Employ Respons Rights J (2012) 24:91–110
DOI 10.1007/s10672-011-9177-z

Career Barriers Experienced by People with Chronic Illness: A U.S. Study

Joy E. Beatty

Abstract This paper examines the career barriers and attitudes of people working in the U.S. with chronic illness. Chronic illness is distinct from disability, with often variable symptoms; symptoms may also be invisible or ambiguous. Social cognitive career theory and illness studies provide the theoretical framing for the specific career barriers of this population. Data comes from interviews with 23 working individuals with chronic illness. The results show that career barriers come from the illness itself (its symptoms and uncertainty), other's reactions to illness, and institutional rules. Misconceptions about illness, pity, and perceptions that people with illness either can't handle challenging work or that they will soon exit the workforce due to their illness were frequently mentioned. Peoples' career paths are influenced in characteristic ways, with patterns of plateauing, redirecting, retreating, and self-employment. They also report a reprioritization of career and personal goals. The findings aim to distinguish the chronic illness experience and its career barriers to help people with illness and their employers develop effective approaches and strategies for working with illness.

Key words Career barriers · Chronic illness · Disability

Chronic illnesses are illnesses that are prolonged, do not resolve spontaneously, and are rarely cured completely (Centers for Disease Control, 2009). Examples are conditions like arthritis, asthma, diabetes, cancer, and HIV. In the United States, chronic illnesses affect nearly 72 million working age adults, which is 39% of the working population (Tu and Cohen 2009). The chronic illness population is difficult to identify because symptoms are often variable, invisible, or ambiguous. Some symptoms of chronic illnesses lead to broader disabilities that limit people's ability to work, and these cases may be captured with disability statistics. However, improvements in medical treatment make it increasingly possible for people to manage a chronic illness and work, and no statistics are available for

---

J. E. Beatty (✉)
Management Studies Department, University of Michigan–Dearborn, 19000 Hubbard Drive,
Fairlane Center South 130, Dearborn, MI 48126, USA
e-mail: jebeatty@umd.umich.edu

people working with non-disabling symptoms. Estimates are that 15–20% of employees have a chronic illness (Munir *et al*. 2007). As the Baby Boom cohort ages, life expectancy increases, and retirement ages continue to climb (Johnson 2007), the prevalence of chronic illness in the workplace is likely to rise.

Most workplaces operate with the assumption that people are physically and mentally able to complete their job tasks without interference from their bodies; bodies and physical health are taken for granted (Pinder 1995). Control of the body is integral to the very nature of agency and of being accepted and trusted by others as a competent social actor (Giddens 1991; Radley 1994). Illness threatens one's sense of control, forcing one to acknowledge, attend to, and accommodate the body in the workplace (Charmaz 1983; Corbin and Strauss 1987).

Much can be learned about everyday life by studying those situations in which the routine order is disrupted (Giddens 1979; Goffman 1959). Illness is one such disruption (Bury 1982; Parsons 1951), and its effects on individuals in the workplace are the focal point of this paper. This population is understudied, and the needs of employees with chronic illness are often hidden and unspoken. Illness is framed as a personal issue to be coped with independently, in private. At the same time, illness is a shared, intersubjective, and social experience—shaped by the responses and reactions of others, and one's experiences interacting with the larger social system. Chronic illnesses vary widely in their symptoms, yet there are common themes of the illness experience which will be explored here. Workplaces can benefit from increased awareness of chronic illness issues to develop better structural supports for this group of employees.

This paper examines the career experiences of people with chronic illness, specifically their career barriers, career paths, and the role of work in their lives. It is based on the analysis of interview data from 23 employees with chronic illness working in the U.S. The paper begins with a discussion of the organizational context of working with chronic illness, describing some of the special features of chronic illness that present challenges in the workplace. The conceptual framework of career barriers is introduced, drawing upon social cognitive career theory and illness studies. Then the study methodology and results are explained, featuring the voice of participants as much as possible to give rich details. The discussion offers practical implications with support strategies that people with illness and their employers can use to address career barriers.

Chronic Illness as a Workplace Issue

People with chronic illness continue to work, and a diagnosis of achronic illness does not automatically signal the end of one's employment. Illness researchers (Pinder 1995; Register 1987), vocational specialists (Allaire *et al*. 2003) and practitioners (Joffe and Friedlander 2008) actually encourage people with chronic illness to continue working. Workplace schedules and structures help people maintain their normal life patterns, diverting their attention from the troubles of their ongoing illness (Pinder 1995). Supportive social relationships with work colleagues can also help people cope with difficult, uncertain, and serious illness symptoms (Register 1987). Maintaining employment is especially important for U.S. workers because of high healthcare costs and reliance on employer provided health care.

Healthcare in the United States is expensive. Comparison data across eight countries (Australia, Canada, France, Germany, the Netherlands, New Zealand, the United Kingdom, and the United States) shows that the U.S. has the highest costs, the most gaps in care, and the highest cost sharing even for people with insurance (Schoen *et al.* 2009). The other listed countries have systems with universal coverage and comprehensive minimum benefits. But in the U.S., 65% population aged 18–64 have employer-provided group health insurance (AHRQ 2009). By federal mandate, employer group health plans cannot deny coverage or exclude pre-existing health conditions. Individuals can purchase their own private plans in the U.S., but they are expensive and often carry exclusions. Health insurers are not required to provide coverage to individuals, and they can deny coverage to those with the most expensive conditions (Pendo 2009). Employer-provided group health insurance plans may bind employees with chronic illness to a particular job, leading to a phenomenon unique to the U.S. system known as "job lock". Empirical research suggests job lock does occur and shapes employees' career trajectories: Employees with chronic illness who rely on employer-provided health care have 40% lower job mobility than the average population (Stroupe *et al.* 2001).

Organizations have policies addressing illness and disability, but these policies often fail to address some of the special features of chronic illness. Illness policies are mostly designed for acute illnesses, which typically follow a pattern of relatively quick onset of noticeable symptoms, a brief period of illness, and subsequent recovery to normal (Kane *et al.* 2005). Sick leave policies allow employees a number of paid absences to recover from illness, generally assumed to be short-term illness. By contrast, chronic illnesses are long-term, sometimes with ambiguous symptoms that take months or years to diagnose. The trajectory of chronic illness may get progressively worse, or may have symptoms that wax and wane in periodic "flares".

Sick leave policies for managing acute illness do not give the flexibility needed to manage chronic illness. Evidence comes from Munir *et al.*'s (2008) study of employees in the UK with chronic illness. They found strict policies about how many short-term absences were allowed, and that employees may receive warnings and disciplinary actions if they exceeded this number. Employees could be forced to disclose their illness to justify their absences. Once revealed, illness information could then influence others' perceptions of the employee and lead to discrimination. Thus, even when supportive organizational policies exist, people with chronic illness may avoid using them due to the perceived risks of disclosure. Evidence is again seen in Munir *et al.*'s (2008) study which found that only half of the employees managing a chronic illness had disclosed at work. Instead of calling in sick and having to justify themselves, employees in their study practiced "presenteeism", defined as working when ill. Presenteeism is associated with higher psychological and health-related distress for employees with chronic illness (Munir *et al.* 2007) because it can conflict with appropriate care regimens and exacerbate illness conditions. Taking approved time off can actually promote better long-term health outcomes for people with chronic illness.

Organizations also have policies for disability. People are defined as disabled if they have an impairment that substantially limits one or more major life activities, a record of such an impairment, or are regarded as having such an impairment (Americans with Disability Act 1991). In the U.S., the leading causes of disability are arthritis, back or spine problems, and heart trouble (Brault *et al.* 2009).

Legislation such as the Americans with Disabilities Act in the U.S. and the Equality Act 2010 in the UK require organizations to provide accommodations that enable people to continue working. Such legislation has increased awareness and given a normative framework for an organizational response. Eventually, if work becomes impossible due to a disability, additional legislation helps determine an employee's eligibility for federal disability benefits.

Similar to chronic illness, disability tends to be a longer-term condition. Chronic illnesses cause two-thirds of the disabling conditions reported in the United States (LaPlante 1996), but not all disabilities are caused by illness. While chronic illness symptoms may be inconvenient and limiting from time to time, they may not meet the threshold of "functional disabilities" required for disability accommodation. Further, to receive accommodation people have to disclose their condition, which many people with chronic illness tend to avoid. The policies in place for illness and disability are not well-aligned with key features of chronic illness, so people with chronic illness may fall in the "space between" without policy and structural supports.

Career Barriers

Given the special features of chronic illness identified above, people with chronic illness are likely to face some career barriers as they work to achieve their career goals. Barriers have been studied as an element of social cognitive career theory, which highlights the importance of choice and agency in career decision making as people cope with a range of contextual factors and limitations. The theory states that occupational interests are shaped by self-efficacy beliefs, outcome expectations, and personal goals. Self-efficacy beliefs are peoples' beliefs that they can execute a course of action. They are developed from learning experiences, most directly from past accomplishments and failures. Past successes raise self-efficacy, and repeated failures lower it (Lent *et al.* 2000).Chronic illness has been shown to have a negative effect on work self-efficacy (Roessler and Rumrill 1994; Schneider 1988). Outcome expectations are the imagined consequences of a course of action, and are also based on appraisals of past outcomes and socialization experiences. Personal goals are part of the theory because they allow people to self-regulate their efforts in the absence of external reinforcement.

Career barriers are defined as external conditions or internal states that make career progress difficult (Swanson *et al.* 1996); these include actual barriers that have happened in the past, as well as expected future barriers. When people perceive that a career interest is blocked by some kind of career barrier, they are less likely to pursue the interest as a career goal (Brown and Lent 1996). Career barriers influence people's intentions to continue working, as well as their intention to stay with their current employer or to seek new employment elsewhere.

The presence and effect of barriers can vary across time, depending on the developmental tasks the person faces. Career barriers can be managed with coping strategies and contextual support (Fabian *et al.* 2009). Coping efficacy refers to how well the individual believes they can cope with the barrier. Psychosocial support mitigates career barriers by improving resilience and encouraging people to seek interventions to overcome their barriers.

Career barriers are often measured with a survey instrument from Swanson *et al.* (1996), with dimensions including sex and racial discrimination, role conflict, disapproval of significant others, and job market problems (with 16 dimensions in all). However, Lent *et al.* (2000) suggest that barriers are specific to the population of interest, varying with their characteristics and developmental stage. Survey research by Martin *et al.* (2003) with a U.S. sample of individuals with HIV/AIDS found six illness-specific career barriers: concerns regarding benefits loss, work-related health, job skills, discrimination, personal health care, and workplace accommodation. Similarly, in their survey study of career barriers for people with disabilities in the U.S., Fabian *et al.* (2009) found loss of health insurance and concerns about physical health to be a barrier. They also identified lack of transportation as a barrier. Both these studies used survey instruments to rate the prevalence of an identified list of barriers. The current study uses a qualitative approach to understand not only career barriers, but also the career paths that develop in response to these barriers. The research questions for this study are *(1) What career barriers are experienced by people with chronic illness, and how do they influence career paths?,* and*(2) How does the illness influence career and personal priorities?*

Methods

Sample and Procedures

The sample was drawn from a larger group of people participating in a survey study about chronic illness in the workplace in the U.S. (N=199), recruited from illness clinics, advocacy group electronic bulletin boards, and advocacy group events. Participants were currently employed in full-time or part-time work, and had one of two illnesses, epilepsy or multiple sclerosis (MS). These illnesses were selected because they vary in theoretically interesting ways with respect to stigma and illness trajectory; epilepsy has higher stigma (Scambler and Hopkins 1986; Schneider and Conrad 1980), and MS has highly variable symptoms which can be visible and/or intrusive (such as balance and mobility problems and vision loss) (Devins *et al*. 1993). The survey information was used as a pre-screen to identify a sample varying in occupation (professional or non-professional), work schedule (full or part time), age, gender, length of time with illness, and illness severity. For the epilepsy group, illness severity was measured by seizure frequency and whether seizures were controllable with medications; for the MS group, it was measured by the frequency of six common MS symptoms. Twenty-three interviews were completed between October and December 2002. See Table 1 for the characteristics of participants.

Semi-structured interviews lasting from 20 to 70 min were conducted in face-to-face meetings at the participant’s home or workplace, or by phone for those who lived far away. The data collection method was narrative inquiry (Chase 2005; Reisman 2008) which sees participants as narrators, seeking descriptions of what happened, and allowing expression of emotions, thoughts, and interpretations (Chase 2005). Open-ended questions addressed how the participant/narrator came to be in their current job, the influence of illness on their daily work experience and social interactions at work, and their feelings about their career path. The data were first-person narratives that convey the subjectivity of the participants. The people who volunteered for interviews had stories they wanted to tell, and it made sense to let them tell them in their own ways.

Interviews were taped and transcribed for analysis. Qualrus™ software was used for data reduction and theme coding, tagging specific passages with key words or phrases (Tesch 1990). As relationships emerged, tags were connected into broader categories and relationships that would best illustrate the career experiences and attitudes of the sample.

Direct quotes are used from a broad range of participants to show the collective story and common themes of this group.

Locating myself in this research, I have lived with a chronic illness for over 20 years. My personal experiences with illness and work shaped my lines of inquiry. Participants were aware of my illness because they frequently asked “so why are you studying this?” before agreeing to participate in the interview. While this paper is generally written in a third person voice and aims to tell the stories of participants, I do have some first person experience in the domain. As illnesses are often invisible, my participants seemed pleased

Table 1 Study sample.

Occupation	Work schedule	Age	Gender	Years with illness	Illness severity
Epilepsy					
Receptionist/secretary	Full time	50	Female	36	moderate
Retail sales clerk in a department store	Part time	43	Female	3	low
Clerk in a state agency	Full time	41	Female	3	high
Certified recreational therapist in a hospital	Part time	35	Female	35	high
Data analyst and safety officer for a state agency	Full time	36	Male	12	moderate
Teachers aide	Full time	37	Female	22	high
Senior application engineer	Full time	40	Male	30	low
Tax compliance officer for a federal agency	Full time	46	Male	19	moderate
Editor	Full time	32	Female	24	high
Retail sales clerk in a department store	Part time	19	Female	19	high
Police officer	Full time	50	Male	2	low
Payroll clerk in a government agency	Full time	46	Male	22	high
Multiple sclerosis					
Insurance estimator, self-employed	Part time	50	Male	3	high
Truck driver	Full time	36	Male	4	low
Bartender	Full time	30	Male	1	high
Attorney for city government	Full time	38	Male	1	low
Director of sales and IT	Full time	34	Male	2	moderate
Staff scientist/lab manager	Full time	31	Female	7	moderate
Financial consultant	Full time	27	Female	2	moderate
Machinist	Full time	38	Male	2	high
Senior bank teller	Part time	33	Female	1	high
University program manager and financial officer	Full time	46	Female	4	moderate
Freelance accountant	Full time	35	Female	9	low

to share their stories with an empathetic listener, and my "insider" status may have made them more willing to share their experiences.

Results

The results of this study support and extend prior research on career barriers related to chronic illness. Specifically career barriers were identified related to illness symptoms, other people's reactions to illness, and institutional rules. Participants' career paths showed four responses to these career barriers: plateauing, redirecting, retreating, and self-employment. A portion of participants noted they had reprioritized their views of career success to focus more on personal goals.

Career Barriers

Participants in this study described career barriers that came from three sources. First, as one might expect, there were barriers caused by the physical and psychological aspects of the illness itself. Second, there were barriers caused by others' reactions to their illness. The third source, transportation barriers, applied only to the epilepsy participants.

Participants reported that chronic illness symptoms could cause physical and cognitive limitations that affected their ability to perform in their current job tasks. For epilepsy, the issues were seizures and side effects from medication, mentioned by ten of the 12 participants. For MS, the dominant symptoms were numbness, pain, and mobility issues, mentioned by nine of the 11 participants. The effects could be cumulative over time, leading to gradual changes in performance. Two examples follow:

> When I first found out there was something wrong, my hands were numb, my arms were numb, and my torso. I use a calculator, and do a lot of word-processing so when you can't feel your fingers, it's a problem. [female, MS]
>
> ———
>
> The other aspect of the job is it's very detail oriented, and there's a lot to be remembered. People were telling me when I came into the job and started training there, they don't know how a person off the street can do it. And on top of that, because of my epilepsy, my memory is not the sharpest. I found the learning was very difficult. I did well in the class, but that was when I was just looking up things in the textbook. Out in the actual physical environment where we had to put it all together it was tougher, a lot tougher. [male, epilepsy]

The variability of chronic illness symptoms could also make planning and scheduling difficult. Participants had to be flexible and had to set daily schedules aside if their symptoms were acting up. The following quote highlights how the uncertainty about daily symptoms complicates a normal work schedule:

> Mostly with me it's that there are cognitive issues as well as fatigue issues that are very debilitating, and it has pretty much forced me to realign and reschedule all of my daily activities. The reason for that primarily is my day doesn't really begin until around 10 AM, and judging on what kind of a day I'm having, there's no way to gauge ahead of time how you're going to be on a day-to-day basis. You have to prioritize things as well as you can, and just get to the things that you're capable of doing. Things that you can't do, you just have to let them go. [male, MS].

Together, the chronic illness symptoms and the uncertainty of the symptoms were career barriers because people periodically had difficulty performing their job tasks and they could not predict or plan for when these difficulties might occur.

Additional career barriers come from other people's reactions to the illness and its symptoms. Major themes were others' misconceptions and pity. Participants saw these as career barriers because they felt others were making inaccurate attributions about their illness, their behaviors, and their job performance. They felt that this damaged their work reputation by prompting others to question their job competency, ultimately threatening their potential for advancement. Eleven participants discussed misconceptions about the symptoms and trajectories of their chronic illness as career barriers. Here are two such examples:

> I actually at one point in time had an employee ask me could she catch epilepsy from me. A lot of people don't understand that it's totally beyond your control. One supervisor I had wanted to know if there any way I could let her know in advance

> when I was going to have a seizure. Or could I maybe kind of hold them off until breaks or lunch? [female, epilepsy]
>
> ——
>
> Before I was stricken with MS, I had no idea what it was, but it certainly conjured up images of death and despair in my mind. When I heard "multiple sclerosis" I expected to see a person either in a wheelchair or walking with those crazy braces attached to their arms, and I find that most other people have the same images. So when I tell them, "Yeah, I've got MS, and there are days I can't walk real well and days I can't leave the house," they say, "Yeah, but the days that you can get out, you certainly look perfectly normal and you're capable of doing all these things." And I say, "Well, yes I am, and I have no idea why you were thinking otherwise." I just find that there are those crazy …people have these ideas, these pre-conceived notions that have no basis, but those notions are pretty much what drives the vehicle. It's lack of knowledge. [male, MS]

Some comments suggested that participants felt they were being stereotyped by other's misconceptions of their illness. It frustrated them when they felt like they were seen as the "poster child" for their illness condition, instead of as an individual who happens to have an illness. In the following example, a participant with epilepsy recounts his anger when a group of his co-workers hung a poster directly outside his office (without asking him) that explained seizure recognition and diagrammed the appropriate first aid procedures. He assumes they thought this was a friendly show of support, but he feared this poster would signal to others that the person inside the office had epilepsy. He explains:

> It felt like I was being singled out again, and it was taking my epilepsy before the person. And, here again, they weren't looking at **my** condition. Epilepsy is an individual condition. When someone says epilepsy, there are 30 different types of seizures, and so each person has their own condition. And so when you say "seizures" or "epilepsy," it really doesn't do the person justice because you're enveloping them into a huge category of different types of conditions. [male, epilepsy]

A similar career barrier to misconceptions was pity and "feeling sorry", reported by five participants. They appreciated that others meant well, but displays of pity annoyed them because they felt they were being treated differently. This sentiment can be seen in the comment above about being "singled out", and the comment below further illustrates some of this tension between appreciation and annoyance:

> I did a post-doc at the university where I was actually working in a lab doing MS research. That was interesting because the person I worked for was an expert in MS, and so he really watched me and he knew when I was having a bad day or when I was in pain. He was really hyper-sensitive to it, and he'd say, "You look tired. Why don't you go home early today?" At first that was nice, but then it started to get on my nerves a little bit because I felt like, I'm not … I don't know, I don't know … I'm not helpless. I can take care of myself. That was a situation I got myself out of. [female, MS]

This comment suggests that pity or sympathy was a career barrier when participants felt that others were looking down on them, because they felt their status in the organization was lowered. As one MS participants summed it up: *People feel sorry for you, so it kind of goes from their sympathy to their feeling sorry for you. And somebody you kind of feel sorry* *for, you kind of tend to look down on."* Despite the fact that they may occasionally have needed help from others, they did not want to be seen as people who needed help.

Another significant career barrier related to others' reactions to illness was the sense that others doubted their job competency. Over half of the participants were concerned that others assumed their illness would interfere with their job competency. In this example, a participant recounts an experience with her prior boss:

> Between my boss and me, I think my epilepsy caused issues. I don't know. I could be wrong because it was obviously never said aloud. I don't know if he ever felt I was capable of really doing the job because I think he thought my epilepsy was such an impediment. He was unsure of when it was going to happen. It was this uncontrolled factor of, "When is it just going to strike? When is she just suddenly not going to be at her desk"? [female, epilepsy]

Another participant felt that her co-workers who did not know about or understand her illness symptoms questioned her work ethic, thinking she was lazy. In this comment she talks about how this made her feel uncomfortable:

> You can't tell if someone has epilepsy unless they tell you. So if you are not working up to "normal" standards, up to the level of everyone else, they think you are not trying hard [and that] you're inferior because they don't realize all the stuff you go through with this illness. […]They would gossip about me behind my back, "Oh, she's such a slacker, she doesn't do her job, blah blah blah," and that's hard to deal with. I did just not feel comfortable working in that type of environment. [female, epilepsy]

Perceptions of incompetency, of "not being able to handle it", may eventually play out in a self-fulfilling prophecy because people with chronic illness could be denied the developmental opportunities necessary to build their skills. In fact five epilepsy participants told stories of being involuntarily demoted following illness episodes to less demanding, less rewarding jobs (involuntary demotions did not occur to any of the MS participants). Epilepsy is more highly stigmatized than MS, and its effects tend to cause more social disruption. This was clearly a career barrier caused by others perceptions and fears of chronic illness symptoms. The following is an example of one such demotion:

> Probably a month or so after that [large seizure], I was put into a different department, Public Works, as a data analyst. They didn't even ask me or explain the situation to me. They called up one day and told me, "Would you be interested in this job?" I said, "What are its duties?"They said, "Well, we don't have any." Then I said, "Why don't you give me a call back when you have the job duties, and I'll consider it then." They called the next day and e-mailed me the job duties. I said, "What if I don't take this job?" They said, "Well, you'll be fired." I was just like, "OK, I don't have a choice here." [male, epilepsy]

The examples about misunderstandings and questions about job competency highlight one of the tensions of illness. Participants don't know the future path of their illness and may share similar thoughts and fears about disability, their ability to continue working, and even death. However, when others held these thoughts they saw it as a career barrier because they feared it could damage their career opportunities. This participant explains this barrier:

> Well, actually, I had one person ask me if I would die. I've had other people ask me how long I'd be able to work. People look at you and they automatically think you're

> ill, you may not be able to handle your job. I think the main thing is I don't want people to reduce my work, or assume that I can't assume another job because I have this disease. I'm worried that there are some people out there that might not consider me because they don't understand the illness either. They don't understand that there are varying types, and just because I have it doesn't mean that I'm automatically going to have to apply for disability. [female, MS]

An additional career barrier was noted by ten of the 12 epilepsy participants and merits mention here. Transportation issues were a serious problem for this group. Driver's licensing laws in the U.S. require people to be seizure-free for a period of three to 12 months (the specific periods vary by state) (Krumholz 2009), and similar laws apply in other countries (Ooi and Gutrecht 2000). Participants' work opportunities were therefore constrained by public transportation, or the availability of alternate transportation from family and friends. They noted that the public transportation options available to people with disabilities seemed to be primarily for people with mobility issues (e.g., people in wheelchairs). When they contacted government offices to learn if they were eligible for transportation they were told they "weren't disabled enough" to qualify. Two participants mentioned they had driven to and from work with suspended drivers' licenses during periods when their seizures were active because they had few other options to get to work. This is consistent with Bautista and Wludyka's (2006) study of epilepsy and driving, in which 20% of their sample with current seizure activity continued to drive, including 24% of those with daily seizures. Economic factors (such as the need to get to work) were the leading cause of this risky driving behavior in that study.

Considering the career barriers identified by participants in the broader context of social cognitive career theory, connections can be made to self-efficacy and career goals. The difficulties participants faced from their illness symptoms and others' reactions to their illness decreased their self-efficacy and lead to overall lower career goals. Six participants expressed that they had permanently lowered their career expectations in response to illness, and in some cases they expressed disappointment about their lower goals. Here are two characteristic comments which emphasize low self-efficacy, and that participants are acutely aware of their own limitations:

> I think a lot of it has to do with feeling as if I'm disappointing people because I don't, I haven't ever really felt like, and I don't even feel now that I'll be able to take care of myself for the rest of my life. There's a certain resentment in me that I feel that I am underemployed. I have a Bachelors of Arts in English, and I have a Masters of Science in Education, but there's always something holding me back and saying don't push yourself here, don't try and get too ahead of yourself. [female, epilepsy]
>
> ——
>
> I don't see much changing. I don't ever expect to be able to go back to work full time. I have too many, too many problems. The best I can hope for is to stabilize my health, and be able to work part time regularly and consistently, and be able to bring home that extra money. And without being sick, because without being sick it's comfortable. I can't afford a vacation to Aruba, but I can buy groceries and that sort of thing. That's what I look forward to. That's my goal, just to have everything stable enough. That would be my normal life. I don't ever expect to be able to go back to work full time, and get back to the rat race. [female, epilepsy]

Career Barriers and Career Paths

The sections above have outlined a range of career barriers experienced by people with chronic illness. Career barriers were widely noted, and participants navigated their career paths in characteristic ways, either remaining in their jobs or to find new work. Four major career paths were found: Plateauing, redirecting, retreating, and self-employment.

The most common career path in this study was plateauing, which occurred for nine participants. A plateau is defined as remaining in a job role for such a long time that progression to a higher level is unlikely. They stayed in their jobs for a number of reasons. Some expected they would face discrimination on the job market. Some were afraid of losing health insurance, consistent with the concept of job lock. And some had low self-efficacy beliefs about their ability to take on more challenging work.

People with chronic illness are aware that their condition puts them at a disadvantage in the job market competing with "normal" people. Perceived discrimination is subtle, but participants are suspicious that it has played a role in their slow career progression and has placed them at a disadvantage. As this participant explains,

> I don't know if stigmatizing is the right word. I feel that it's holding me back, but I cannot prove it. It's certainly a negative factor. If me and somebody else were applying for the same job, and we were equal, if everything comes out even, they'd get it. Maybe even if I was a little bit better, they'd still get it. That's how I feel. I mean, I'm at a definite disadvantage. [male, epilepsy]

Given the uncertainty of their illness, job security was especially important. Six of the participants who plateaued worked in government jobs characterized by job security, steady pay, and good benefits packages. They acknowledged that these jobs are not exciting developmental positions, yet they were willing to sacrifice career advancement for security.

It is also worth noting that plateauing was not always a voluntary strategy. Six participants admitted they were underemployed, trapped in jobs below their training and capabilities. They would have liked to break through their career barriers, but for a variety of reasons, both internal and external, they had not. Four of them worked in difficult, low-paying jobs with high turnover. They stayed in these jobs because they were unsure if they could get a better job. Here this participant explains that she derives job security from her bad job because her employer is too desperate for workers to fire her for illness-related absences:

> Participant: They don't treat their employees very well where I work right now. We get paid bottom of the barrel, barely minimum wage, and very few benefits, and are expected to do what is a fairly difficult job and a hard job for little pay. And they wonder why it's a revolving door. People come in and train, and they work for a week, and then we never see them again.
> Interviewer: Why do you stay there if it's a bad job?
> Participant: Because in any other job I would probably lose my job because of the absenteeism. This is a place where they are probably not going to fire me. I have been there for a year and a half.
> Interviewer: So, would you say you're underemployed?
> Participant: Oh, absolutely, absolutely. [female, epilepsy]

These participants do not seek better jobs because they do not want to have to explain their chronic illness over and over again, and they do not want the hassle of becoming established in a new work environment. When asked why he does not seek a new job since he is unhappy in his present job, this epilepsy participant explains:

> Well, I don't think I can. It's just gonna' be the same crap all over again. If I go into another work place, I can see from my past work experiences that it's going to be the same when I go into another one—the lack of understanding, the lack of the ability for someone to confront it and talk about it truthfully and forthright, without feeling that they're going to be sued or something like that. [male, epilepsy]

Both the above comments imply that participants have low self-efficacy and outcome expectations regarding finding better work which they have developed from their past experiences on the job market. Staying in their non-developmental jobs is a manifestation of decreased career goals, consistent with social cognitive career theory.

The prevalence of plateauing is consistent with research on the job mobility of people with chronic illness. Pelkowski and Berger (2001) found that people with chronic illness were more likely to stay with their current employer, partly for reasons of health insurance job lock. In another study using survey data on older workers from the Health and Retirement Study, Daly and Bound (1996) found that 50% of people experiencing health problems stayed in current jobs, 25% left the workforce, and 25% changed jobs to less demanding jobs.

Another career path that developed in response to career barriers was **redirecting** to a different kind of work. In some cases participants told stories of changing their career goals because of expected future problems yet to occur. They anticipated the physical symptoms and determined that they presented a risk for their desired career path. In early career stages, people changed their career training to incorporate perceived future career barriers. In later career stages, changing paths was more complex due to specific training investments they had already made.

Five participants in this study changed their career goals during their initial training period. Some shifted goals after exploring the career and either failing or finding it unsatisfactory; others shifted preemptively without experimentation. The following example shows a participant who explored and made her own determination that the career would not fit with her physical limitations:

> Participant: I started school in nursing, and the college tried to boot me out of the nursing program because of my seizures. I fought them, and they couldn't do it. But I ended up dropping out after a year and 3 months of a two-year R.N. school because I found the seizures were too much.
> Interviewer: Too much for you, or for them?
> Participant: For me. I mean I wasn't going to let the college tell me what I could or couldn't be. I was keeping up the grades, but I found it to be too difficult with the work load, so I got a liberal arts degree from this college and then I moved over to a university. [female, epilepsy]

In another early career case, a participant planned to become a police officer. He received his MS diagnosis shortly after completing the civil service test. Although only experiencing mild MS symptoms at the time, he withdrew from the police academy list because he felt that the fatigue and mobility issues would eventually interfere with his goal "walk the beat", and he wasn't interested in a more sedentary desk job with the police department. He switched away from police work entirely. Consistent with social cognitive career theory, these examples illustrate how low self-efficacy can lead to a change in occupational choice.

In another case, institutional rules prompted a participant with epilepsy who wanted to join the military to redirect early in his career. The U.S. military has rules for enlistment stating that to be eligible a person with epilepsy must be free from seizures for 5 years without taking seizure control medication (Department of the Army 2010), so he was prohibited from pursuing this career path and developed alternative goals.

As mentioned above, considerations about health insurance and security also played into these early career redirections as people reprioritized; challenging work and high pay could no longer be the only goals since they had to consider how future illness might affect their ability to work. In one example a participant with epilepsy had wanted to be a stockbroker working on commission. He decided instead to switch to a job with the Internal Revenue Service as a tax compliance officer—a job with a steady paycheck, but lower pay and status. As he explained, “I had to. I needed a job, and the government offered excellent job security.”

For people later in their careers, they sought to redirect to jobs that built on their existing career experience and training. They had already invested in training and development, and they aimed to find ways to exploit that experience in less physically or cognitively demanding jobs. Five participants in this study had recently switched jobs or planned to switch soon because they were having difficulty performing their jobs. Two participants changed to similar types of work, but in less intense environments. For example, an editor of a quick-paced daily newspaper switched to a slower-paced editing position with a market research firm, and a Ph.D. chemist who was in an 80-hour a week academic research position switched to a less demanding chemist job for a pharmaceutical company.

For some participants, it wasn’t an option to build on prior training. Three had switched or were planning to switch to new job areas because they felt they could no longer meet the physical requirements of their line of work. One participant was a machinist in a tool shop, where he had worked for 13 years until being laid off approximately a month before the interview. In that job he stood on a concrete floor 8 h a day, in a shop without air conditioning. He now sought work in an air-conditioned environment, perhaps in a service or clerical job, that would not require standing for long periods. Another participant planned to quit his job as a bartender because of the physical demands. As he explains:

> I have enjoyed learning about the bar industry, but I think physically I can’t stay in this environment. In order to make really good money doing this, I have to put in the time which would be the five in a row, six in a row, sometimes seven in a row of nine-hour shifts. I can’t physically. I really think that the scheduling and the hours led to possibly the cause of the exacerbations [of my illness]. I’ve been on a sort of four-day work week now for about 2 months. I’ve noticed a little difference in my energy levels, so hopefully this will help. [male, MS]

A third response to career barriers was retreating. This response is distinct from redirecting because it involves a conscious choice to decrease their work effort. Five participants in this study purposely switched jobs to a lower-level job. They had been advancing in professional and managerial careers but found the pace of these jobs to be too intense for them. Their illness symptoms and regimen required them to take time off from work, diverting energy required for them to meet the demands of their higher-level jobs. They took a mixture of approaches: two changed to lower-level jobs, two reduced their hours to part-time, and one did the same type of work but at a lower level. A participant who switched jobs from a professional job to a less demanding service job and also reduced her hours from full time to part time explains her rationale for this shift:

> I would love to work full time at what I do, which is desktop publishing and editing. But I can't handle the stress and I can't handle 40 h. That's a kind of job where you take you work home at night, in your head at least even if you are not working at home. You are thinking about tomorrow, you're thinking about how can I fix this problem? I now work at [a department store], I sell clothes, I punch out. That's it. [female, epilepsy]

These comments reveal both low self-efficacy and coping efficacy beliefs. She does not believe she can physically handle the job tasks, and she does not believe she can cope with the stress of the more difficult job.

Another participant explains how she learned from her illness experiences that she ought to remain in a lower level job and not seek promotions. She recounts arriving at this after an illness episode which kept her in the hospital for several months:

> I kept saying to my therapist [in the hospital], "I should never have left clerical, I've got to get back into the clerical field, that is where I belong." When I got back, I was no longer in worker's comp. They had found me a job in clerical, and I was back into my field. And I learned from that experience that I am the most comfortable in the clerical field, and I will never get out of it again. When I go looking for a job, that's what I go looking for. I have not sought promotions. I learned where I was most comfortable, and to just stay there. [female, epilepsy]

This participant demonstrates some coping efficacy because she has learned what is best for her. However, she has accepted a lower career goal that forgoes any future promotions, similar to the plateauing strategies outlined above.

The last response to career barriers was self-employment, a kind of "opting out" of the career game. Only two participants in this study with MS were self-employed, but their stories represent a more dramatic response that merits mention. In their cases, the difficulties of their illness experience prompted them to look for flexibility and autonomy, and self-employment was a good fit. As one explained, the physical constraints of illness made it too difficult for him to maintain more traditional employment. His comments suggest low self-efficacy and outcome beliefs about his ability to be hired or perform in a "regular" job:

> To tell you the truth, thank God that I am self-employed because in my mind I am not employable in a conventional fashion, primarily because I'm totally unable to maintain a regular work schedule, a regular 9 to 5 type of thing. It's just totally out of the question. That in conjunction with the number of "down days," which I'm estimating to be about 50% of the time for me. That renders me unemployable in my mind. I certainly wouldn't want to hire anybody with those types of symptoms, or that type of a work outlook. [male, MS]

While these responses to career barriers are explained separately, in practice they were often woven together over time in response to symptoms and the employment context. A participant might redirect to a new career goal, retreat to a lesser position (say for example shifting to part time work), and then eventually plateau at that job.

Reprioritizing Success

Some of the examples above show people describing their careers with regret and anger. Participants wanted to have different careers, but their illness symptoms precluded those paths. Or they were trying their best on those paths and felt they were making some progress, but other people's misconceptions and stereotypes stymied their career progress. This, however, is not the complete story. Intermingled with disappointment about what careers that might have been, about a third of the participants expressed a new values clarity about their work-life priorities. The biological disruption of chronic illness (Bury 1982) had given them the opportunity to reflect on prior life goals and develop self-awareness. They reprioritized their work-life balance, and they felt better off for having done so. The following quote from an epilepsy participant illustrates the sense of relief from aligning her goals with her physical abilities, and moving from a very demanding job to a less demanding one:

> It's really hard in a way because the job that I was in was the end-all be-all for me. I wanted, above everything else, to be an editor at a daily newspaper. When I actually got there a couple of years ago I was thrilled, like, this is what I was waiting for, this is where I wanted finally to be. When it turned out to be this high-stress, high-pressure, pressure-cooker, I didn't anticipate that. I knew there would be stress, I just didn't realize the extent. When I got out, I thought I'm really, really glad I got the chance to do what I always wanted to do, but now I'm in this job that helps me appreciate how much easier my life can be, how much more relaxed my life can be. [female, epilepsy]

This kind of reflection is an acknowledged part of career change and development, as people adapt to life and career stages (Hall 2002; Super 1990). Chronic illness was a trigger for this reflection, much the way other developmental events are (e.g., marriage, births, deaths, etc.).As participants reprioritized, they developed new views of success. Their focus changed from objective, external definitions of career success to more subjective, personal definitions. They were no longer willing to sacrifice their personal lives to "make it" in the organizational and professional hierarchy. They wanted instead more time for themselves, and to invest time in relationships with family and friends. One volunteer with MS who works in Hollywood as a freelance accountant for entertainment programs explains this shift in her priorities:

> It certainly made me and my husband really look at quality of life over the brass ring. Since I was first diagnosed, we've really struggled with that. You want to work and be successful, but you don't want to just devote your life to it. You want to have a life. I'm working on a sitcom right now because that's a little easier pace. I could make more money if I worked on a one-hour show or worked on a movie, but I don't want to put in 12 to 14 h days. [female, MS]

All participants in this study were diagnosed with illness in the early or middle stages of their careers, with their ages at onset of illness ranging from birth to 47 years (the average age at onset of 26.5 years);65% of the participants were under the age of 30 when they were diagnosed. Thus the trigger of chronic illness tended to happen in conjunction with other early and midlife concerns around becoming established.

Working was still very important to them. Participants noted that their jobs got them out of the house and stopped them from dwelling on their physical difficulties. Maintaining jobs helped them feel good about themselves, proving to themselves and others that illness did not have to stop them from having normal lives. However, even within their work, these participants had reprioritized to embrace and increase the parts of their work they enjoy, and to decrease or eliminate the parts that they disliked. In the following passage, a 38-year old district attorney explains how his attitude towards his job changed after both he and his wife were diagnosed with serious chronic illnesses:

> For me illness definitely makes the job less of my priority, but it's kind of a double-edged sword. It makes you want to do things that are important to you or that are meaningful to you in your job because you want to do something that matters. It makes you really want to disregard and walk away from all of the BS, all the hassles, all the political squabbles and infighting you have to deal with in a job. I really don't care about the promotional stuff or the bureaucratic stuff or any of those things. I care about what's meaningful to me in the work, but all the bullshit you have to deal with, I really don't care. And that is illness. That's my illness and my wife's illness, I have no doubt about that. [male, MS]

This participant was planning to quit his job soon and take a year off to travel and relax with his wife: "We're going to take a year off and frankly do a year of retirement now." He has not made explicit plans for a job when he returns, but he trusts that he will be able to use his skills as an attorney to find new work.

Discussion

This paper has described the career barriers that people with chronic illness face, and how their career paths develop in response to these barriers. Because the chronic illness population is often invisible, one goal of this paper is to increase awareness and understanding of the difficulties and challenges of working with a chronic illness. People with illness can benefit from knowing how others have adapted to working with chronic illness, and employers can benefit from understanding more about the kinds of career problems this population experiences.

Before summarizing the implications of this study, several limitations should be noted. The data from this study is self-reported, and may be subject to different respondent biases. It is also cross-sectional data; findings about career paths should therefore be understood as participants' current subjective sense-making of their past career decisions, and how these decisions have lead to their current situation. The sample included two specific illness populations, so it is possible that some of the findings are unique to these illnesses; this is likely the case for the transportation issues experienced by the epilepsy participants. Epilepsy and MS have very different illness trajectories. The epilepsy participants had their illness an average of 18.9 years, while the MS sample had theirs' an average of 3.3 years. It is possible that time played a role in their coping and adaptation, but this has not been explored here. These limitations present opportunities for future research that includes a wider range of illnesses, objective measures of job performance, and longitudinal data to learn how coping and attitudes change over time.

The US focus of this study is also a limitation. Cross-cultural comparisons would be useful to learn about the universal issues and best practices for coping with them. Some comparisons can be drawn from chronic illness studies conducted in other countries, most notably Munir and colleague's (2005, 2008, 2007) work in the UK, and Vickers' (1997, 2000, 2003) work in Australia. Perhaps the next step is to conduct a multi-country study with common research questions and methods.

Recommendations

Chronic illness may constrain career progression, leading to underemployment and lower long-term career goals. It has been noted that chronic illness has distinct features from acute illness and disability, and that the policies and structures used to handle those conditions do not fully meet the needs of people with chronic illness. They are not "disabled enough" to trigger some of the disability solutions, yet they may need more structured support than typically available with short-term sick leave. Participants in this study negotiated their job roles with their supervisors and coworkers, and as the stories show, they had varying levels of success. The stories here point to several kinds of support and interventions that may help.

First, as suggested in social cognitive career theory (Brown and Lent 1996), it is important to help people establish realistic self-efficacy and outcome beliefs of how their illness may influence their career. Developing support networks of people with chronic illness could help newly diagnosed employees consider some of the options open to them, and to illustrate that it is possible to maintain a work life if one so desires. Illness-specific support groups can be found through illness advocacy groups, and employers might make more direct connections with these organizations as support for their employees.

Also relevant to self-efficacy and outcome expectations, employees' career stages and level of training will influence options available to them. For people with established careers who have already invested in training, career counselors might encourage people to take a broad inventory of their job skills and interests to identify potentially transferrable skills, and also to be more open to the idea of starting one's own business because of the flexibility it can provide.

Second, coping efficacy and psychosocial support should be developed by building employees confidence in their coping ability. People are sometimes hesitant to ask for help and support, and the potential stigma of chronic illness may make people with illness even more hesitant to make such requests. Reminding them of the full scope of their existing resources to help them cope, and establishing cultural norms that it is acceptable to use them, could be helpful for building for coping efficacy.

Third, at the organizational level, efforts should be made as early as possible to support people staying at work, for example through accommodations and psychosocial support. Disability policies and programs tend to focus on longer-term disability, and the subsequent "return to work" following disability leaves. However, allowing people to leave work may be damaging for their self-image as productive adults (Rumrill 1996). Rumrill (1996) notes that once a person with illness disengages from work, there are risks that they will not return. The loss of Social Security disability payments may be a disincentive to return to work, and people experience a social detachment from their work colleagues.

Research suggests that effort should be invested earlier in the process, before people go out on extended disability leaves (Allaire *et al*. 2003; Munir *et al*. 2008). In a randomized intervention study, Allaire *et al*. (2003) conducted vocational rehabilitation for clients with rheumatoid arthritis who were still employed but at risk of job loss. They found that giving participants positive messages about their ability to work, as well as information on self-advocacy and asking for accommodations, was associated with decreased rates of job loss. The effects were long-lasting and still detectable 3.5 years after the intervention. The point is to help people stay at work now, while they are employed, instead of having them leave and (possibly) return later.

Fourth, organizations should take steps to ensure that the job tasks are intrinsically motivating; jobs should remain challenging and interesting, even if the job tasks have to be redefined due to illness symptoms. This recommendation is based on participants' comments about reprioritizing, focusing on the parts of the jobs they like. Parallels can also be drawn from Westaby *et al*. (2005) study of employees with terminal illness. They found that employee's intrinsic motivation for their work was associated with intentions to keep working, and that it was a stronger predictor than extrinsic motivation (i.e., pay). In other words employees were more willing to stay at work if the work was interesting, even when their time to live was limited. As they suggested, "Organizations should be very sensitive to not inadvertently reduce the intrinsic nature of jobs if an accommodating job change is required. Otherwise, employees may withdraw from work altogether or pursue employment elsewhere" (Westaby *et al*. 2005, p. 1302).

Lastly, it is important to have current knowledge on employment law and federal laws affecting illness and disability, such as the Americans with Disabilities Act and the Family Medical Leave Act in the U.S. But legal issues should be handled carefully because once words like "disability", "ADA", and "accommodation" are used it tends to trigger a legalistic and adversarial tone. Participants noted that once they mentioned the word accommodation, the lawyers were called in, and informal collaboration would dwindle. Their employment was then likely to be seen as a liability, from which the organization must be protected.

Organizations might also consider more training and support for line managers regarding chronic illness issues, as they are the front line for support (or lack thereof) (Munir *et al*. 2008). It is helpful to get more information about the specific illness situation the employee faces. If the employee is willing to discuss their situation, employers can ask for information about the employee's illness and the kinds of symptoms he or she has. Unfortunately the legal context of the employment relationship around issues of privacy and discrimination can make these discussions sensitive for both the employer and employee. Yet, the experiences of many people in this study suggest that they are generally willing to discuss their illness, and would actually welcome the opportunity to explain their symptoms. Some mentioned that they had tried to give their supervisors information prepared by illness advocacy organizations, to help dispel some of the myths about their particular illness. They also noted that having more information available can increase co-workers' comfort levels, since it may be socially awkward for co-workers to directly ask questions about illness symptoms and treatment. Influencing the social context for illness is important because while illness is necessarily lived by individuals, the social meanings of illness critically shape the experience and can be more difficult to cope with than the physical symptoms.

References

AHRQ. (2009). *Medical expenditure panel survey: Health insurance coverage*. Rockville, MD: Retrieved from http://www.meps.ahrq.gov/mepsweb/data_stats/summ_tables/hc/hlth_insr/2009/t1_a09.pdf

Allaire, S. H., Li, W., & LaValley, M. P. (2003). Reduction of job loss in persons with rheumatic diseases receiving vocational rehabilitation. *Arthritis and Rheumatism, 48*(11), 3212–3218.

Americans with Disabilities Act of 1990, 101–336 C.F.R. § 2 (1991)

Bautista, R. E. D., & Wludyka, P. (2006). Driving prevalence and factors associated with driving among patients with epilepsy. *Epilepsy & Behavior, 9*(4), 625–631.

Brault, M. W., Hootman, J., Helmick, C. G., Theis, K. S., Armour, B. S. (2009). Prevalence and most common causes of disability among adults—United States, 2005 *Morbidity & mortality weekly report*, vol. 58 (pp. 421–426). Centers for Disease Control. Atlanta, GA.

Brown, S. D., & Lent, R. W. (1996). A social cognitive framework for career choice counseling. *Career Development Quarterly, 44*(4), 354–366.

Bury, M. (1982). Chronic illness as biological disruption. *Sociology of Health & Illness, 4*(2), 167–182.

Centers for Disease Control and Prevention. (2009). Chronic diseases at a glance 2009. Atlanta, GA: National Center for Chronic Disease Prevention and Health Promotion.

Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. *Sociology of Health & Illness, 5*(2), 168–195.

Chase, S. E. (2005). Narrative inquiry: Multiple lenses, approaches, voices. In N. K. Denzin & Y. S. Lincoln (Eds.), *Sage handbook of qualitative methods* (3rd ed., pp. 651–679). Thousand Oaks: Sage.

Corbin, J., & Strauss, A. (1987). Accompaniments of chronic illness: Changes in body, self, biography, and biographical time. In J. Roth & P. Conrad (Eds.), *Research in the sociology of health care, vol. 6* (pp. 249–281). Greenwich: JAI.

Daly, M. C., & Bound, J. (1996). Worker adaptation and employer accommodation following the onset of a health impairment. *Journals of Gerontology, 51B*(2), S53–S60.

Department of the Army. (2010). *Standards of medical fitness*. (Army Regulation 40–501, Rapid Action Revision). Washington, DC.

Devins, G. M., Edworthy, S. M., Seland, P., Klein, G. M., Paul, L. C., & Mandin, H. (1993). Differences in illness intrusiveness across rheumatoid arthritis, end-stage renal disease, and multiple sclerosis. *The Journal of Nervous and Mental Disease, 181*(6), 377–381.

Fabian, E. S., Etheridge, G., & Beveridge, S. (2009). Differences in perceptions of career barriers and supports for people with disabilities by demographic, background, and case status factors. *Journal of Rehabilitation, 75*(1), 41–49.

Giddens, A. (1979). *Central problems in social theory.* London: Macmillan.

Giddens, A. (1991). *Modernity and self identity.* Cambridge: Polity.

Goffman, E. (1959). *The presentation of self in everyday life*. New York: Doubleday.

Hall, D. T. (2002). *Careers in and out of organizations*. Thousand Oaks: Sage.

Joffe, R., & Friedlander, J. (2008). *Women, work, and autoimmune disease: Keep working, girlfriend!* New York: Demos Medical Publishing.

Johnson, R. (2007). *Should people work longer, and will they?* Washington: Urban Institute.

Kane, R. L., Priester, R., & Totten, A. M. (2005). *Meeting the challenge of chronic illness*. Baltimore: Johns Hopkins University Press.

Krumholz, A. (2009). Driving issues in epilepsy: Past, present, and future. *Epilepsy Currents, 9*(2), 31–35.

LaPlante, M. P. (1996). *Disability statistics abstract, Health conditions and impairments causing disability. Disability Statistics Abstract, 16* Retrieved June 4, 2011, from http://dsc.ucsf.edu/pub_listing.php?pub_type=abstract.

Lent, R. W., Brown, S. D., & Hackett, G. (2000). Contextual supports and barriers to career choice: A social cognitive analysis. *Journal of Counseling Psychology, 47*(1), 36–49.

Martin, D. J., Brooks, R. A., Ortiz, D. J., & Veniegas, R. C. (2003). Perceived employment barriers and their relation to workforce-entry intent among people with HIV/AIDS. *Journal of Occupational Health Psychology, 8*(3), 181–194.

Munir, F., Leka, S., & Griffiths, A. (2005). Dealing with self-management of chronic illness at work: Predictors for self-disclosure. *Social Science & Medicine, 60*, 1397–1407.

Munir, F., Yarker, J., & Haslam, C. (2008). Sickness absence management: Encouraging attendance or 'risk-taking' presenteeism in employees with chronic illness? *Disability and Rehabilitation, 30*(19), 1461–1472.

Munir, F., Yarker, J., Haslam, C., Long, H., Leka, S., Griffiths, A., et al. (2007). Work factors related to psychological and health-related distress among employees with chronic illness. *Journal of Occupational Rehabilitation, 17*, 259–277.

Ooi, W. W., & Gutrecht, J. A. (2000). International regulations for automobile driving and epilepsy. *Journal of Travel Medicine, 7*(1), 1–4.

Parsons, T. (1951). *The social system*. Glencoe: Free.

Pelkowski, J. M., & Berger, M. C. (2001). The onset of health problems and the propensity of workers to change employers and occupations. *Growth and Change, 34*(3), 276–298.

Pendo, E. (2009). Working sick: Lessons of chronic illness for health care reform. *Yale Journal of Health Policy, Law, and Ethics, 9*(3), 1–18.

Pinder, R. (1995). Bringing back the body without the blame?: The experience of ill and disabled people at work. *Sociology of Health & Illness, 17*, 605–631.

Radley, A. (1994). *Making sense of illness: The social psychology of health and disease*. London: Sage.

Register, C. (1987). *Living with chronic illness: Days of patience and passion*. New York: Free.

Reisman, C. K. (2008). *Narrative methods for the human sciences*. Thousand Oaks: Sage.

Roessler, R. T., & Rumrill, P. D. (1994). Strategies for enhancing career maintenance self-efficacy of people with multiple sclerosis. *Journal of Rehabilitation, 60*, 54–59.

Rumrill, P. D. (1996). *Employment issues and multiple sclerosis*. New York: Demos.

Scambler, G., & Hopkins, A. (1986). Being epileptic: Coming to terms with stigma. *Sociology of Health & Illness, 8*, 26–43.

Schneider, J. W. (1988). Disability as moral experience: Epilepsy and self in routine relationships. *Journal of Social Issues, 44*(1), 63–78.

Schneider, J. W., & Conrad, P. (1980). In the closet with illness: Epilepsy, stigma potential, and information control. *Social Problems, 28*, 32–44.

Schoen, C., Osborn, R., How, S. K. H., Doty, M. M., Peugh, J. (2009). In chronic condition: Experiences of patients with complex health care needs, in eight countries, 2008. *Health Affairs* (web exclusive): W1–W16.

Stroupe, K. T., Kinney, E. D., & Kniesner, T. J. J. (2001). Chronic illness and health insurance-related job lock. *Journal of Policy Analysis and Management, 20*(3), 525–544.

Super, D. E. (1990). A life-span, life-space to career development. In D. Brown & L. Brooks (Eds.), *Career choice and development* (2nd ed., pp. 197–261). San Francisco: Jossey Bass.

Swanson, J. L., Daniels, K. K., & Tokar, D. M. (1996). Assessing perceptions of career-related barriers: The career barriers inventory. *Journal of Career Assessment, 4*, 219–244.

Tesch, R. (1990). *Qualitative research: Analysis types and software tools*. New York: Falmer.

Tu, H., & Cohen, G. (2009). *Financial and health burdens of chronic conditions grow, vol. 24*. Washington: Center for Studying Health System Change.

Vickers, M. H. (1997). Life at work with “invisible” chronic illness: The “unseen”, unspoken, unrecognized dilemma of disclosure. *Journal of Workplace Learning, 9*(7), 240–252.

Vickers, M. H. (2000). The “invisibly” chronically ill as unexamined organizational fringe-dwellers: Voices of ambiguity, confusion, and uncertainty. *Research in the Sociology of Work, 9*, 3–21.

Vickers, M. H. (2003). Expectations of consistency in organizational life: Stories of inconsistency from people with unseen chronic illness. *Employee Responsibilities and Rights Journal, 15*(2), 85–98.

Westaby, J. D., Versenyi, A., & Hausmann, R. C. (2005). Intentions to work during terminal illness: An exploratory study of antecedent conditions. *Journal of Applied Psychology, 90*(6), 1297–1305.