

My experience with ME/CFS and implications: A personal narrative

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Abstract. Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a chronic, debilitating health condition characterized by overwhelming fatigue and post-exertional malaise, or exacerbation of symptoms following physical, mental, or emotional exertion. ME/CFS often impacts every aspect of an individual's life, and one's new reality may be much different from the daily life experienced before the onset of the condition. Though the long-term effects of COVID-19 have brought increased attention to chronic fatigue and related disorders, ME/CFS is still vastly understudied and frequently misunderstood. People with ME/CFS are often passed between various healthcare providers as evidence-based treatments remain scarce. These patients are sometimes sent to rehabilitation professionals, who often lack appropriate education and experience with this patient population. This article describes the experience of a young woman and physical therapist with ME/CFS following COVID-19 infection, as well as potential implications for rehabilitation professionals and those who care for those with this condition.

Keywords: Myalgic encephalomyelitis, postviral fatigue syndrome, PASC, long COVID, rehabilitation

1. Introduction

My experience with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) began in the spring of 2020, following an infection with COVID-19. While the illness I experienced after being infected with COVID-19 was the worst of my life to that point, I fully expected to recover and be back to my usual self soon. I was not even aware of ME/CFS then, and I certainly did not anticipate what would unfold over the following months. As a physical therapy student in a busy first year of courses, I returned to my studies as quickly as possible. I pushed forward for a few months, then finally made an appointment with my physician after it was clear that something was wrong. It had been months since my infection, but my joints ached constantly. One day,

I was sure I had sprained a knee ligament because the pain was so sharp. I had frequent low-grade fevers, a headache I could not shake, difficulty thinking, and unrelenting exhaustion. Appointment after appointment, I was left with nothing. Every test under the sun seemed to be thrown at me in the next few months, but everything would return negative. I appeared to be getting worse, spending all my energy each day keeping up with my schoolwork and spending the rest of the day wanting only to go to bed again. I kept attending appointment after appointment but left feeling just as helpless as I was before. Even getting to an appointment and getting through the appointment would leave me completely wiped for the rest of the day.

I began to see articles detailing the experience of those with long-term symptoms following COVID-19 infection, and I quickly read each as soon as they became available. The experience and symptoms of those with post-acute sequelae of SARS-COV-2

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infection (PASC), commonly called long COVID, resonated with me immediately. Highly functioning professionals were struck down in a matter of days by an illness that others would recover from without issue. Some couldn't work, while others were limited to a small percentage of their previous capacity. Overwhelming exhaustion continued to be my primary limiting symptom, and I was diagnosed with ME/CFS about a year following my COVID-19 infection.

I became interested in ME/CFS and conditions involving chronic fatigue as I expanded my knowledge of long COVID. Being diagnosed with the condition helped me make sense of some I had been experiencing. My ME/CFS would be considered "mild" by most classification systems, underscoring how severely this illness can affect an individual in all capacities. I continue to be a full-time student and try to participate in other activities as much as possible, but my world has been turned upside down by this condition. I hope to offer my experience with ME/CFS from both the perspective of a physical therapist and a young woman attempting to continue living her life. I know others like me suffer from relatively hidden fatigue and appear to many exactly as they were before in public settings while their life plans, worldview, and physical abilities have been shaken to the core. In the following sections, I hope to introduce ME/CFS and share my experience relating to physical, cognitive, and mental health changes that I have experienced as a result, as well as implications for rehabilitation professionals and those who care for people with this condition.

2. ME/CFS

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a chronic condition characterized by overwhelming fatigue that is not relieved by rest [1]. While extreme fatigue is considered a hallmark symptom of this condition, other symptoms are common, including issues with sleeping, headaches, cognitive dysfunction, flu-like symptoms, shortness of breath, autonomic dysfunction, gastrointestinal distress, and muscle and joint pain [2, 3]. Post-exertional malaise (PEM), or worsened symptoms following physical, mental, or emotional exertion that would not have caused aggravation before becoming ill, is an important component of ME/CFS [4]. These episodes of worsened symptoms may be described as a "crash," and recovery may take days or weeks [5]. Women are about three times more likely to be

diagnosed with this condition, and the peak incidence occurs between the ages of 10 and 45 [6, 7]. ME/CFS can significantly impact many areas of an individual's life, and up to 75% of those with the condition are not working [8]. ME/CFS also frequently presents with comorbid conditions, often other complex, chronic conditions such as fibromyalgia, irritable bowel syndrome, myofascial pain syndrome, and interstitial cystitis [9, 10].

The cause of ME/CFS has not been established, but links to various infections and changes to the immune system or energy metabolism systems have been suggested [11, 12]. There are few established treatments, but activity pacing and avoiding PEM by remaining within an individual's energy limits are common recommendations [13]. Though it has been estimated to impact 17–24 million people worldwide and up to 2.5 million Americans, ME/CFS has remained among the lowest-funded conditions in the United States by the National Institutes of Health (NIH) [14, 15].

3. Physical experience with ME/CFS

The change in my physical health since my diagnosis with ME/CFS has been drastic, particularly compared to my previous life. I was formerly an elite triathlete, becoming an All-American and two-time regional champion before a congenital hip defect slowed my career. While the following two hip surgeries effectively ended my career a few years later, ME/CFS took away much more than my athletic career; it took my daily function as I knew it as well. As my athletic career was ending, I threw my efforts into academics, finishing my undergraduate years with multiple majors and minors, as well as hundreds of hours committed to volunteer work, physical therapy observation hours, and research. There was a feeling of safety in focusing my efforts on academics and my professional success; I yearned for control over my daily life again and thought it would be harder for a physical injury to rip academic success away from me as it had my triathlon career. ME/CFS has certainly changed how I view my autonomy over daily life as well as professional and athletic success.

The most severe symptom that I have experienced daily has been unrelenting exhaustion. I often describe it as having a battery that is at a maximum of 10% full, draining quickly. Once the battery is drained, I cannot charge it. I frequently have the

option to be either physically or cognitively present, but rarely both simultaneously. My muscles often burn when I walk, as if I had just completed an interval set on the track. I am exhausted by mid-afternoon daily and spend most of my evening laying in a chair or bed, working through schoolwork or research material as much as possible on my darkened phone screen, often drifting to sleep multiple times while attempting to perform one task. Lights and sounds seem many times brighter and louder than they once were. At home, I work in darkness as often as I can. I have blackout curtains in each window of my room and always keep them closed. There are days when normal lights make it feel like I am in bright sunlight, and I start to get an aura, warning of a pending migraine. My sound sensitivity has increased greatly as well. Normal conversation volume, or even cars driving by when I drive with my windows open, often triggers my symptoms.

I have had almost daily headaches since my infection, and a worsening migraine headache is the first symptom I experience when I “crash” or do too much in a day. If I don’t treat the migraine in time, it will linger for days. If I push too much, it is almost inevitable that a headache will follow. After a crash has started, it is nearly impossible to do anything at all. I ache all over, am exhausted, feel nauseous, and my heart races. I cannot do anything requiring physical exertion. If I try to do schoolwork or other less physically demanding activities, the migraine and cascade of symptoms worsen, and I am left either sleeping or staring blankly at the wall. It feels like being a prisoner in my own body; I both physically and cognitively cannot do anything, no matter how much I want to.

Most days, I struggle to eat. Since I got sick, I have not been hungry and rely on reminders to eat. During some periods, the nausea will be so severe that I can manage only 500 calories of bland foods daily. At one point, I lost 15 pounds from my healthy weight and honestly felt like the weight loss might never stop. I also developed orthostatic intolerance that is so significant that I am on a beta blocker to lower my heart rate in my 20s after being an elite endurance athlete less than five years ago. Before treatment, my heart rate would jump over 100 beats per minute when moving from supine to standing. Episodes of lightheadedness, vertigo, palpitations, and nausea accompany position changes, and I must now think through a movement and potential implications before acting, especially if it has been multiple hours since my last beta blocker dose. I frequently

struggle to breathe, even with low levels of exertion. I have had a chronic cough since I was sick, and my throat is sore almost daily. On my best days, I estimate that I am functioning at about 20% of my previous physical abilities.

4. Cognitive effects of ME/CFS

The cognitive effects of long COVID and ME/CFS have been startling. I used to pride myself on my memory, excelling in classes requiring the retention of large amounts of material. Now, I will pause during the middle of a sentence, unable to find the words, or even forget what I am saying midway through a thought. Some days while driving, I cannot recall where I am going and why. It is hard to carry on a conversation, and I often feel like my brain is buffering, as though I have a few seconds of delay before my brain can comprehend information it used to understand immediately. I dread interpersonal situations now, anxious about the all too familiar feeling of my mind going blank, freezing, and getting stuck. If I am interrupted while talking, I cannot pick up where I left off. I constantly feel like I have just woken up in the middle of the night, like I am sleepwalking. The very thought of new situations or meeting new people is overwhelming. I constantly feel like I am doing many things at once and can rarely focus on one thing at a time.

5. Mental health effects of ME/CFS

I openly acknowledge that I was, and still am, absolutely shattered by my experience with ME/CFS. Just like anyone else, I had plans, goals, and dreams. Unlike some other medical conditions, I do not think anyone could experience ME/CFS and not be profoundly affected in almost every aspect of their lives. A concept that has fascinated me since beginning my journey with ME/CFS is that most with ME/CFS had a well-established lifestyle before they became sick. There is a “before” and “after” that many can categorize their lives by. To grieve a person still alive, particularly oneself, is a surreal experience and one that I am not sure I will ever be able to adequately describe. I feel as if I have a weight held over me daily, sometimes suffocatingly heavy. Some days it’s an emptiness that I cannot identify; it feels as if I don’t even have the energy to comprehend what has happened, and I have lost something so basic that I did

not think I could lose it. I no longer remember what it feels like to be healthy. On other days, I will see a reminder of my past life and the loss feels tangible.

Just as with most forms of grief, my ability to deal with my new life varies by the day. Some days I can look back at a memory and smile, and some days I cannot stop weeping. My productivity is much the same. There are days I feel that I can contribute and days I can accomplish something meaningful. Then there are days when I can barely make it down the hallway, when I cannot stop the tears, and I miss it all so much. The days seem to blend; the only real goal is to survive until I can sleep again. I wish for a day of my old life, even just an hour. It feels like getting trapped in your own body without ever having a break. I feel like I have been treading water in the middle of an ocean, my head barely above the water, for nearly three years without a minute of rest.

Having the most basic parts of my life ripped away led to significant challenges to my outlook on life and my goals. I no longer have control over everything that was meaningful to me, and I realistically acknowledge that I will never again reach my maximum potential. As an athlete, and as a student, I reached peaks that few will reach, and it hurts to know that I will never again rise to those heights. I believe there is no “correct” way of coping with any chronic illness, and this holds true for ME/CFS. I still struggle with how to move forward, and I likely always will. I am and expect to always be angry, and while many might consider anger to be an undesired emotion, I feel it has often been the only force pushing me forward. Many days seem aimless, and my desire to live varies by the day. It can seem impossible to push forward when everything you care about has been changed beyond recognition or demolished, and your health limits new directions. However, on the days I am angry or feel even a glimmer of the competitive fire I once had, I feel a connection to my former self and briefly feel alive once again.

I consider myself broken and believe I would rather be authentic and broken than pretend to be healed and at peace. Coming to terms with one’s new life is a very personal journey, and I would caution against expecting the person with ME/CFS to be the person they once were. It is impossible to say what aspect of my health has been impacted the most since my illness, as I feel the categories are not comparable. However, just as is the case with most life-changing diagnoses, my mental health has been dramatically affected, and I will never view the world and my autonomy in it as I once did.

6. Implications for rehabilitation professionals

I am also a physical therapist. While generally conflicted to admit this in the context of ME/CFS due to many rehabilitation professionals’ dismissal of complex, chronic conditions such as ME/CFS, I do think my experience as a student, professional, and patient of the rehabilitation sciences profession has helped me identify where issues in the field currently lie concerning ME/CFS and other chronic conditions. In my view, the culture of the rehabilitation science professions, and by extension the traditional medical community at large, is a central issue. Many with poorly understood conditions such as ME/CFS continue to be dismissed and undertreated by the medical community.

I feel that a change in the culture of rehabilitation sciences toward complex, chronic conditions such as ME/CFS must begin in schools. I do not think this issue of negative culture toward complex, chronic conditions is unique to less established schools or schools with fewer resources. I am a recent graduate of a Doctor of Physical Therapy program considered among the most prestigious in the United States. I have countless examples from my education alone that have convinced me that the issue with culture in the field of physical therapy with regard to complex, chronic conditions such as ME/CFS starts from the very beginning of training. There was next to no education regarding ME/CFS and little regarding other complex, chronic conditions such as irritable bowel syndrome, interstitial cystitis, and various chronic or atypical pain syndromes. However, respect for those with these conditions often seems worse than knowledge about them. There seems to be little consideration of the lived experience of those with these complex, chronic conditions. I remember sitting in class in physical therapy school as a faculty member derided those with complex, chronic conditions as using their symptoms as “an excuse not to do anything” or for “attention” and stated that those with chronic pain develop their condition because “they have never experienced pain before in their lives,” stating that others “just want workers’ compensation.” A clinical instructor told me about those with chronic pain: “dealing with even one of them is too many.” Given exposure to these comments as a young professional at a well-respected physical therapy school, it is no surprise to me to see how patients with ME/CFS have been treated in many healthcare settings.

However, I have also worked with clinicians who have taken an interest in these conditions, sought out additional education, and have asked for my ideas on how to best help these patients and what the field needs to do to improve each patient's experience. I think the culture in the rehabilitation sciences is a serious problem, but I do feel that there are clinicians interested in helping this population. Even if changing the entire medical establishment's acknowledgment and respect for conditions such as ME/CFS might be far-fetched, I think having a small but strong contingent of those rehabilitation professionals interested and passionate about learning more about and treating people with these conditions can make a difference.

As rehabilitation professionals, I feel that the most important words a patient can hear from us are that they are believed and that their symptoms are real. From my experience as both a student and patient, I am aware that few healthcare professionals are knowledgeable about ME/CFS. As a patient, I have been told that my symptoms are due to stress and that I "just notice symptoms more." However, I think there is an even more important problem to address than lack of education. It is unreasonable to expect every healthcare professional to be an expert on every condition. A change in mindset is more important than brief education that can be quickly forgotten. Some practitioners may treat those with conditions like ME/CFS and chronic pain as inferior because they worry that if those patients do not improve as a "normal" patient would, it reflects negatively on their abilities as a healthcare professional. I caution us from viewing these conditions this way, as even modest objective improvements can make meaningful changes in an individual's quality of life. Acknowledging that we have more to learn about the condition and that we are committed to caring for the patient regardless of the diagnosis in their chart is a better place to start. While we may think it would be frustrating to hear "I don't know"- and it is- I feel we owe our patients honesty, transparency, and a willingness to educate ourselves and apply our training the best we can for each patient. There is no way that we can be prepared for every condition that every patient that could walk through our doors may present with; however, we can adopt a mindset of continual growth and development, empathy, and a willingness to serve all.

We frequently hear of patient-centered care in the healthcare professions, but in my view, we rarely

see it in action in the context of complex, chronic conditions. I think there are many reasons for this: billing practices and medical management, healthcare infrastructure, limited time with our patients, lack of education, and a culture normalizing the thought that patients with complex, chronic conditions are overreacting, lazy, or having issues dealing with symptoms that we all experience. These issues are not easy to address but working on the culture and the ability to retain an open mind and mindset of constant learning and growth is one of the most important starting points.

Another important change I think we can make as a healthcare field is how we discuss psychiatric comorbidities such as depressive and anxiety disorders, which are common among those with complex, chronic conditions [16]. I cannot even remember the number of times I have seen a note in a patient's chart start with "patient with depression and anxiety presents with..." I would challenge us to consider why we are writing this phrase, particularly as an opening statement. Do these two conditions somehow invalidate what the patient tells us? Do these two conditions make us think that the patient's physiological complaints are any less severe? Instead, I challenge us to see anxiety and depressive conditions as mere comorbid conditions that we should be aware of as providers. Research indicates that mood and anxiety disorders can be both predisposing factors *and* sequelae to complex, chronic conditions [17]. As providers, we simply cannot and should not make assumptions. With the example of ME/CFS in mind, I cannot imagine a way that these complex, chronic symptoms that devastate the life we once knew would not cause a level of anxiety and depressive symptoms in almost everyone with the condition. I would encourage us to think of treating psychiatric illness and psychological symptoms as equal to physiological symptoms but not deferring treatment for physiological symptoms because psychological symptoms are present. The presence of any psychiatric disorder should not discount the patient's experience of any other symptoms.

I also feel that one of the worst things we can do as a clinician for those with ME/CFS is guaranteeing the patient that they will feel better or referring to "when you are better." For complex, chronic conditions with no end in sight, I think it is vital to identify ways that the patient can still participate in their life in ways meaningful to them as they are, rather than waiting for an improvement that may never come. However, I caution against offering statements involving "at

least you can still . . . ” as the patient’s loss should never be discounted, and only they can define what is meaningful to them.

7. Caring for people with ME/CFS

To those who care for someone with ME/CFS, I feel the most important words for someone with ME/CFS to hear is that they are still valued as a person. It is common in daily life to hear compliments about our actions or our accomplishments. I caution against emphasizing only these aspects with patients with ME/CFS, as those with ME/CFS often have little control over what they can accomplish daily, and productivity can vary greatly. Instead, letting them know that we value them as friends, partners, or colleagues can be more important, emphasizing their qualities as a person rather than objective success. In addition, general statements such as “let me know how I can help” put the person with ME/CFS in a position in which they must invest more energy to get assistance. I have often been so lost and exhausted that I have no idea where to even start concerning asking for help. If you would like to aid a person with ME/CFS, I would encourage asking if you can perform a specific task for them such as “can I cook dinner?” or if you can tell the person with ME/CFS is experiencing a crash, ask “can we postpone our plans to a day you are feeling less exhausted?” I find it is easier to answer these questions and easier to accept help offered in this way as well.

Family or friends are among the most likely to see a person with ME/CFS as they are struggling the most. Concerning my own experience, I can sometimes hold my health together long enough to appear somewhat normal in public but crash as soon as I get home. Grief is certainly not a linear process, and neither is living with ME/CFS. I feel that allowing people with ME/CFS to define themselves and their experience with their illness is vital. I think there is frequently a cultural expectation for positivity, if for no other reason but to avoid making those around us uncomfortable. While focusing solely on loss may not be the best coping strategy, I do think it is important for us to acknowledge our thoughts, feelings, and doubts without having to find a “silver lining” that may not always be present. Accepting those we love as they are, not how we would like them to be, is a critical step in showing support for those who may be struggling.

8. Conclusions

If there is one concept that I have learned through my experience with ME/CFS, it is that the common perception that we can understand another person and their situation could not be more misguided. When I was an elite triathlete less than a decade ago, I could never have comprehended a fraction of what I now live with daily. I encourage us to view all individuals we encounter similarly. ME/CFS has affected every aspect of my health, my outlook, and my plans. However, I do not think you have to have experienced ME/CFS to offer an open mind, your heart, and support to those with this condition. I grieve what I have lost daily, not just in terms of the past but also my plans and dreams for the future. I frequently wonder how this condition will impact what I will be able to do with my life. However, I find purpose in sharing my experience and the resulting implications as I understand them.

I hope that advances in research will drive both improved treatments for patients as well as increased training and acknowledgment of ME/CFS in rehabilitation science and medical schools. Until then, I expect that many people with this condition will continue to struggle through each day. The situation can seem hopeless at times. However, I will never discount each person’s chance to make a true difference by believing these patients, learning from them, and advocating for all who experience ME/CFS.

Ethical approval

Not applicable.

Informed consent

Not applicable.

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Conflict of interest

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