

“Being a Patient’s a Full Time Job”:
Perspectives of People with ME/CFS Towards Work Incentives

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Abstract

Chronic fatigue syndrome (ME/CFS) is a debilitating illness of uncertain etiology that is characterized by variable degrees of post-exertional malaise. While many Americans suffer from this condition and a majority of them are unemployed, it is surrounded by significant social, cultural, and scientific controversy, and there is no consensus on its cause, symptomology, and, significantly, treatment—despite decades of research. In this study, 15 people with ME/CFS who receive SSDI and/or SSI were interviewed about their attitudes towards return to work and to the Social Security Administration (SSA) work incentive programs such as Ticket to Work. The study sought to understand how a context of scientific controversy over rehabilitation treatments impacts return to work. It was found that lack of treatment options, the iatrogenic effects of appointments and paperwork, the inconsistency of debilitating symptoms, and the fear of the reapplication process were all reported as barriers to return to work. This study shows how stigma and scientific controversy compound the task of rehabilitation and suggests potential areas of policy intervention.

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Background

Chronic fatigue syndrome (CFS), also known as myalgic encephalomyelitis (hereafter ME/CFS), is a long-term, multi-system illness of uncertain cause that is characterized by variable degrees of post-exertional malaise (CDC, 2017). With estimates suggesting up to 2.5 million Americans living with the condition, ME/ME/CFS may affect as many Americans as HIV/AIDS and multiple sclerosis combined (Institute of Medicine, 2015). However, a significantly smaller number of Americans are actually diagnosed with ME/CFS. This is because, three decades since it was initially defined by the U.S. Centers for Disease Control (CDC) in 1988, ME/CFS remains a medical puzzle: patients report disbelief from doctors and even their families and friends, there are no U.S. Food and Drug Administration (FDA) approved treatments, there is no consensus regarding its cause, and doctors remain underinformed about the disease (IOM, 2015). It thus remains a prime example of what social scientists of medicine have termed contested illness (Dumit, 2006).

Once stereotyped as “Yuppie flu” when it emerged in the 1980s, ME/CFS was reputed to be a disease of perfectionistic “educated adult white women” (Straus, 1988) many of whom were simply feigning illness in order to gain relief from their responsibility to work (Abbey & Garfinkel, 1991). To counter these notions and the dismissals of their condition, a vibrant and visible patient-activist community has emerged around ME/CFS that is insistent on the necessity of more research into causes, the search for a cure, and, above all, the reality of their condition. This movement has experienced some success, with ME/CFS subsequently witnessing a degree of societal de-stigmatization and modest recognition in the form of research funding, yet there are still no biomarkers for ME/CFS, no definitive diagnostic tests, and no consensus among medical professionals as to the best way to treat ME/CFS or rehabilitate people with ME/CFS (PWMEs) (NIH, 2017).

This research investigates how sociocultural factors influence decisions to pursue return to work incentives such as Ticket to Work (TTW) among 15 patients who receive Social Security Disability Insurance or Supplemental Security Income (SSDI/SSI). According to the Institute of Medicine (2015), 54% of PWMEs report being unemployed, and recovery is typically a lengthy or indefinite process, as there are no clear variables or treatment protocols predicting positive work outcomes. In a context of stigma and poor prognosis, the prospect of returning to work is daunting for many PWMEs who receive SSDI/SSI.

Stigma, Disability, and Rehabilitation

Disability insurance is one of few formal ways in which ME/CFS has been recognized as a debilitating and real condition, though it is not an unproblematic one (Klimas and Patarca, 1997). While a ME/CFS diagnosis alone does not qualify one for SSDI/SSI, many PWMEs successfully seek SSDI/SSI, as evidenced by a recent policy ruling (SSA 2014) providing guidelines for evaluating cases involving ME/CFS. This policy spells out the fact that laboratory medical testing for ME/CFS is generally inconclusive; a ME/CFS diagnosis alone is insufficient and therefore must be supplemented with other ways of establishing impaired functionality. Social science scholars have typically understood the successful medicalization of a disease

entity in terms of its recognition by medical professionals and their consensus surrounding the unambiguously *medical* character of the problem at hand (Conrad, 1992). Yet, as the case of ME/CFS demonstrates, a diagnosis can gain partial legitimacy (e.g., not viewed as completely psychogenic or feigned) in the absence of definitive medical knowledge and in the enduring presence of significant scientific controversy and social stigmatization. This paradox makes ME/CFS an ideal case study through which to understand relationships between the legitimation of disease, the ability to work, and disability insurance because it is a relatively unique and concrete example of how a diagnostic entity can exist and receive institutional support in the absence of medical consensus and without well-defined treatment pathways.

There is no consensus on the best way to treat ME/CFS in order to restore functional capacity and potentially facilitate return to work. ME/CFS has no FDA-approved treatments (FDA 2013). Unfortunately, only two techniques, exercise therapy (GET) and cognitive behavioral therapy (CBT), have been justified via limited evidence from randomized controlled trials (RCTs) (Nijs & Malfliet, 2016). RCTs are a “gold standard” of evidence-based medicine (EBM) (Timmermans and Berg, 2003). Nevertheless, GET and CBT remain two of the most controversial strategies through which to pursue ME/CFS treatment, with evidence suggesting GET makes the condition worse (Twisk & Maes, 2009), and subjective accounts from ME/CFS patients reporting near-universally negative outcomes from GET/CBT (Gladwell, Pheby, Rodriguez, & Poland, 2014). This context—a significantly constrained landscape for rehabilitation options, littered with scientific controversy and uncertainty—loops back into the stigma and incomplete medicalization patients associated with their disease.

Like medicalization, the concept of the “sick role” has been a defining paradigm in the field of medical sociology. Parsons (1951) notes that illness is one of few ways individuals in society gain exemption from their normal social obligations such as going to school or, importantly, to work. Parsons points to certain responsibilities the sick person has in return for the relief of obligation, such as the responsibility to get better. By extension, for the SSA, “disability” is itself defined as the *inability to work*, and one goal of SSA is to incentivize rehabilitation and return to work. But as Parsons writes, in order for the sick person to inhabit the sick role, the “claim to exemption must be socially defined and validated” (456). The case of ME/CFS and other contested illnesses complicate the sick role because rehabilitation, return to work, and even the validity of the illness are challenged when profound controversy exists over the condition at hand.

Scholarship in STS has also demonstrated the role that classificatory systems and regulatory bureaus like the International Classification of Diseases or the Food and Drug Administration can play in shaping how an illness is understood (Bowker and Star, 2000), even helping to define “health” (Dumit, 2012) and “disease” (Greene, 2007), themselves. These scholars do not necessarily address disability insurance as one such apparatus, nor do they unpack the slippery relationship between disability and chronic illness (cf. Wendell, 2001). While disability studies has emphasized the role of disability insurance in defining the normal and the pathological (Schweik, 2010; Rose, 2017), they have mostly limited their research to the historical origins of disability insurance in the US, which lie in the early twentieth century; my project will address this gap by examining the contemporary implications of the ability to work and the definition of disability. Wailoo’s (2014) important study is a notable exception, demonstrating how determinations of chronic pain and disability became political up through the

turn of the twenty-first century because of pain's ambiguity and its resistance to reliable measurement.

New, contested, or emerging illnesses are frequently subject to scientific controversy. But Epstein (1993) compellingly demonstrates that, in the case of HIV/AIDS research in the 1980s, experiments did not by themselves “solve” scientific controversy; this is especially true when patients are highly educated about, and organized around, their illness. Here, scientific uncertainty is not the cause of controversy, but its result, and thus additional research often does little to “settle” controversies (333). Murphy (2006) has applied this insight to sick building syndrome, a condition that, much like ME/CFS, came to light through the efforts of lay-expert patient-activists but whose etiology and realism were surrounded by doubt and uncertainty. However, while each considers the role of government plays in the management of scientific controversy, neither study this through the lens of disability or the SSA.

Finally, applied research on ME/CFS has shown that PWMEs are often highly dissatisfied with their existing options for rehabilitation (Gladwell et al., 2014; Heiman, 1995; Nijs & Malfliet, 2016). These studies have been survey-based and while they provide compelling empirical evidence of the fact of dissatisfaction, they underestimate the profundity of scientific controversy that surrounds ME/CFS research and the sociocultural factors that may make GET and CBT unappealing to PWMEs. For instance, Gladwell et al. (2014) suggest that more information on protocols will improve the ME/CFS patient's experience with rehabilitation, but they miss the reasons PWMEs are distrustful of rehabilitation in the first place, in ways that more information may not ameliorate. Moreover, the applied research on ME/CFS rehabilitation has primarily been conducted in the United Kingdom, where there is a nationalized health care system; this limits its translatability to the US context.

This study was designed to close these gaps in the research. While applied studies have identified obstacles for return to work for PWMEs, the larger social context constraining options for rehabilitation has been overlooked. By utilizing in-depth interviews, this exploratory study aims to provide fruitful directions for further research and directions for potential policy interventions.

Research Design, Methods, and Data Analysis

Methodology. This exploratory study was designed to understand perceptions of rehabilitation and return to work among PWMEs who receive SSDI/SSI. There were two main research questions:

1. Do social factors—such as disease stigma and the sick role—impact PWMEs' decisions to utilize or not utilize work incentives? Does the receipt of SSDI/SSI benefits bestow social legitimation, and consequently, is the possibility of losing SSDI/SSI benefits linked to the loss of legitimacy?
2. How do lack of treatment options impact PWMEs' perceptions of return to work?

To answer these questions and to fill the gap in the existing literature, an exploratory approach was chosen, comprised of 15 semi-structured interviews of approximately 45 to 60 minutes in length. An interview schedule with questions was developed in advance of recruitment. Qualitative methods and the semi-structured nature of the interviews were chosen due to the lack of research in this area. The goal was to develop theories given that themes could not be postulated in advance.

Participants. Using a community ME/CFS listserv comprised of a nationwide network of PWMEs, I recruited participants who currently receive SSDI/SSI and invited them to enter demographic and contact information via a secure Google Form. While online distribution methods can sometimes limit access for people with certain impairments (CITE), this demographic expressed during interviews the ways in which listservs and online communities were lifelines for them as bed- or house-bound people.

I sought to interview 20 PWMEs. After a two-week period of recruitment, n=37 responses were registered to account for attrition. Next, applicants were screened for demographic representativeness and eligibility. Most respondents reported identification as both female and non-Hispanic white, with only n=3 males responding and n=3 other-than non-Hispanic whites. One respondent was ineligible, bringing the total number of eligible participants to n=36. After attempting to schedule interviews with all 36 of the eligible patients, only n=16 were able to successfully schedule and complete the interview. There was one patient who was excluded from this study due to the fact she relayed during our interview that she did not believe she was correctly diagnosed with ME/CFS. All individuals had been formally diagnosed with ME/CFS, although some (n=3) were not certain that they were receiving SSDI/SSI “for” ME/CFS, and the stories of many interviewees were characterized by a complex layering of co-morbid diseases.

Out of the 15 patients included in the study, n=12 were non-Hispanic white, n=2 were Hispanic white, and n=1 was Black. In addition, n=14 were female and n=1 was male. Ages ranged from 39 to 63 years old, and the mean age was 51.6 years old. While ME/CFS affects people of all races equally (Jason et al. 1999) and women are overrepresented in my sample, this age range is demographically representative, as it typically affects people ages 40 to 60 (CDC 2018). Since recruitment was completed online and interviewees were given the option of completing the interview over the phone or video call, participants lived in a variety of locations across the country, although the most common state (n=6) was New York.

The mean length of time since approval for SSDI/SSI was 9.4 years, with participants ranging from having been on SSDI/SSI for a few months to over two decades. The number of years living with ME/CFS ranged from 3 years up to 29 years, with an average of 13.5 years sick. The time between getting sick and receiving SSDI/SSI also varied, from within six months to 14 years, with a mean of 4 years. Fifteen participants received SSDI and one participant received SSI. All participants were familiar with Ticket to Work and work incentives. However, only one participant had attempted to utilize Ticket to Work. After participants were recruited, they were assigned numerical identifiers and then pseudonyms.

Procedures. The 45 to 60-minute interviews consisted of four sets of semi-structured questions: (1) the process of getting diagnosed with ME/CFS; (2) the decision to apply, and process of

applying, to SSDI/SSI; (3) current home life, activity level, and social support; and (4) decisions to utilize Ticket to Work. Interviews took place over the phone (n=11), video chat (n=3), or in-person if the individual was able to travel (n=1 interview). They were recorded with an audio recorder and then transcribed. All interviewees were contacted for brief (15 to 30-minute) follow up interviews.

Data analysis. The transcriptions were coded using Atlas.ti. I began with in vivo and descriptive codes as the basis for upper-level themes. The descriptive themes included “application process,” “social support,” “diagnosis/testing,” “management/treatment,” and “work.” I then developed sub-codes that became the basis for identifying emerging themes and patterns across interviews. I created a network analysis that identified linkages between codes consistent across interviews. In order to ensure the validity of the data, I cross-checked between official documents and the interview transcripts. In addition, the basis for the top-level theories and claims in this paper had to be represented in a majority of the interviews.

Findings/Results

In relating the process of applying for SSDI/SSI, people with ME/CFS spoke fondly and nostalgically about their ability to work, but all expressed their doubt that they could ever return. Work was a painful subject for many interviewees. For them, the ability to work was more than just a stream of income. Losing the ability to work frequently also meant loss of personal identity, the severing of social ties, and the reluctant acceptance that they are “truly disabled.” While this might suggest that SSA work incentives would be useful to PWMEs, most interviewees expressed that these program “don’t apply” to them or “aren’t set up” for PWMEs. Moreover, many expressed reluctance to try to go back to work in the face of constrained options for treatments, the fatiguing nature of everyday life activities, the consistent hours and commuting demanded by most workplaces, and the fear of their condition getting worse if they tried to work again and thus the accompanying difficulty of reapplying. The reasons and contexts for these explanations will be explored in the discussion section.

Constrained treatment options

For many interviewees, lack of treatment options was both the cause of their leave from work, and an obstacle to returning to work. Given the absence of FDA-approved treatments and limited strategies for symptom management, the number one technique reported by interviewees was learning how to “pace” and live within their limits. The experience of trying to continue to work despite debilitating fatigue left an enduring impression for many PWMEs. For many, symptom relief—however minimal—arrived only after they stopped working and were able to pace themselves.

Many PWMEs reported that they had attempted to continue to work despite growing symptom severity and the diagnosis of ME/CFS. Many developed elaborate strategies to manage fatigue in the absence of other treatments. Indeed, for two patients, learning that there were no treatments came hand-in-hand with receiving the diagnosis:

In the end, [the doctor] said, “Well, you know I hate to tell you this, because we can't do anything about it. But I think you do have chronic fatigue syndrome.”

- Linda, 63, Oregon

[The doctor] diagnosed me with chronic fatigue syndrome and he said, “I'm sorry, but there is no treatment for it. You know, you just have to learn to live with that.”

- Marjorie, 56, Illinois

Some spent the weekends nearly entirely in bed just to be well enough to go to work on Monday. Glenda, a woman in her 60s who once had a busy career in interior design in New York City, reported retrospectively on her routine: “I took out my suit Friday. I took out my shoes Saturday, back in bed. Took out everything else I needed on Sunday. And Monday morning, I was up at five o'clock. I was about to drive into Manhattan [but] I couldn't even crawl down the hall to the shower.” Similarly, commuting took a toll on many PWMEs and the creative strategies to manage the fatigue became increasingly untenable. Eleanor, a woman in her late 50s, reported, Eleanor reported, “I got a hotel room right near my office. And I basically took a taxi to work, taxied back, [then] crashed in the hotel room.” She did this for “a little over six weeks” until it became impossible to continue this commute. Likewise, Crystal, a former nurse from Queens, recounted her futile quest to continue to work:

I adopted different strategies to try to get to work...you have to push through everything and take breaks. I had to call a cab to get to the train. And that was my break after getting dressed, right? So, phew, I can sit in the cab. Get my bearings, walk down to the train, catch my train, and I got a seat because that's the first stop. So I catch my break there to get a little bit of rest. Then I have to catch my second train, and sometimes I would get a seat, sometimes not. Then I would get to work, and I get to then sit quietly for a minute to get myself together--but not really, because you're the assistant director of nursing and people need you, so you're not really getting a break.

The level of detail she gave was representative of the ways in which minute tasks become difficult to manage for PWMEs.

Optimism surrounding treatment prospects varied, and it was negatively correlated with age and length of time sick. For example, Stephanie, tied with one other participant as the youngest in the study at age 39, relayed that while she has not found anything that works for her yet, “I'm still searching.” Joyce, who has been sick for less than three years, expressed a degree of hope: “In the back of my head, I keep thinking, 'Well, what if they come up with something? I could be one of the people who gets better.’” On the other hand, Bee, who has been sick since the early 1990s, told me: “I got to tell you, in 23 years, I've sort of given up hope that I'm getting better.” Judy, who has been sick for 29 years, similarly expressed skepticism: “And the people who've recovered, you know, they just want to give you all this advice and, 'I did this.' And I'm kind of like skeptical...you're just like, (*in disbelieving tone*) ‘Really? *You recovered?*’” Interviewees emphasized that they would like to get better, but none had experienced enough treatment success to be able to seriously consider return to work.

Fatiguing appointments

For PWMEs, fatigue results from exertion of all kinds—physical, mental, and emotional. Thus, all interviewees reported difficulty with everyday life activities such as household chores, errands, and hygiene. But what is perhaps more surprising is that many reported that the difficulty of managing the condition itself entailed iatrogenic effects; the many appointments and piles of paperwork to contend with exacerbated symptoms and made return to paid labor seem even more difficult. Participants mentioned both routine doctors' appointments and also specifically the functional capacity evaluations required by SSA.

Indeed, intriguingly, as one interviewee described it, “being a patient's already full time.” This statement might be applied to a number of chronic conditions, but other participants described the specificity for ME/CFS, where debilitating “crashes” can seem disproportionate to the energy expended—energy which does not have to be physical but also might be mental or emotional—and yet is often “invisible” to the outside world. The dearth of scientific knowledge and institutional protocols surrounding ME/CFS made moving through these processes more difficult:

You're writing these letters when your brain can't cohere what you're saying. And you're trying to walk your doctor through it and she's not familiar with this, even though she's done disability--because she's used to more cut-and-dry physical disability, like this person lost their legs...She knows how to write that. [But] how do you write: “Yes, all her stuff works, but none of it works well, and it's completely unpredictable when it's going to go poorly. And after she takes her shower and does these things, she can't actually leave the house--she's so exhausted.” That's not normal. You can't write that up easily.

- Joyce, 48, Wisconsin

For me, trying to fill out the *forms* for disability, I got very sick.

- Marsha, 52, Delaware

On top of the difficulties of trying to manage their condition, Ticket to Work seemed a daunting prospect. One interviewee reported feeling “inundated” with information, despite her background as an HR professional:

It's just been a complete roller coaster and, I can't even *process* half of the information of what they're sending. And for someone with an HR background, I can't *imagine* what it's like for somebody that *doesn't* have that kind of background.

- Melanie, 39, Maryland

The nature of labor: Consistent hours and travel demanded by most workplaces

Participants held a variety of careers before getting sick, although most were white collar professions, typical “9-to-5 office job[s],” as one participant put it. The former professions of most participants were ones that required commuting. Commuting was a major factor in PWMEs' loss of capacity to work, and it similarly played a role in their capacity to imagine ever

returning. For Joel, a 52-year-old from New York, it was “not the work so much. It's getting back and forth to work.” Even his commute—at the time, only a 15-minute walk—became too much to handle. Similarly, when Joel attempted to return to work and enrolled in a reskilling program, the commute to the training facility became an obstacle: “And I got to the point where, I was determined to go, because it was only three weeks so I was determined to go all 15 days. I just wanted to prove to myself that I could do that. But by the time the third week came, to go for a 9:30 to 2 to session up there, I was arriving at 1:30.” This experience led Joel to think, “okay, I can never do this,” and the resulting crashes made him pessimistic about the prospect of rehabilitation. Linda expressed a similar sentiment: “There's no way that any of the three of us [me and my friends with ME/CFS] could ever hold a job because we just wouldn't be able to go there.”

All the steps involved in the return to work process take travel, time, and energy that PWMEs did not feel they had. For instance, Marsha “can't even go into an office for an interview right now,” much less commute to the job on even a semi-regular basis. Melanie expressed that the TTW centers are inaccessible to her:

From where I am to the Social Security places they do around here, it's about 20 minutes. And that 20 minutes with traffic in the Baltimore area could be an hour...Driving myself wouldn't necessarily be something I [could do]--I'd have to be having a really, really good day, and it's not something that I can plan for, for an appointment. So I'd have to arrange to have somebody take me if that was the case. But even just sitting there—you know, sound and light sensitivity is just something I seriously deal with. Even on good days, it can go from being okay, to, I can't be around any sounds at all.

Working from home was cited as a potentially appealing option for many. Joel once made small sources of income through selling items online, but he was turned down for an otherwise appealing job due to the fact that he would not be able to come into their offices for a training: “I can do X amount of hour's work from home, but it was *leaving* home that was the problem.” Stephanie was able to stay at her former job for longer than she might otherwise have due to a work from home policy: “The saving grace was that they were allowing you to work from home two days a week, and go in three days a week. But I would basically come home from work and crash.” Although this was difficult, it was when they took the policy away that Stephanie finally had to leave her job.

Despite some possibilities for working from home, participants also mentioned further obstacles. Crystal brought up the recurring problem of consistency, even if commuting was out of the picture: “I have to say, what employer's going to hire somebody that can show up one day and then is out for three? And then could show up for two or three days, and is out for one? They don't want to hire you. They don't want anything to do with you. And if you can't be consistent, even if you work at home, no, that doesn't solve anything--because you still have to be consistent.” Indeed, the inability to work predictably and consistency at particular hours was the most frequently mentioned barrier to work. Cynthia, a former nurse who has been sick since 2015 and received SSDI shortly thereafter, spoke wistfully about how much she “loved [her] job” and thought through the possibilities for finding work in the present day:

Right now it's so far out of reach it's unimaginable. But if I could use my nursing even to do something like from home--some kind of, you know, insurance companies have that "call a nurse" service, or something like that? That would be awesome. But again, I'm so limited that I can't imagine anybody saying, "Oh sure, you can work when you want for when you're feeling well enough and not work when you don't. And yeah sure you could do two-hour shifts!" My needs are so great, and my accommodations that I would need to be able to do any kind of work like that, would be so great, that it just can't happen.

Similarly, Brenda, a 56-year-old from California, discussed return to work with her doctor, but it was determined that she could not be consistent enough to try it: "I actually sat down my doctor and we really sat down and we really talked about it. And we both agreed. He said, 'There's just no way, because, could you plan on going into an office? Every single day or every other day on a schedule?' And the answer is no, because each day is different."

Non-hourly work, such as piece work or freelance work, could be one alternative. Josephine, who began work as a freelancer when she started getting sick but before applying for SSDI, expressed concern over how freelancing income would play into determinations of substantial gainful activity:

It's not set up for somebody that was professional and wants to freelance. It's set up for people who are working hourly. And there's no way I can commit to *anything* that's hourly...I was like, well, what if I'm actually just working a hundred hours for \$10,000? That's what my fee is. They're like, "Well, no. Yeah, see, we're not going to see it that way. We're going to see it that you worked these many hours under a reasonable salary."

The way in which gainful activity is calculated (according to income earned) might not reflect the number of hours worked in a freelancing context, especially in an illness whose impairments are unpredictable.

Fear of the reapplication process/fear of getting worse

The fourth and final major factor in considerations of return to work was the prospect of getting worse. The experiences of PWMEs with the disability determinations process varied, but those who were granted approval without having to appeal (n=7) nearly all reported feeling like "one of the lucky ones" or "blessed." Nonetheless, many individuals had to appeal multiple times before being granted approval, and most expressed that they would not like to have to go through the process again.

While several individuals were under the (false) impression that a trial work period would get them "kicked off," most expressed a more generalized anxiety about TTW and work incentives:

My mom sort of felt that if you sign up to return, if you do that, the Social Security will kind of watch you more closely and try to stop paying you. So she's always been very nervous about that whole idea.

- Stephanie

Will that make a big red chalk on my Social Security disability files? It's really anxiety-provoking.

- Linda

I was one of the ones where everyone told me—this was back in the day—do *not* touch that program, because once you start working, and you can sustain, within the hour, they can take you off disability.

- Marsha

In contrast to Marsha, Joel knew that SSA would need to know that he could sustain gainful activity for several months in order for there to be any consequences to his SSDI. Nevertheless, the threshold “was just this weird thing that was hanging over my head” because even if he was able to earn a good amount of money selling items online, he did not think he would be able to sustain it for long enough to earn a livelihood. The risk of going over the threshold and having to reapply was too high for most interviewees, compounded by (1) the difficulty of securing SSDI/SSI in the first place, and (2) the “crash” that would result from having tried to work. Glenda summed up the attitudes of many interviewees when she emphasized to me, “I don't want the stress of reapplying *ever* again.”

Discussion/Implications

The attitudes of people with ME/CFS receiving SSDI/SSI toward return to work were assessed in this exploratory study. Barriers to participating in TTW and other work incentives were described by participants in terms of (1) the lack of treatment or rehabilitative options for ME/CFS; (2) the way in which SSA paperwork, appointments, and routine doctors' appointments already consumed much of their limited amounts of energy; (3) the inconsistency of their symptoms and the trouble of commuting; and (4) the fear of the reapplication process. These point to directions for future research and potential policy implications. Further research might explore whether the difficulty of the determinations process impacts return to work, especially when it comes to contested illnesses that are stigmatized and whose sufferers might inhabit a “sick role” only tenuously. Additionally, the nature of work available to those who do want to work, and the accessibility of reskilling programs, might be reassessed to better accommodate the needs of those who are disabled by chronic, poorly understood conditions.

Does the difficulty of the determinations process impact return to work?

Participants consistently either (a) emphasized the difficulty of the determinations process, or (b) expressed how “lucky” they felt that they had a relatively easy time with approval for SSDI/SSI given the nature of ME/CFS. There were no exceptions among the 15 participants in this study. While most participants mentioned the stigma and lack of awareness surrounding ME/CFS as adding to the difficulty of securing SSDI/SSI in the first place, it might be the case that this is true of other chronic, difficult-to-define conditions, as well. This is a direction for

future research; potentially, a longitudinal study might be designed, tracing individuals through the determinations process and then assessing attitudes toward return to work.

Accessibility of reskilling programs

For the 15 participants in this study, the prospect of returning to work was a daunting one, and the programs designed to facilitate return to work were frequently described as inaccessible. For instance, commuting to training centers in the middle of the city might be difficult for people who are unable to drive themselves and for whom even commuting is exhausting. Once at the center, the bright lights and loud noises of a busy office are enough to send some PWMEs into a “crash.”

These programs should be reassessed for accessibility for all disabilities, including sensory processing impairments and chemical sensitivities. Out of all of the potential barriers to employment for disabled people, the inaccessibility of training centers at the outset of their process may be an especially discouraging sign to PWMEs who want to return to work. Since commuting at all is a challenge for PWMEs, providing transportation or developing in-home consultations or webinars should be considered. Just as asynchronous digital communication technologies are changing the role and shape of physical workplaces, the SSA might similarly utilize technologies that give people with chronic illnesses remote access to its programs.

Developing alternatives to hourly wage labor and commuting

In the United States, hourly wage labor conducted outside of the home has been a standard form of employment since the demise of the putting out system in the late nineteenth century and the regulation of piece work in the early twentieth (Rose 2017). While widely considered a victory over exploitative labor practices, the elimination of piece work and the standardization of hourly labor nonetheless privilege a certain skillset that most PWMEs do not have: the ability to commute to work and to engage in paid labor at predictable, set hours. PWMEs interviewed in this study had highly variable levels of productivity that were not predictable according to certain times of day or days of the week. Thus, this makes them unappealing to American employers, who hire a majority (58.5%) of their workers on an hourly basis (BLS 2016).

Asynchronous digital communications technologies enabled by the internet have increased possibilities for alternative arrangements of labor. Among the most prominent shift these technologies have engendered is the rise of telecommuting, which detethers work from any particular physical location. This detethering enabled at least two individuals in this study to continue to work after becoming sick with ME/CFS. One was a freelancer. When after the recession of 2008, freelancing opportunities dried up, this individual had to apply for SSDI. While freelancing work is something she could continue to do, she reported that SSA evaluations of substantial gainful activity—based on total earnings rather than hours worked—would not be able to accurately compute the extent to which she is disabled. The second individual had to apply for SSDI after her work discontinued a telecommuting policy. Overall, commuting was a major barrier, if not the biggest barrier, to employment for PWMEs in this study.

Nevertheless, exertion of any kind can be harmful for PWMEs, compounded by lack of treatment options or strategies for symptom relief. The kinds of accommodations that would have to be envisioned in such a context are radical. They were difficult even for the PWMEs in this study to imagine, much less for the employers to be able to operationalize within the current arrangements of most American workplaces. Employers would have to allow workers to show up on their own time, to be productive when they can be productive, and to take breaks whenever they may be needed, no matter how unpredictable. Anything less—as the people in this study repeatedly emphasized—may lead to debilitating crashes that make their impairments worse in the long-term. This insight is supported by limited biomedical research that demonstrates the deleterious effects of exercise on this patient population (Twisk and Maes 2009). Encouragement of return to work may be dangerous for the people suffering with ME/CFS, and moreover, it may also be a counterproductive strategy for the SSA, leading to increased debilitation and potentially permanent loss of functional capacity, rather than the stated goal of rehabilitation. Further research and a re-envisioning of work may be needed in order to see a future wherein disabled PWMEs can seek employment.

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