrics/Department of Behavioural Sciences and Social Medicine, Florida State University College of Medicine, Tallahassee, FL, USA

²Department of Sociology, University of Tampa, Tampa, FL, USA

Abstract In this collaborative autoethnography, we examine the processes whereby people may reframe their interpretations and understandings of health and illness as a result of new diagnostic information. In so doing, we utilise the first author's experience receiving a conclusive diagnosis of cystic fibrosis after years of misdiagnosis to outline some ways changes in diagnosis facilitate shifts in illness management, the nature of health and illness and the experience of the self in relation to health and medicine. Furthermore, we discuss the ways this case reveals the importance of examining and comparing the social construction and transformation of health and illness within and between different individual and collective lived experiences over time. In closing, we draw out theoretical and empirical implications for understanding transformations in the nature of health and illness over the life course as well as future directions for research investigating shifts in illness management and understanding over time (A virtual abstract of this paper is available to view at: https://www.youtube.com/channel/UC_979cmCmR9rLrKuD7z0ycA).

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An emerging line of research examines the complexities of illness management in daily life (see, e.g. Charmaz 1983, Cragun and Sumerau 2017, Nowakowski 2016a, Rier 2000). Implications of these studies include that people fashion identities in relation to the health conditions they manage at times and especially in relation to chronic conditions over the life course (Nowakowski 2016b). They also reveal how illness management represents a dynamic, active process that shifts and changes over time in relation to social resources, medical events and varied locations within social structural hierarchies embedded within the larger society (Calasanti and Selvin 2001). While these studies have invigorated our understanding of illness management in many ways, many gaps in the literature remain. What happens when, as part of illness management, people experience transformations in the diagnosis and experience of health and illness over the life course, and how do they experience these shifts?

We examine these questions through a collaborative autoethnography of the first author's experiences gaining a conclusive diagnosis of cystic fibrosis (CF) after years of misdiagnosis. Specifically, we utilise the first author's experience of a transformation in diagnosis to illustrate

processes of reframing or redefining health and illness people may experience at times when *known* illness management changes into *new* illness management strategies as a result of transformations in the meaning of a given set of symptoms. In so doing, we synthesise and extend analyses on the social construction of health and illness by demonstrating how people may be called to revise understandings of their own health-related management processes as a result of a new ‘definition of the situation’ (Goffman 1974). It is not our intention, however, to generalise these findings to the larger population of people with CF or other chronic conditions. Rather, we use the data from this case to elaborate experiences people may face at times when prior knowledge about their health and illness shift in relation to new information over time, which may be examined in varied settings and populations throughout society.

The social construction of health and illness

Over the past few decades, sociologists have demonstrated many ways social meanings, patterns and inequalities fundamentally cause and otherwise influence health and illness (see, e.g. Burnham 2012, Charmaz 2000, Link and Phelan 1995). Rather than purely biological phenomena, health and illness represent socially constructed labels placed upon biological symptoms and experiences. Such labels also shift in relation to changes in medical knowledge, social norms, experiences within varied social locations and access to resources including but not limited to healthcare, medical knowledge and diagnosis. These studies also show how broader societal inequalities like race (Grollman 2012), class (Dew *et al.* 2005), gender (Nowakowski and Sumerau 2015), sexualities (Beasley 2008) and religion (Cragun *et al.* 2016) influence and shape processes of illness diagnosis and management among doctors and patients. Overall, these studies suggest that understanding health and illness requires making sense of the social construction and experience of these concepts over time (see also Cockerham 2007, Dannefer 2003, Quadagno 1994).

Understanding the social construction of health and illness, however, requires making sense of the ways medical practitioners diagnose a given set of symptoms as a particular illness to be managed (Barker 2010). Put simply, the social construction of health and illness in a given case relies heavily upon the ways medical authorities and patients, individually and collectively, define and label an illness by assigning meaning to a set of symptoms in relation to existing medical hypotheses and understandings about a given set of biological phenomena. Following Goffman (1974), this type of process may be referred to as framing or creating a definition of the situation to guide action (see also Barker 2010). This process involves the interpretive work people do to define what is going on here and what should be done in response to a given set of goings-on. We may thus conceptualise health and illness status as a result of the processes whereby medical authorities and patients frame a given set of symptoms as a particular illness or an unknown constellation of biological issues without a current label (see also Barker 2010). When a given illness is framed accurately, the strategies proscribed may aid in the management of the condition over time. By the same token, an incorrect framing may have disastrous effects on the attempt to manage a given set of symptoms and necessitate a reframing – or reconstruction – of what the condition is and how to manage it. Indeed, the concept of accuracy in framing requires attention to multiple perspectives that may be relevant in analysing a social phenomenon such as chronic illness.

Understanding the social construction of health and illness in relation to the ways conditions and responses to said conditions are framed, also requires recognition of diagnosis – like all humanly created knowledges (Blumer 1969) – as an ongoing process of reflection, interpretation, adjustment and maintenance undertaken in relation to shifting resources and sources of

data or stimuli (Nowakowski 2016a). Rather than immutable realities within the bodies of people, diagnoses represent the mutable consequences of interaction, interpretation and reflection wherein people utilise the resources at their disposal *at a given time* to *hypothesise* the likely, possible or probable sources of symptoms (Barker 2010). As a result, it is important to remember that any hypotheses or predicted outcome in the abstract may be incorrect when extrapolated to a specific case in the empirical world (Blumer 1969). Rather than an absolute answer, then, diagnoses are – like all scientific and other cultural propositions – ongoing works in progress that must be revised, adjusted and questioned as new data, information, insights, technologies and possibilities emerge over time. As such, framing illnesses via diagnosis may well be a generic process – or common process of social activity ongoing throughout society in varied ways and places that accomplish similar goals in many settings or contexts (Prus 1996) – of contemporary health and illness experience.

Building on these insights, this article utilises the example of the first author's diagnosis with CF after years of misdiagnosis to outline some ways health and illness understandings may be reframed in response to new diagnoses as well as the ways people manage such changes in diagnostic status. Before presenting our analysis, however, we outline the use of collaborative autoethnography to synthesise and extend existing scholarship on the social construction of health and illness over the life course. In conclusion, we outline some ways our analysis suggests future paths of research for understanding both the social construction of health and illness and practices of reframing health and illness as a result of shifting diagnostic and other health information over time.

Methods and analysis

In order to examine the experience of diagnostic transformation in relation to health and illness, we utilise collaborative autoethnography (Chang *et al.* 2013). Autoethnography combines autobiography and ethnography. Autobiographical methods, for example, rely upon the ability of a person to retrospectively and selectively write about experience utilising memory, interviews and existing texts like photographs and journals (Didion 2005). Ethnography, however, involves the participation and/or observation of cultural experience and activity to facilitate understanding of a group's interactional practice, common values and shared experience (Geertz 1973). Autoethnography thus involves integrating these techniques by retrospectively and selectively capturing experiences while situating these experiences within existing cultural contexts (Adams 2011).

While autoethnography relies upon an integration of personal reflection and cultural analysis, this does not mean one can simply tell a story. Rather, autoethnographers must distance themselves from personal experience in order to reflect upon the ways said experience relates to larger cultural patterns (Crawley 2012). An autoethnographer thus uses personal experience to make unique and unfamiliar aspects of social life familiar to both insiders (i.e. those with similar experiences) and outsiders (i.e. those without a shared point of reference). One way to accomplish this is through collaboration (Chang *et al.* 2013).

Following Chang *et al.* (2013), collaborative autoethnography is the process of doing autoethnography with others at varying levels of participation (see also Ellis and Rawicki (2013) for example, and discussion of many types of collaborative autoethnographic practice and analyses). In some cases, for example, researchers experiencing the same phenomena will collaboratively create reflections, discuss emerging themes and compose analyses throughout the entirety of the project (see Geist-Martin *et al.* 2010). On the other hand, one or more researchers may document deeply personal experiences and then solicit other researchers for

the purposes of analysis and interpretation (see, e.g. Lietz *et al.* 2006). For the purpose of this article, we adopt the latter model wherein the first author documented experiences with new management of CF after receiving the diagnosis, and later recruited the second author to analyse said documentation in relation to existing health and illness scholarship.

We find collaborative autoethnography especially useful for the current project for two reasons. First, collaborative autoethnography allows us to utilise both the first author's 'firsthand familiarity' (Blumer 1969, 38) with the experience, and the second author's observation of the experience. This allows us to examine both 'what goes on in social life under one's nose' (Blumer 1969, 50) and the ways these experiences align with or contradict existing observations in social scientific literature. Second, collaborative autoethnography allows us to critically examine the experiences of a person managing a chronic condition and a change in diagnosis of an illness through the lens of someone without that condition who witnessed the transformation. Our combined standpoints thus offer an opportunity to examine transformations in health and illness from multiple perspectives at the same time.

In fact, our approach here may be especially important in relation to understanding the social construction of health and illness in people's lives because it allows an outsider to witness and examine the, often deeply private, health-related experiences, emotions and thoughts of another during a time of interpersonal, emotional and cognitive change. Considering that people often exercise much caution in sharing health experience, status and details (especially in the case of chronic conditions that may lead others to treat them differently, see Cahill and Eggleston 1994), opportunities to gather in-depth data on another person's in-the-moment experience of complex health and illness experiences are rare (see also Charmaz 2000). As such, our approach here offers an opportunity to place more common interview, survey and experimental findings into the context of lived health and illness experience (see also Nowakowski 2016a).

For the purposes of our analysis, the first author provided the second author with both a full documentation set of the fieldnotes contained in the #cfadventures stream they created in a social media online forum to document their experience, and verbal notes and explanations of feelings and thoughts through the process that the first author took notes on in a journal. The second author then went through all the available materials as well as notes on other conversations about the experience with the first author and others close to the first author. In so doing, the second author outlined themes throughout the experience that reveal facets of adjusting to diagnostic change that may guide future research. The second author then shared the outline with the first author, and collaboratively, we went over the analysis, codes and patterns in a back and forth fashion to refine its lessons for health and illness scholarship.

In specific terms, our overall process began with the first author generating field notes throughout 2017. The first author archived these notes in chronological order as a single aggregated file with date stamps for each set. The resulting file contained over 60 pages of single-spaced pages. After generating this content, the first author shared with the second author and gave them time to reflect on its contents. During initial analyses, we did not discuss the notes or how they might be framed – the goal was to gain an organic reaction from the second author to the data collection of the first author. This approach established an 'insider' and 'outsider' perspective on the field notes utilised throughout the preparation of this article. The second author then began preparing a draft of a potential manuscript that was shared back and forth between the authors multiple times – with discussions about the emerging analysis occurring at the same time – as we revised and clarified the analysis.

For the use of future studies, we here offer a couple examples of the process. First, in terms of outlining the article itself, the first author initially saw the manuscript as a narrower discussion on illness management. Their field notes and journal and early communications with the

second author utilised more targeted language in relation to CF and ageing, rather than the broader theoretical discussion of illness change and diagnostic shifts. At the same time, the second author's early manuscript draft focused on the wider implications of the narrative and drew these out into a discussion of diagnostic transformation that became the current article. In a collaborative fashion, as well as an illustration of the usefulness of multiple perspectives on the same data (Ellis and Rawicki 2013), we debated and discussed these approaches as the work took shape and integrated the two – the specific experience as a case for focusing on the wider implications – to form the current article.

A second example of both the process of the article formation and the usefulness of collaborative autoethnographic methods can be seen in the formatting of the analysis section that follows below. Specifically, the second author initially focused heavily on framing techniques, meaning making in narrative context, and a more abstract theoretical discussion of the case. Upon reviewing these early drafts, however, the first author emphasised the importance of speaking more directly to illness experience and concrete application of this work for future studies and intervention possibilities. Again, this distinction in approach led to debates and discussions about the overall goal of the work, and in this case we adopted the first author's elaboration of the ways the piece could foster greater abstract and application-focused theorising over time from others by serving as a model for future studies. As a result, the analysis below was revised and reshaped to focus on the concrete experience of illness and diagnostic change with observations throughout that could guide further study in this area in more elaborate theoretical and empirical matters over time.

With these observations about process and analytic techniques outlined for potential use in future studies adopting collaborative autoethnographic approaches to health-related experiences, we now turn to our analyses of the ways the first author experienced diagnostic change and lessons such events have for future studies of health and illness. Specifically, what follows is the direct result of these processes and lessons: an in-depth critical analysis of the most common themes in the first author's experience of adapting to the reframing of their health and illness status after a new diagnosis, situated simultaneously in the insights and standpoints of both authors and focused on the experience with suggestions for further theorising and applicability in future studies embedded throughout and discussed in the conclusion.

Reframing health and illness

Before proceeding with our analysis of adjustments people may make in relation to the reframing of health and illness in their lives, we outline the diagnosis experience that led to this process of transformation in the first author's case. In so doing, as suggested by autoethnographers in health and beyond (see Adams 2011, Cragun and Sumerau 2017, Nowakowski 2016b), we utilise the first person narrative for this section to capture both (1) the personal experience of the first author, and (2) the ways social factors influenced this series of events. We further outline these factors because, as Barker (2010) notes, experiences of diagnosis, re-diagnosis and contested diagnosis often receive much less attention in studies of health and illness, and as a result, the current project offers an important opportunity to explore what goes on in the day-to-day diagnostic experience of a specific case.

As of the writing of this article, I (the first author) am a person with a mainstream physical presentation of CF. However, I have an extremely uncommon genetic profile for someone with the disease. Growing up in a biomedical research laboratory that included genetic projects, I learned a lot about the discovery of the CF transmembrane conductance regulator (CFTR) gene in 1989 (nearly 6 years after I was born). Yet, even though I was first tested for CF around

age 5, I did not know much about the vast landscape of nuances in the genetic origins of the disease until well into my adult life. Between 1989 and 2016, when my tentative and poorly implemented diagnostic experience became a conclusive and urgent diagnosis of CF, scientists identified over 2,000 genetic mutations associated with at least one documented case of the condition. I would later learn that my own mutation, a substitution at location 1584 on one of my CFTR genes, had never yet been seen in any other case of CF in the United States. In so doing, I began to understand the contested nature of diagnostic attempts in relation to my own health over the course of my life.

In many ways, my own case offers an exemplary reminder of the social construction of health and diagnosis. Like most people whom medical professionals consider potential cases of CF, for example, I underwent a sweat test at an early age. While this has long been treated as a gold standard in diagnostic protocols for CF, this screening tool neither reliably identifies the disease in everyone who has it nor conclusively rules it out in everyone who does not have it. There were also two problems with this test in my case. First, I have never been able to produce much sweat at all. The only places where my body will reliably sweat are my under-arms and face, but even this requires exposure to intense heat for long periods of time. Second, some people with CF lose chloride ions more through other routes, such as intestines and kidneys, and in these cases, the sweat test is not very useful. In my case, doctors missed the best empirical diagnosis of my condition due to these limitations in the probability-based or standard testing protocol.

Unsurprisingly, there was ample context for why the process of diagnosing my CF became long and convoluted. This owed in part to the uncommon genetics referenced above, but also involved some other intricacies. I exhibited many of the core symptoms of CF from birth onwards. These included a variety of lung problems such as recurrent bronchitis and pneumonia, repeated infections of the sinuses and tonsils, intermittent bouts of constipation and bowel obstructions and frequent diarrhoea with a greasy texture. These patterned daily events led to a series of adverse acute health events, including two hospitalizations at age 4 that prompted clinicians to investigate the possibility that I had CF.

Although CF remained the suspected diagnosis, a conclusive diagnosis was not made until adulthood for two interrelated reasons. First, the CFTR gene was only just in the process of being discovered. Genetic testing for mutations on that gene would not be widely available for many years to come, and thus could not be used in diagnosing CF in the late 1980s. Second, CF was diagnosed at the time using only one test: a collection and analysis of sweat from the skin of patients. This test proved problematic for many people because it required being able to produce a substantial volume of sweat. The suspicion that I had CF was thus never confirmed in childhood.

This suspicion became an ambiguity in my health history as I – like many other people living with CF during that time – aged out of paediatric care. Adult CF care remained an emerging specialty in the 1990s, and transitional care was almost nonexistent even for adolescent patients who had a conclusive diagnosis. I thus received no further follow-up on the possibility that I had CF after childhood. This lack of CF-focused follow-up persisted well into my adult years despite worsening symptoms that included progressive failure of exocrine pancreatic function, loss of mucous membrane tissue to persistent infections, evidence of incipient kidney disease, copious weight loss, heart problems introduced by chronic electrolyte wasting and several years of intractable pneumonia. Because the effort to diagnose CF was inconclusive in childhood, this history became a catch-22 in which clinicians never reopened that investigation because they viewed it as having already been closed.

The experience of having what was in many ways a very obvious diagnosis first heavily contested and then desperately leveraged after over three decades of damage to my body thus

sets the scene for the analysis here. At first, I was infuriated more than anything, but at the same time, my own activity as a medical researcher left me feeling intrigued as well at the ways cases might slip through the cracks when diagnostic protocols become too rigid as a result of interpreting the average case (from a correlation or other method) as an absolute truth (instead of one probability among other possible answers). At the same time, I had to adjust my self-image as someone conclusively diagnosed with CF rather than the person searching for what underlying condition was facilitating my symptoms and outcomes throughout the years. Drawing on my experiences doing medical evaluation, teaching, outreach and collaborative mixed-methodological research, I knew my best path forward was to shine a light on how I managed this transformation while studying how it played out in my life.

To this end, I began keeping field notes as I had done in previous work during my career, and I selected a public forum for these endeavours to share this information with other health professionals and people managing CF. I utilised a hashtag #cfadventures, and began chronicling my experiences with myself, with medical authorities, with the condition and my growing knowledge of it, and with my health-related past in relation to the emotions and thoughts I had during these endeavours. This allowed me to document my experiences and to process my complex and conflicted emotions about the processes of gaining appropriate care.

The hashtag efforts drew accolades from people in many different areas, and I was invited into specialised online communities focused on CF. Within these networks, I was stunned by the number of stories I saw that echoed mine in multiple ways. I also met people with more traditional ‘late diagnosis’ stories whose disease was only identifiable because of ancillary issues that came up in relation to fertility or some other health event. As I became more integrated into these communities, I began reflecting more actively about my evolving sense of self and the insights these transformations might provide for other researchers. It was at this point that I began collecting and organising the mass of fieldnotes I had generated through the hashtag, my own correspondence and personal writing and my reflections on these lived experiences in relation to my knowledge and work as a health researcher.

When I sought to analyse the materials, however, I drew upon my history of engaging in collaborative research as well as my recognition that the data could look very different to me (as the one experiencing and collecting it) and someone else (as a viewer of the experience). As a result, I recruited the second author, a fellow researcher trained in mixed-methodological and interdisciplinary arts and sciences, to analyse the data in search of patterns and insights that could further sociologies of health, illness, diagnosis, and the self. As we have engaged in collaborative projects on many subjects before (see, e.g. Nowakowski 2016a,b, Nowakowski and Sumerau 2015, 2017), we began collaboratively working on the materials as outlined above and sought to understand lessons for future study from my case.

In the sections that follow, we shift back to a third person and utilise examples from my (the first author’s) fieldnotes to outline the ways the reframing of my health and illness diagnosis and status led to processes of adjustment, which may be examined in other cases, settings and lives. Throughout the analysis, we offer illustrative examples of the processes the first author experienced due to space limitations, and the inability to show all the examples in a given article. Furthermore, while we treat each of these processes as analytically distinct for the purpose of providing a clear typology for future research, it is important to note that such processes generally occur in tandem and in relation to each other in practice. Finally, here we focus on processes of (1) cognitive, (2) emotional and (3) bodily adjustment, but we in no way mean to suggest these are the only processes people may experience during transformations of health and illness over the life course. Rather, we focus on these processes as they often appear throughout literature on health and illness, and may thus provide a baseline typology for future research concerning the adjustment of self and illness management in relation to

shifting diagnostic status over the life course. In so doing, we urge future studies to tease out the myriad of theoretical and application implications that could be found in systematic socio-logical study of diagnostic change over the life course and in relation to varied illnesses.

Cognitive adjustments

Researchers have explored some ways that newly diagnosed conditions (Courtenay 2000), new treatment protocols (Nowakowski 2016a) and events during and following medical decisions (Cragun and Sumerau 2017) often involve cognitive adjustments, or an adjustment in the way one thinks about the body, health and the self (Charmaz 1983). Researchers have also shown some ways that shifts in any identity category can generate periods of reflection and consideration capable of shifting viewpoints and perspectives about any particular issue or experience (see, e.g. Ezzell 2009, McQueeney 2009, Sumerau 2012). In this section, we outline some ways the first author experienced cognitive disruptions and reflection as a result of reframing understandings of their own health and illness after being conclusively diagnosed.

In some cases, cognitive adjustments arise in relation to difficult times and hopes for a better future (Nowakowski 2016b). In his study of the ways people utilise prayer, for example, Sharp (2010) demonstrated how hopeful thoughts and cognitive manoeuvrings could provide people with symbolic resources for managing difficult situations even if such situations showed no signs of changing. As illustrated in the following excerpt, the first author engaged in similar types of framing in relation to their CF diagnosis at hard moments:

I'm still here. I'm still breathing and living and striving. I may be struggling brutally right now, but I am making steady progress now in partnership with my care team. I will live a better life one day – I have to believe that I will. Hope has gotten me this far and it will give me wings yet. I just want those wings to grow big and strong enough to lift up other kids with CF whose families are fighting to get them a conclusive diagnosis and effective care.

Similar to the ways people in mixed-orientation marriages (Wolkomir 2009) and people managing illnesses collaboratively in a relationship (Nowakowski and Sumerau 2017) make sense of tough moments by postulating a better future or purpose for their struggles, people may make sense of transformations in their health and illness by focusing on something positive that may come out of their hard times. In so doing, as noted with Sharp's (2010) interviewees, people may give themselves something beyond their immediate circumstances to focus on, which may ease the strain of facing difficult circumstances in the immediate moment.

At other times, such changes may lead to a re-evaluation of prior habits and patterns (Goffman 1967). In the case of illness management, for example, people may reframe their approaches to this or that treatment or doctor or care routine (Barker 2010). At the same time, they may, as illustrated in the first author's case, reconsider habits related to social support and relationships when difficult circumstances push them to think of new ways they can manage or respond to the resources at their disposal (Charmaz 1983). The following fieldnote excerpt offers a typical example of this type of cognitive adjustment:

I tend to view my own worth as very tied to what I give to others. This is good because it inspires me to use the resources I have to make the world a better place. It is also problematic because it makes me worry that seeking support from others will make me a burden. I have consistently rejected this fear with exactly three people in my life: my spouse, my mom, and my dad. [With others] I've kept pretty much all of them at arms' length in

different ways because I worried about overwhelming them, because I figured I could handle things on my own, because I thought it would be ‘an exercise in privilege’ to reach out when I already have so much love and understanding from my family.

Consistent with more masculine approaches to managing negative events, health-related and otherwise (Schrock and Schwalbe 2009), the first author notes the ways they sought to manage, control and handle their health and illness mostly alone prior to the new diagnosis. With the new information, however, their reframing of themselves and their health-related strategies facilitated reflection about other ways they could take advantage of potential avenues for social support and care. Mirroring cognitive decision-making processes among other people with chronic health conditions (Cahill and Eggleston 1994), for example, they sought to ascertain – or make sense of – when it would be more prudent to request care alongside other times when handling things themselves made the most sense.

Another common experience for people experiencing transformations involves the acquisition – and integration – of new knowledges and understandings about a given circumstance or stimuli (Goffman 1974). Especially considering the sophistication of medical science and the complexity of human bodies, this may be even more common in relation to changes in diagnosis, health status and illness recognition. As the first author suggests in the following example, sometimes incorporating new information requires recognising unrecognised issues or flaws in prior understandings of the self, body and mind:

I've . . . been learning a lot . . . about the difference between *improved symptoms* and *controlled symptoms*. Knowing that my kidneys are stressed but not badly damaged has opened up a line of inquiry I'd never really followed . . . I'm starting to put some pieces together and realize that as a result of living in such profound misery with certain symptoms for a long time, I have a very warped sense of where my baseline should be.

Similar to people learning the codes or rules for presenting a new identity (Goffman 1959), people experiencing health and illness shifts may have to reframe any number of practices and expectations in a new light (see also Charmaz 2000).

These cognitive adjustments may also be ongoing in the case of chronic conditions (Nowakowski 2016a). At the same time, however, they may spark reflections about what we take for granted versus what we consider critically (see also Nowakowski 2017). The first author, as shown in the next example, encountered many such cases of reconsideration and reflection concerning medical science, healthcare and illness management while reframing their own health and illness:

We spend so much time thinking about what is ‘normal’ that we often forget to consider what is *usual*. Yet this is often what is more relevant for clinical care from one day to the next. I will never have a ‘normal’ serum potassium level, most likely. But the treatment I get keeps me feeling reasonably good and prevents me from landing back in the ICU. It keeps my heart beating and my muscles functioning properly. It keeps the smell of raw onions – the eternal scent of death – from creeping up out of my throat. It keeps my skin from flaking off in sheets. I realize that's a bit of an ‘arson, murder, and jaywalking’ list, but that's life with any kind of progressive disease, isn't it? From the macabre to the absurd and back again. It's why we have Markow chain models. It's why I do what I do for a living. I just hope I won't always have to be such a case in point of my own research.

Overall, the examples in this section highlight the ways that transformations in health and illness may lead to cognitive adjustments. While the nature and details of such processes

represent an intriguing empirical question, the first author's efforts coupled with insights from existing work on identity change in relation to shifting statuses – within and beyond health-related identities – suggest there may be much to learn from the ways people reframe their cognitive understandings of themselves and the nature of health and illness as a result of diagnostic change.

Emotional adjustments

Like everything else in social life studied to date (Turner and Stets 2005), reframing health and illness also impacts and generates emotions. Following Hochschild (1983), emotions arise in relation to social stimuli, but also direct our attention to the ways we feel about a given social phenomena, status, identity or location at the same time (see also Simon and Nath 2004). Alongside cognitive and bodily reactions, emotions direct our attention to whatever circumstances we experience at a given time while also facilitating the processing of new information about the world, ourselves and any other component of human life (see also Thoits 1989). In this section, we explore some of the emotional reactions and expressions facilitated by the first author's diagnostic transformation.

In many cases, emotional reactions related to healthcare find origins in the activities of medical providers (Birks and Watt 2007). As the next excerpt suggests, healthcare providers can have a dramatic effect on the feelings of people seeking care:

I left . . . feeling very relieved by how much the doctor and his team affirmed my feelings of exhaustion and anger about everything I've had to go through because people wouldn't listen to my family when I was growing up, or if they did listen, they didn't have the skills or resources to treat a CF patient fully.

As Goffman (1967) notes, emotional affirmation often provides a foundation for social bonds as well as possibilities for trust and collaboration (Turner and Stets 2005). As the next excerpt from later in the post about the joy of finding the new healthcare team suggests, such efforts can also ease long-term experiences with negative emotions:

Sometimes even fathoming the idea of feeling better can seem inscrutable and impossible when one has felt so bad for so long. It breaks my heart to think that if I'd allowed myself more outrage [in the past] about my own suffering, maybe things would have gotten better sooner. We focus so much attention on quietly soldiering on through unspeakable adversity, and not enough on what it costs people to do it . . . Living with a rare disease is terribly isolating – so few clinicians understand what your life is like . . . but it only takes a few good people to make you take a hard look at what you've been settling for, and make you ask if maybe you might deserve better.

In other cases, emotional reactions can arise from new circumstances that remind us of prior events (Turner and Stets 2005). In such cases, transformation – even if cognitively sensible at the time – may lead people to revisit both positive and negative moments and emotions at other times in their health and illness trajectories. The following excerpt offers an example of the former case: 'Sometimes this all hits me really hard and I feel the same piercing fear I felt in the beginning.' In the latter case, as the next excerpt suggests, emotional memory can offer reminders of positive moments along the way:

I will be slightly easier to deal with than I was after multiple surgeries, when I apparently lost control of my bowels . . . Let me tell you, anyone can buy a bouquet of flowers, and if you can't buy them, you can probably steal them, but it takes a special kind of romance to

cheerfully clean up your loved one's faeces while attempting to prevent them from face planting on the carpet.

Whether positive, negative or somewhere in between, what these illustrations highlight are the ways new treatments and interactions with healthcare following the reframing of health and illness may generate feelings from and about the past (see Wolkomir 2006 for similar patterns when reframing other identities). In such cases, the newly reframed understanding of health and illness may clash with or complement prior understandings, emotions and norms in many ways.

There will also, as emotions scholars have noted in relation to other changes in the life course (Turner and Stets 2005), be times where emotions take centre stage in our reactions to and adjustments concerning new health and illness realities. In such cases, as illustrated in the next excerpt, it is important to find ways and places to express such emotions while also remaining aware of the necessities generated by the new status:

I mostly feel anger, and beneath it a tender underbelly of fear that I'd like nothing more than to slice open, to spill its poison all over the floor and spare myself its terrible effects. I don't really do fear. I feel it sometimes, but I don't let it stop me. That is life with CF, and one saving grace in all of this has been that it has pushed me to join some groups and connect with others to whom I never have to explain myself because they already know. Sometimes the knowledge that other people out there in the world understand firsthand what I'm going through moves me to tears with its power.

As suggested in countless studies focused on the emotional – and broader health – benefits of supportive social communities (Cragun *et al.* 2016) and the numerous findings concerning the ways people seek group affirmation and connection in response to managing emotions (Wilkins 2008) and marginalised statuses (McQueeney 2009), emotional flourishes accompanying a reframing of one's health and illness may be both overwhelming and a push towards support capable of easing difficult circumstances in illness management. As with cognitive adjustments illustrated in the first author's case, the impact of emotion in health and illness transformations offers fertile ground for systematic analyses and theorising, which might aid in-depth understanding of the ways people feel health and illness throughout their lives.

Bodily adjustments

While cognitive and emotional reactions provide much for future studies of diagnostic change, health, like other social identities (Gimlin 2002), is ultimately an embodied experience wherein what we think, feel and do becomes written on the body in meaningful and powerful ways (Turner 1991). Put simply, we both feel health and illness in our bodies, and utilise our bodies to manage, make sense of and navigate our illness concerns and pursuit of lasting health (Nowakowski 2016a). When reframing prior understandings of health and illness, then, we will also engage in many bodily adjustments alongside our emotional and cognitive shifts. In this section, we outline some bodily adjustments brought upon by diagnostic change.

Especially in cases of health and illness (see, e.g. Cahill and Eggleston 1994, Nowakowski 2016a, Turner 1991), the body plays a primary role in the experience of the self. This is because bodily symptoms and treatment strategies take centre stage as one seeks to make sense of physical and biological sources of pain, frustration, function, dysfunction and pleasure all at the same time while making sense of symptomatology, treatment suggestions and diagnostic hypotheses in relation to such bodily signals. At times, as the first author notes in the following excerpt, this can be tiring even in the midst of good news: 'Feeling much more comfortable after finishing the antibiotics, but beyond exhausted. Every day feels like incipient sleep.'

At other times, as illustrated in the next excerpt, exhaustion blends with confusion and unanswered questions about how this or that bodily phenomenon responds to a given treatment:

We still don't know what's going on with my kidneys but are following up with nephrology over the next few weeks to get that sorted out. It will be nice to get some answers and hopefully not have to deal with all these fluid retention issues for the rest of my life. It has not been a fun few years on that front. In the meantime, getting confirmation that my pancreas has taken some damage from the CF at least makes me feel less bewildered by why I have been so exhausted all the time and felt generally unwell every day. I'm hopeful that the enzymes will help me feel better.

In moments like this, the embodiment of functional difficulties with biological organs blends with emotional and cognitive attempts to adjust to new diagnosis and make sense of what is going on in the body. Like the first author, many people living with chronic or acute conditions impacting bodily function must engage in constant framing and reframing to make sense of these intersections of bodily, emotional and cognitive stimuli.

Especially considering the potential exhaustion available at any time in illness management (Charmaz 2000), bodily adjustments related to things like nutrition, medication types and samples, sleep and relaxation can become paramount in the process of making sense of transformations in health and illness (see also Nowakowski 2016b). As the first author notes, even something as simple, or mundane, as sleep can become a health and illness 'event' or 'significant consideration' at these moments:

My sleep has been more restful the past few days, even on nights where I have had trouble falling or staying asleep. I talked to the nurse from my CF provider's office about this when they called to follow up with me earlier today. I could hear them smiling a little over the phone, and they told me this is an encouraging sign that the CREON is effectively replacing the enzymes I can no longer produce in sufficient quantity.

As suggested in the prior excerpt, acquiring new medications and forms of care may generate both changes in bodily reaction and norms, and important observations of how things change bodily and otherwise in the patient's life. This type of change and observation, as illustrated in the next excerpt, can become ever-present while one seeks to make sense of constant shifts as a result of new insights concerning a given disease, diagnosis and medical treatment protocol:

I have also started wearing my calf compression sleeves full time to help with the oedema. I probably should have been doing this for years – or not, because I should have been treated for all this nonsense much sooner, but I digress. Anyway, better late than never. They help so much and it's nice to get through an entire day of work without my legs swelling terribly and feeling exquisitely painful by the evening.

Whether we look at adjustments in sleeping patterns or the amount of swelling one might face at a given time in comparison to prior times, bodily adjustments – and the attempt to make sense of and express them cognitively and emotionally – may become constant for people managing transformations in the body as a result of changes in health and illness status.

As the first author noted in many different posts, all these different embodied experiences can become a kind of 'adventure.' This is because each day may present new stimuli when one is embarking on different treatment protocols and medications facilitated by a transformation in health and illness status. The following excerpt provides an illustrative case:

Having my face scoped was interesting. I didn't like the lidocaine/phenylephrine spray used to numb and clear my sinuses – felt very odd and tasted like garbage. Scoping itself felt sort of like being pinched on the inside. Doc found some small polyps and said they were very usual for someone with CF. Apparently you can get little benign polyps from repeated infections; they're probably scar tissue like the nodules on my lungs. No surprises there. The only symptom we are working on addressing at the time being is the recurring fissures in my nostrils. Doc prescribed a steroid ointment for that, which I picked up earlier today. This ointment feels a lot better than the milder steroid cream I was using before, which didn't make much difference with the fissures but made the inside of my nostrils feel funny.

Although we could offer many more examples from throughout the fieldnotes, the point here remains the same – alongside the cognitive and emotional adjustment processes necessary for making sense of a diagnostic shift, people will likely also experience constant bodily reactions to these changes following a reframing of diagnostic labels. Following insights from other scholarship focused on illness management over time (see, e.g. Charmaz 1983, Nowakowski 2016a, Rier 2000), these observations suggest there may be much to learn from systematic analyses of the ways people reframe health and illness with and within their bodies as well as the ways they make sense of these embodied shifts cognitively, emotionally and medically over time and in varied situations and settings. These lessons echo and affirm the general call issued by Timmermans and Haas (2008) for active engagement of embodiment concepts in the medical sociology of chronic illness.

Conclusions

Although studies focused on the social construction of health and illness as well as processes of illness management have proliferated in recent years, there are still many gaps within the field. We have drawn upon the first author's experience gaining a conclusive diagnosis of CF after years of misdiagnosis to reveal some spaces in need of theoretical and empirical elaboration. To this end, we used collaborative autoethnographic analysis techniques to unpack processes of reframing health and illness in relation to new diagnostic information and treatment. In so doing, our analysis showcases some ways people may have to accomplish cognitive, emotional and bodily adjustments when existing notions of health and illness are reframed over the life course, which may provide opportunities for further exploring the ways people live with and through health and illness over time in varied contexts.

These findings also reveal some ways health and illness scholarship could benefit from greater attention to diagnosis and diagnostic changes (see also Barker 2010). Although researchers often explore the ways people manage health and illness in relation to static or stable chronic conditions adequately framed at an earlier point, we know little about the ways people respond when prior misdiagnosis is corrected at a later date. Similarly, whereas scholars often focus on well-known and clearly diagnosed health and illness labels, we have less information about the experience of people existing in between contested and stable diagnostic criteria.

Addressing contested illness explicitly has often required amplifying the voices of patients directly. Earlier literatures on HIV/AIDS (Mane and Aggleton 2001) and heart disease (Chiaramonte and Friend 2006) bear this out with respect to the experiences of female-looking patients. In both cases, dominant narratives suggested these conditions were exclusively for people of male sex. Centring the voices and experiences of non-male patients with similar underlying issues helped to demonstrate the diversity of populations impacted by HIV/AIDS

and heart disease. Likewise, social and clinical literatures on chronic illness are presently expanding to highlight the diversity of populations impacted by other contested conditions such as fibromyalgia (Armentor 2017), Lyme disease (Rebman *et al.* 2017) and chronic fatigue immunodeficiency syndrome (Clarke and James 2003). Like many other contested conditions, these diseases were initially framed as originating in the minds of female-looking people (see Martin and Lemos 2002). Research centring the voices of affected individuals has revealed these and other contested conditions to be both physiological in nature and capable of impacting people of any sex (Rosenberg 2006).

The importance of exploring contested conditions also extends beyond the realm of physical health. This manuscript itself illustrates how diseases that are primarily physiological in nature can have broad-ranging impacts across multiple domains of health. CF directly affects the social, emotional and behavioural health of people who live with it (Quittner *et al.* 2005). It also has deep implications for environmental health management (Davidson *et al.* 1995). Likewise, these impacts extend across time and context. The process of diagnosing CF brings its own unique challenges, especially in cases where the process requires multiple attempts or yields conflicting results. Our explorations of narratives specific to CF thus inform a broader call for use of autoethnography in the critical sociology of diagnosis (see Jutel 2011).

We further affirm and encourage the use of personal narratives beyond autoethnography as tools for illuminating theoretical constructs in the experience and management of chronic illness. Many early examples of the value of this approach came from the literature on cancer experiences. This literature includes explicit attention to diagnosis and misdiagnosis (Paget 1988) and the ways these experiences can engage the firsthand perspectives (Paget and DeVault 1993). Other key examples from earlier literature on cancer include: explorations of intertwining individual perspectives (Butler and Rosenblum 1991); discourse on fear of symptom recurrence (Horlick-Jones 2011); and exposition on the nuances of interventional care (Riessman 2015). Reaching beyond narratives specific to cancer, earlier literature on illness experiences also includes attention to humanistic perspectives centring individual journeys (Plummer 2010), and reflections on the broader value of storytelling about chronic illness (Frank 1998).

Calling on these traditions throughout this piece, we have noted numerous ways frames, or definitions of a given health and illness situation, influence the entirety of illness management and reaction to new medical information over time. We thus echo *both* Barker's (2010) call for greater attention to the social construction of what health and illness are in specific cases and Charmaz's (1983; Charmaz 2000) ongoing calls for systematic analyses of the ways people narrate and manage health and illness over time in relation to shifting meanings, circumstances and situations. The combination of such efforts may reveal many missing pieces in the ways health and illness play out and become relevant throughout the lives of people.

Our findings also complicate existing tendencies to sometimes focus *only* on predicted probabilities and broad-scale hypothesising in making sense of health and illness. Although such endeavours are especially important when seeking to make sense of broad-scale patterns and distributions in health and illness throughout society (see Grollman 2012), they may facilitate limited or inaccurate understandings of what health and/or illness may look and be like in given specific, empirical, lived cases. Furthermore, overreliance on probability, as Barker (2010) notes, may lead to blind spots in the complexities of health and illness within concrete bodies and lives. Echoing much other qualitative work on the social construction of health and illness over time (see, e.g. Charmaz 1983, Nowakowski 2016a, Rier 2000), our findings remind us to continue always going beyond the probabilities to systematically ascertain what happens beyond a given data set in the empirical experiences of actual patients, doctors, health patterns and illness trajectories over time.

Address for correspondence: J. E. Sumerau, 401 West Kennedy Blvd. Box Q, Tampa, FL 33606, USA. E-mail: jsumerau@ut.edu

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