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# Career Transitions Caused by Chronic Illness: A Career Construction Perspective

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Career Transitions Caused by Chronic Illness: A Career Construction Perspective

A dissertation submitted in partial fulfillment  
of the requirements for the degree of  
Doctor of Philosophy in Counselor Education

by

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May 2019  
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This dissertation is approved for recommendation to the Graduate Council.

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## **Abstract**

People living with chronic illness face significant challenges when it comes to finding and maintaining employment. There is ample research available that discussed the challenges and barriers to employment for this population. However, there is a lack of research devoted to interventions dedicated to assisting people with chronic illness in career exploration and development. This study attempted to address one possible intervention to assist people with chronic illness identify and pursue possible careers. The purpose of this research study was to explore the impact of participating in the Career Construction Interview on the career exploration of individuals facing a forced career transition due to the onset or exacerbation of a chronic illness. A qualitative instrumental multiple case study design was used, specifically a collective case study with an explanatory design. Three females with chronic illness participated in this study and completed four interviews. In answering the research questions, eight open codes fitting into two categories were discovered and five axial codes, also known as themes, were determined. Results from this study found that the Career Construction Interview was helpful to the participants in assisting them with making decisions about potential careers and options for employment.

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## **Dedication**

This dissertation is dedicated to all the chronic illness warriors out there, especially my zebra tribe. May we always wear our stripes proudly, continue to push for new research, and spread awareness. Thank you to all those who have taught me, supported me, and inspired me to never ever give up.

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## **CHAPTER 1: INTRODUCTION**

This chapter provides an introduction for this study, a justification for why the study was needed, background on the researcher and the researcher's perspective. Deficiencies in the current research are presented. The goal of the study is explained, and the research questions are examined.

### **Problem**

One important concern for those living with chronic illness is how their chronic illness will impact career choices and their ability to work. This concern is true for adolescents to mature adults. Those with chronic illness worry about being able to find a job (Meldrum, Tsao, & Zeltzer, 2009; Miauton, Narring, & Michaud, 2009; Wolman, Resnick, Harris, & Blum, 1994) or worry about finding a job without discrimination (Taylor, Gibson, & Franck, 2008). Joffe (2016) summarized the concern for people with chronic health issues:

Whether difficult symptoms mean that your current career path will become a dead end or that you can no longer do the job you've been doing, chronic illness often leads a person to seek a new job or career. And most are unprepared. (para. 4).

Beatty and Joffe (2006) reported that "chronic illness drives career transitions" (p. 184). For many individuals, the diagnosis of one or more chronic health conditions means that the individual is no longer able to continue in the current career due to symptoms and effects of the chronic illness. Therefore, individuals that are still able to work but no longer able to continue in the chosen profession must seek out a new career that will be able to be engaged in within the context of limitations or barriers due to the chronic condition.

### **Justification of the Problem**

According to the National Health Council (2014), there are approximately 133 million people in the United States living with at least one chronic illness. By the year 2020, it is

projected that that number will grow to 157 million and 81 million of those people will have multiple chronic conditions (Center for Managing Chronic Disease, 2016). A chronic illness is defined as “a health problem that lasts over three months, affects ... normal activities, and requires lots of hospitalizations and/or home health care and/or extensive medical care” (Boyse, Boujaoude, & Laundry, 2012, para. 2). The Center for Managing Chronic Disease (2016) states that “chronic diseases are long-lasting conditions that usually can be controlled but not cured. People living with chronic illnesses often must manage daily symptoms that affect their quality of life, and experience acute health problems and complications that can shorten their life expectancy” (para. 1).

### **Deficiencies in the Evidence**

While research exists surrounding career and chronic illness, there is a lack of research specifically focused on individuals facing a forced career transition due to the onset of a chronic health condition. Much of the information that is available comes from personal anecdotes such as online blogs and e-magazine articles. My own experience of dealing with a forced career transition and encounters with others in similar situations highlighted to me the lack of resources available for people experiencing a forced career transition due to the onset of a chronic illness. I know many individuals who have had to explore different career possibilities than they had originally planned because changing or worsening health issues caused their original careers to become no longer possible. As I have reflected on my own experience and watched others like me struggle, and looked to the literature, I realized there is a significant lack of research about these individuals and about ways to help these individuals explore career possibilities that are reasonable and possible, even with the barriers and limitations that come because of living with one or more chronic health conditions.

## Researcher's Perspective

In January 2011, I was diagnosed with a chronic physical health condition and then additional chronic health conditions in subsequent years. My diagnosis led to the end of my teaching career, which forced me to re-examine my life and my plans for my future. It was this experience, and my passion for helping others like me, that led me to completing a master's degree in Counseling and Career Development and eventually pursuing a doctoral degree in Counselor Education and Supervision with an emphasis in Rehabilitation. By pursuing this research, I hope to be the person that I needed after my diagnosis, to be able to help others navigate the process of career transition after a chronic illness diagnosis, to make a difference, not only in their lives, but in the knowledge and perceptions of those who work with these individuals.

I can intimately relate to the challenges faced by individuals facing a forced career transition due to the onset of a chronic illness when it comes to exploring career possibilities. I remember what it was like to find out that my dream job that I worked towards my entire life was no longer a possibility and I wondered what I was going to do now. I wonder every day if I am going to be able to successfully complete my graduate degree and be able to work. If I am able to work, how long will that last? What happens if my condition gets worse? I worry about the future and wonder how my disease will affect my hopes and plans for my life.

Fortunately, I have been able to make new plans, discover new hopes for the future, and that is what keeps me going on the days where I get overwhelmed with my condition. I am pursuing this specific activity because the goal is to help individuals living with chronic illness focus on what they *can do* rather than what they *cannot do*, as well as remind them of who they truly are, and what types of career environments will be best for them. As someone who has had

a positive and life changing experience by participating in the Career Construction Interview, I hope to give others the same opportunity that I was given in answering my career navigation problems and reaffirming who I was on the inside as a whole person, and not just a person with multiple chronic conditions.

I am choosing to design a qualitative research study because I want to give a voice to individuals with chronic health conditions experiencing a forced career transition and expose them to one method of exploring possible careers after the forced end of a career due to the onset of a chronic condition.

### **Purpose of the Study**

The purpose of this research study was to explore the impact of participating in the Career Construction Interview on the career exploration of individuals facing a forced career transition due to the onset or exacerbation of a chronic illness.

### **Research Questions**

There are two research questions the study sought to explore:

- a. What is the experience (social, emotional, mental, and physical) of a person facing a forced career transition due to the onset or exacerbation of a chronic illness?
- b. What is the experience of a person facing a forced career transition due to the onset or exacerbation of a chronic illness participating in the career construction interview process?

### **Definition of Terms**

The following is a list of definitions of terms that are used in this study:

*Chronic health condition* - This study used the definition presented by Boyse, et al., (2012) which is “a health problem that lasts over three months, affects ... normal activities, and requires lots of hospitalizations and/or home health care and/or extensive medical care” (para. 2). This study focused only on physical conditions and did not include mental or psychiatric conditions. Other terms that may be used interchangeably are chronic illness and chronic disease.

*Forced career transition* – I define a forced career transition as a person being unable to continue in his/her current job/career and needing to find another job/career path to pursue. It could be in the same field but a different position or a different position in a different field.

## **Goals**

The onset of many chronic illnesses happens during late adolescence and early adulthood. Many illnesses worsen with age or are degenerative, meaning that the condition is not stable and symptoms may change or worsen as the person ages. For many people, a diagnosis of a chronic illness means major changes in many areas of life, including career goals. Depending on the diagnosis, the treatment, the prognosis, and the effects of the chronic illness, previously planned careers may no longer be possible. This can leave this population feeling lost and confused as to what they are going to do now if their previous plans are no longer an option. The main goal of this study was to evaluate if the career construction interview is an effective activity to help individuals facing a forced career transition due to the onset or exacerbation of a chronic illness explore career possibilities that they may not have previously thought were options. Although it was not a goal of the study, it was my hope that this activity will not only help this population see different career possibilities, but also to see different life possibilities and realize that the diagnosis of a chronic illness does not mean that life is over and they can still have a meaningful life, even if it is a life different than imagined before diagnosis.

## **Summary**

The National Health Council reported that as of 2014, 133 million people in the United States have one or more chronic health conditions. This is over half of all adults in the United States. Maintaining or finding employment is a significant issue for those with chronic health conditions and there is a lack of research around strategies to help these individuals with employment concerns, especially those that are facing a forced career transition due to the onset or exacerbation of a chronic illness. In chapter two, an overview of literature relevant to the proposed study is provided, including pertinent career theories, research applicable to chronic illness and career, as well as an explanation and overview of career construction theory.



## **CHAPTER 2: REVIEW OF THE LITERATURE**

### **Introduction**

While research exists surrounding career and chronic illness, there is a lack of research specifically focused on individuals facing a forced career transition due to the onset or exacerbation of a chronic illness and career exploration and the Career Construction Interview has never been done focusing specifically on this population. Much of the information that is available comes from personal anecdotes such as online blogs, Facebook support groups, and e-magazine articles.

### **Career Theories**

The following section explores different career theories and how they relate to chronic illness and disability. This section is not meant to be representative of every career theory in existence, but only those that are most relevant to the current study.

### **Career Theories and Chronic Illness and Disability**

There are multitudes of career theories available and some are more relevant and relatable for people with chronic illness and disabilities. Some of the most relevant theories are the theories that will be discussed in this section. The first theory is Donald Super's Life-Span, Life-Space theory. "It combines elements of developmental, differential, social, personality, and phenomenological psychology with self-concept and learning theory, and includes some consideration of trait and factor convergence" (Szymanski & Hershenson, 1998, p. 329). Super's career model is often referred to as a life-career rainbow and is composed of five life stages. These life stages are "growth (birth-14), exploration (15-24), establishment (25-44), maintenance (45-64), and decline (65+)" (Szymanski & Hershenson, 1998, p. 330). In relation to people with chronic illness, Szymanski and Hershenson, (1998) stated that "Super's concept of career

maturity has considerable utility with persons ... who have acquired disabilities early in their career development. For people with acquired disabilities, career development can be destabilized and result in the need for reexploration and reestablishment” (p. 332). Given that the onset of a chronic illness typically occurs during early to middle adulthood, many people facing a forced career transition due to the onset of a chronic illness experience a disruption to their establishment stage and must go back to re-experience the exploration stage again in order to move into another career and resume the establishment stage.

The second theory is Holland’s theory, which is a “typology that links six broad personality traits to environments” (Szymanski & Hershenson, 1998, p. 333). Holland came up with six work environments and corresponding personality types: realistic, investigative, artistic, social, enterprising, and conventional. Holland’s theory has been criticized in relation to people with disabilities/chronic illness because of its “emphasis on individual traits, and its relative lack of consideration of societal factors, chance factors, and environmental variables, other than those depicted in the occupational types” (Szymanski & Hershenson, 1998, p. 334-335).

The third theory is Krumboltz’s social learning theory. This theory “suggests that four factors influence career decisions: genetic endowment and special abilities, environmental conditions and events, learning experiences, and task approach skills” (Szymanski & Hershenson, 1998, p. 341). This theory is considered applicable to people with disabilities and chronic illness because it places an emphasis on providing learning experiences and opportunities to try different work experiences through job shadowing, internships, etc. (Szymanski & Hershenson, 1998).

The fourth theory is the Minnesota Theory of Work Adjustment, which was developed with some concern towards individuals with disabilities. Similar to Holland’s theory, this theory

focuses on person (P)-environment (E) fit and interaction. “Fit means that some workers have the set of skills that a job requires but other workers do not, or some jobs require the set of skills that a worker has but other jobs do not” (Dawis, 2005, p. 4). Interaction refers to the person and environments’ “action on and reaction to each other in a mutual give and take” (Dawis, 2005, p. 4). Another key component of this theory is the concept of satisfaction, satisfactoriness, and tenure. Satisfaction refers to the person’s satisfaction with the work environment and satisfactoriness refers to the work environment’s satisfaction with the person. Tenure is the amount of time a person stays employed in a certain work environment (Dawis, 2005). The criticism of this theory and its applicability for people with disabilities is similar to the criticism of Holland’s theory in that “trait-factor approaches do nothing to compensate for the limited early experiences of persons with congenital disabilities or to suggest supportive interventions that can permit persons with disabilities to enter, function, and sustain themselves in the work environment” (Szymanski & Hershenson, 1998, p. 345).

The fifth theory to be discussed in Hershenson’s Model of Work Adjustment (Szymanski and Hershenson, 1998). This theory combines career development and work adjustment theories and was developed after the Minnesota Theory of Work Adjustment and is meant to apply to people with both congenital and acquired disabilities. This theory proposes that there are three domains within a person: work personality, work competencies, and work goals and these domains work together.

For persons with acquired disabilities, this means that the initial impact of disability on work adjustment results from the interaction of established work competencies with the functional limitations resulting from the disability, the specific job tasks of the current or desired position, and the possibilities for job modification. (Szymanski & Hershenson, 1998, p. 347)

## Career Construction Theory and Life Design

The theory behind the Career Construction Interview is career construction theory by Mark Savickas. “The theory of career construction explains the interpretive and interpersonal processes through which individuals impose meaning and direction on their vocational behavior” (Savickas, 2005, p. 42). Career construction theory updates and expands upon Super’s theory and also incorporates the Holland hexagon. Savickas (2005) explains his theory best,

Career construction theory, simply stated, asserts that individuals construct their careers by imposing meaning on their vocational behavior and occupational experience. Whereas the objective definition of career denotes the sequence of positions occupied by a person from school through retirement, the subjective definition used in career construction theory is not the sum of the work experience but rather a patterning of these experiences into a cohesive whole that produces a meaningful story. Herein, *career* denotes a subjective construction that imposes personal meaning on past memories, present experiences, and future aspirations by weaving them into a life theme that patterns the individual’s work life. (p. 43).

Career construction theory looks at not only what career a person wants to pursue, but overall what the person wants his/her life to look like and how career can be incorporated into a person’s life design. Savickas looks at three main overarching concepts in the life of an individual: vocational personality, career adaptability, and life themes. The concept of life themes, as described by Savickas below,

postulate that in expressing vocational preferences, individuals put into occupational terminology their ideas of the kinds of people they are; in entering an occupation, they seek to implement a concept of themselves; and after stabilizing in an occupation, they seek to realize their potential and preserve self-esteem. (Savickas, 2005, p. 44)

The goal, from a career construction perspective, is to see these life themes in action in all areas of life, not just in occupational life. Savickas’ work around career construction theory led him to what he calls life designing. “The paradigm for life design interventions constructs career through small stories, reconstructs the stories into a life portrait, and co-constructs intentions that advance the career story into a new episode” (Savickas, 2012, p. 13). The questions asked during

the Career Construction interview are given in the subsequent methods section, as well as the guidelines for interpreting the answers given and constructing the life portrait of the interviewee.

### **Living with Chronic Illness**

Thorne (1999) provided a succinct summary of being diagnosed with and living with chronic illness when she stated that chronic illness “takes on significance in the lives of people not only because of its inherent nature but also, and often more importantly, because of its psychosocial construction in terms of lifestyle departures, role changes, identity transformations, spiritual crises, or biographical disruptions” (p. 398). People living with chronic illness can experience a wide variety of physical symptoms and restrictions as well as social and emotional restrictions and obstacles (Hill, 2014). Keponen and Kielhofner (2006) reported that “chronic pain interferes with all aspects of functioning, because movement, effort, and assuming different positions increase pain. Consequently, pain is reported to limit work, family life, activities of daily living, and leisure” (p. 211-212). Loss of a sense of self was captured in this statement, “Chronically ill persons frequently experience a crumbling away of their former self-images without simultaneous development of equally valued new ones” (Charmaz, 1983, p. 168).

“Individuals who experience a chronic illness...will invariably go through a process of psychosocial adaptation, where disability or illness becomes an integrated part of the individual’s life, identity, self-concept, and body image” (Smedema, Bakken-Gillen, & Dalton, 2009, p. 51). Many people go through a grieving process, similar to the stages of grief by Elizabeth Kubler-Ross, when diagnosed with a chronic illness or when their illness worsens and changes must be made in their daily lives. Kubler-Ross’ stages of grief are denial, anger, bargaining, depression, and acceptance (Gregory, n.d.). The two most relevant stages for people adjusting to life with chronic illness are denial and acceptance, in the context of adjustment to chronic illness. These

labels are most often used by healthcare providers, and may be interpreted negatively by the actual individual with chronic illness. “The internalization of negative information associated with these labels may obstruct the reshaping of self-identity that is fundamental when making the transition to living well with chronic illness” (Telford, Kralik, & Koch, 2006, p. 457). While it is important to recognize these stages in the process of acceptance and adjustment to chronic illness, it is most important to consider the unique perspective of the individual who is living with chronic illness. An article featured on The Mighty, a website for stories about chronic illness and disability, titled “The Stages of Grief After Learning You Can’t Be ‘Fixed’” provides an honest and accurate description of the grieving process after a chronic illness diagnosis.

You’ve gained a diagnosis and have lost the possibility of getting better. In that moment, you’ve lost the dream you’ve played in your mind a thousand times before. The one that kept you hanging in there, that gave you the strength to keep trying. That hope for a healthy future full of infinite possibilities. Being able to function normally again. It can be devastating to lose that dream. You feel like you’ve lost a part of who you are, who you were meant to be. You’ve lost hope. Hope for a cure. All of a sudden, that future dream is shattered. Gone. That part of you, the future you, who you’ve envisioned a thousand times in your mind, crumbles like the imaginary world it was (Prins, 2017, para 5).

According to Dorsett (2010), hope, while many times considered counterproductive to adjustment by medical professionals, in reality hope is “an essential factor that helped them cope” (p. 83). Hope can come in many forms and one form could be through meaningful work. Despite the challenges of living with chronic illness, many people find hope and a renewed sense of identity and purpose through work. The next section will detail the benefits and challenges of working while having a chronic illness.

### **Chronic Illness in the Workplace**

The schedule and structure of a workplace can help people with chronic illness maintain some sense of normalcy, and social support from colleagues at work can be beneficial. (Beatty,

2011). Work is a positive and important part of life that contributes to psychological well-being, social identity, and financial security (Kalsi, Turkistani, Sykes, Lucas, & Zarnegar, 2016) The role of work is considered a valuable and fundamental part of identity (Henriksson, Liedberg, & Gerdle, 2005). This is true for people with and without a chronic illness. For many people with chronic illness, their illness changes their identity and how they see themselves. “Chronic illness can cause a dramatic shift in an individual’s identity, leading to a reassessment of the self and life goals” (Beatty & Joffe, 2006, p.183). In some cases, identity becomes intertwined with illness and it can be hard to separate the two. One way to address this is through career identity. By defining themselves by what they do rather the illness they have, people with chronic illness can find new parts of their identity. This new identity piece can be influenced by the climate and environment of their work and workplace.

There are certain work and workplace situations that are experienced by people living with chronic illness. “Job lock” occurs when employees with chronic illness stay in a job not because they are satisfied with the job or fulfilled by their work, but because they do not want to lose employer provided health insurance (Beatty, 2011). Employees with chronic illness may have frequent absences from work because of their illness and may feel the need to disclose their illness to justify their absences. Employees may also display “presenteeism”, which is where someone attends work even when ill because he/she is afraid of frequent absences or being judged for calling in sick (Beatty, 2011). People may quit their jobs rather than ask for or attempt to use accommodations (Roessler, Rumrill & Fitzgerald, 2004). “Employees with chronic illnesses can also experience workplace ‘spillover,’ which is defined as the extent to which chronic illness affects one’s ability to work coupled with the extent to which working affects one’s ability to manage chronic illness” (Koch, Rumrill, Conyers, & Wohlford, 2013, p. 127).

Job retention is a significant issue for individuals with chronic illness that is oftentimes not addressed as much as job placement. According to Koch et al. (2013):

The onset of many chronic illnesses occurs during individuals' prime working years and can result in numerous barriers to job retention. Among these barriers are the unpredictable or progressive course of many chronic illnesses, the wide range of symptoms, and a fundamental negative bias on the part of employers toward workers with chronic illnesses. (p. 125-126)

There are different intervention approaches that can be used to facilitate job retention for these individuals. These interventions are best introduced as soon as possible after a chronic illness diagnosis. Koch et al. (2013) state:

These approaches empower workers with chronic illnesses to effectively manage their disabilities and maintain their careers by (a) increasing their knowledge about the chronic illness, self-management of symptoms, legal rights, and workplace accommodations; (b) providing them with an understanding of workplace barriers; (c) developing their competencies in accommodation planning, implementation, and evaluation; and (d) increasing their use of accommodations on the actual job site. They also require the coordination of job retention strategies with illness self-management strategies, anticipatory coping and proactive accommodations planning, and involvement and support from employers. (p. 129)

Rumrill, Roessler, and Cook (1998) conducted a study looking at two different interventions for career re-entry for people with multiple sclerosis (MS). One group participated in a telephone career counseling interview; participants were matched with a local employer in their field, as well as a vocational rehabilitation (VR) counselor. Following this, the participant, employer, and VR counselor met to participate in small group Accommodations Planning Team seminars. The seminar was designed to help individuals establish resource networks and job leads, strengthen interviewing skills, consider needs for reasonable accommodations, understand employment rights under the Americans with Disabilities Act, and form a goal-directed placement plan. Following participation in the seminar, participants had telephone and in-person follow up support from both team members and the vocational rehabilitation professional



(Rumrill et al., 1998). They found that individuals with MS need specific employment assistance at a single point in time instead of career counseling over a long period of time. Rumrill et al, call this the “least intervention” principle.

### **Career Development and Chronic Illness**

Beatty and Joffe (2006) report different experiences of people with chronic illness that vary depending on the career stage they are in when they are diagnosed or become symptomatic. Receiving a chronic illness diagnosis in the early career stages has advantages and disadvantages. The advantages are that appropriate goals for career can be set and future career disappointments can be avoided. The disadvantage is that people with chronic illness may foreclose certain career paths before these paths can be fully explored. When a chronic illness is diagnosed later in life, career changes are made because the symptoms and trajectory of the illness will make the job requirements difficult or unable to be accomplished. People may resist changing to another career area because of additional training requirements and a likely decrease in income, as well as a change in work style and vocational identity. People experiencing chronic illness later in life may resist career change unless absolutely necessary, even at the risk of exacerbating their illness and doing tasks that may be harmful to their health (Beatty & Joffe, 2006).

Beatty (2011) conducted a qualitative study looking at career barriers and career paths for people with chronic illness. She interviewed 23 people that were currently working and lived with at least one chronic illness and found that there were four major career paths experienced by people with chronic illness, which are: plateauing, redirecting, retreating, and self-employment. Plateauing is not always voluntary and is defined as “remaining in a job role for such a long time that progression to a higher level is unlikely” (Beatty, 2011, p. 101). Plateauing can happen

because people fear discrimination in the job market, losing employer provided health insurance, fear of job lock, and low career self-efficacy beliefs (Beatty, 2011).

Redirecting happens when a person chooses to change careers to a different kind of work, usually because future health problems were anticipated that could interfere with success in the current or desired career path. Retreating is different than redirecting and is defined as “a conscious choice to decrease their work effort” (Beatty, 2011, p. 103). This strategy usually means changing to a lower level/less-demanding job in the same field or reducing hours at the current job. The decision to employ the retreating strategy may indicate that the person is experiencing low career self-efficacy and low coping efficacy beliefs. Beatty (2011) explains that self-employment is a sort of “‘opting out’ of the career game” (p. 104). The people that pursue this option are usually looking for flexibility and autonomy that may not be found in the traditional workplace or career.

Beatty (2011) also found that “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” (p.100) and that some participants had “permanently lowered their career expectations” (p.100).

### **Self-Efficacy**

The construct of self-efficacy was developed by Albert Bandura and is one’s belief in his/her ability to successfully accomplish a task or activity. There are four sources of information that impact and can modify the formation of self-efficacy expectation: performance accomplishments, vicarious learning or modeling, verbal persuasion, and emotional arousal (Betz & Shifano, 2000). Performance accomplishments refers to times in one’s past that one was able to successfully perform the behavior or action in question. Vicarious learning or modeling

directs one's attention to others in similar situations who have successfully performed the behavior or action that he/she is attempting to perform. Verbal persuasion is usually found in the form of encouragement, praise, and support from others. Emotional arousal suggests that negative emotions such as anxiety should be lowered, while positive emotions such as hope should be raised. All four of these sources should be considered and addressed when working with clients who may be dealing with poor self-efficacy beliefs.

### **Career Self-Efficacy**

Career self-efficacy examines how one's self-efficacy beliefs influence career choices, career performance, and persistence when facing obstacles to obtaining or maintaining a certain career (Sullivan & Mahalik, 2000). Betz and Hackett (1981) suggested that "low self-efficacy expectations may be a major factor in the restriction of women's career options, particularly in women's failure to consider occupations traditionally viewed as more appropriate for males" (p.400). They conducted a study to investigate self-efficacy expectations with regard to 20 specific and well-known occupations. Findings from this study suggested that "expectations of personal efficacy are related to the career choice process" and that "perceptions of low self-efficacy may be an important factor in individual's elimination for possible career options" (p. 408).

### **The Role of the Career or Vocational Counselor in Enhancing Career Self-Efficacy**

It is not only possible and within the scope of the job of the career or vocational counselor to impact a client's self-efficacy, but it is the career or vocational counselor's ethical obligation to do so. The American Counseling Association (ACA) has provided five moral principles that are the cornerstone of their ethical guidelines. Two of those principles, autonomy and beneficence, are particularly applicable in regards to this situation. The principle of

autonomy refers to the responsibility of the counselor to encourage clients to make decisions and act on their own values (Forester-Miller & Davis, 1996). By helping clients to modify their faulty self-efficacy beliefs and build self-efficacy, counselors are encouraging clients to become more autonomous and take control over career decision making. The principle of beneficence refers to the responsibility of the counselor to do good and be proactive (Forester-Miller & Davis, 1996). When counselors help clients to increase self-efficacy and make positive decisions and changes in their lives, then counselors are doing good.

### **Interventions to Promote Career Self-Efficacy**

When searching the literature, limited results were found in regards to interventions to promote career related self-efficacy. Betz (2004) provides a two-step guideline for career counselors to use to incorporate the concept of self-efficacy in practice. Step one is to include the concept of self-efficacy in the initial discussions with the client. Questions should be asked that help the counselor evaluate the client's self-efficacy beliefs around competence in career decision making, performance, or advancement and determine clients' self-imposed limits. Step two is to implement interventions to address domains of behavior that could benefit from an increase in self-efficacy. These interventions should be based on Bandura's four sources of self-efficacy information.

Luzzo, Funk, and Strang (1996) conducted a study examining the effects of a videotaped career intervention on career decision making self-efficacy. The intervention was referred to as attributional retraining material and was an eight minute video in which "both a female and male college graduate described their career development over the course of their late adolescence and early adult years" (Luzzo, Funk, & Strang, 1996, p.382). The graduates described times in their lives when they experienced career obstacles, failures, and indecision and how persistence

helped overcome these difficulties. Participants who had an external career locus of control (influenced by external reinforcements) increased their career decision making self-efficacy significantly after the intervention, but participants with an internal career locus of control did not. Criticism of this intervention includes that the intervention (videotape) was very brief and participants were passive observers instead of active participants (Sullivan & Mahalik, 2000).

Betz and Shifano (2000) conducted a study to look at the effectiveness of an intervention based on self-efficacy theory to increase women's confidence and interests in "Realistic" activities from Holland's theory. According to Holland's theory, "realistic" jobs are "jobs such as automobile mechanic, aircraft controller, surveyor, farmer, electrician. Has mechanical abilities, but may lack social skill" (Spokane & Cruza-Guet, 2005, p. 27). The intervention consisted of professional men and women modeling the desired behaviors. The instructors demonstrated each task, ensured the successful completion of each task by the participants, and both the instructors and participants encouraged and supported each other. Results from the study indicated that "self-efficacy expectations of college women with respect to the Realistic domain of Holland's vocational theory could be significantly increased" (Betz & Shifano, 2000, p. 47) as a result of the intervention.

Sullivan and Mahalik (2000) conducted a study that evaluated the effectiveness of women participating in a career group designed to increase career-related self-efficacy. The intervention consisted of six 90-minute group counseling sessions composed of both didactic and experiential activities and discussions. These sessions were designed to increase career-related self-efficacy. Results from the study indicated that participants in the treatment group increased in career decision-making self-efficacy and vocational exploration and commitment.

## **Deficiencies in Current Research**

This literature has provided evidence of current theories and methods of addressing employment for people with chronic illness. However, while there is significant research available that identifies barriers and difficulties faced regarding employment for people with chronic illness, there is not enough evidence in the current research surrounding interventions and ways to address these barriers and challenges. More research is needed on identifying specific interventions and practices to make employment possible and enjoyable for people with chronic illness. Most people that are not currently working due to chronic illness and disability want to work, they just have not been able to figure out how to make employment possible and feasible within the confines of their limitations. This study attempted to address one possible intervention to help people with chronic illness discover possibilities and options for employment despite having to stop working in their previous jobs because those jobs were not possible due the symptoms and issues related to their conditions.

## **Summary**

This chapter provides a review of applicable literature and theories to the concept of career and chronic illness. Different theories relevant to career and chronic illness such as the theories by Super, Holland, Krumboltz, Hershenson, and the Minnesota Theory of Work Adjustment were discussed. An overview of the most relevant theory to the proposed study, career construction theory, was provided. Common work and career issues for people with chronic illnesses including job retention, presenteeism, career re-entry, self-efficacy, career self-efficacy and other career barriers were also explored. Deficiencies in the current research were discussed. In chapter three, the methodology for conducting the current study was outlined, as

well as data collection and data analysis and the detailed approach to conducting a career construction interview and presenting the life portrait.

## **CHAPTER 3: METHODS**

This chapter will provide an overview of the methodology used for this research study. A description of the participants and how they were recruited is explained, as well as the methods of data transcription and analysis. The interview questions used are included in this section. Finally, validity and trustworthiness are discussed and limitations to the study are explained.

### **Research Design**

This study utilized an instrumental multiple case study design. “Case study research involves the study of an issue explored through one or more cases within a bounded system” (Creswell, 2007, p. 73). “Case studies allow for confirmatory (deductive) as well as explanatory (inductive) findings” (Baskarada, 2014, p. 2). It is an instrumental case study design because instrumental design has the goal of better understanding a specific problem (Hancock & Algozzine, 2011). The specific problem for this study was a person experiencing a forced career transition due to the onset or exacerbation of chronic illness. Within case study design, I used a collective case study with an explanatory design (Hancock & Algozzine, 2011). In this type of case study (also called a multiple case study), one issue or concern is selected and the researcher chooses multiple cases to study the issue (Creswell, 2007). For this study, the issue or concern was a forced career transition of people with chronic illness. The explanatory design allows the researcher to “establish cause-and-effect relationships. Their primary purpose is to determine how events occur and which ones may influence particular outcomes” (Hancock & Algozzine, p. 37). For this study, I looked at why forced career transitions occur and a possible way to help people with chronic illness explore new careers through the Career Construction Interview. This approach allowed me as the researcher to gain in depth understanding of barriers to career exploration, how the participants explore potential careers, and the effectiveness of the Career



Construction Interview with individuals facing a forced career transition due to the onset or exacerbation of a chronic illness.

### **Participants**

In order to gain multiple perspectives of individuals facing a forced career transition due to the onset or exacerbation of a chronic illness, I utilized a purposeful, homogeneous sample of three adults who were within two years of the diagnosis or exacerbation of one or more chronic health conditions and had to change their career because of the impact of their condition(s). Creswell in Onwuegbuzie and Collins (2007) recommends three to five participants for case study design. The participants were selected based on two criteria: the diagnosis or worsening of a chronic physical illness within the last two years and experiencing the loss of current or previous career because of the impact of the chronic condition(s). Participants were identified based on people I already knew and postings about the research study on a variety of Facebook support groups for people with chronic illness. I posted an advertisement for the study in various Facebook support groups and asked people who were interested in participating in the study to email or private message me. When messages were received, the purpose of the study and details about participation in the study were explained. If the person agreed to participate in the study, interviews with the participant were scheduled. At the conclusion of each final interview, the participant was asked if he/she knew anyone else who was interested in participating. Two additional women participated in the first interview, but during this interview, it was determined that they did not meet the criteria for the study, as both women were currently employed and had no plans to change jobs or careers in the near future.

## **Data Collection**

Before beginning data collection, approval was obtained from the University of Arkansas Institutional Review Board (IRB). A copy of this approval is included in Appendix A. The approved renewal of this protocol is in Appendix B. For this study, data was collected in the forms of semi-structured interviews, completion of the Career Construction Interview, and presentation of the Life Portrait. There was a total of four meetings between the interviewer and participant. The first meeting was a semi-structured interview involved the informed consent process, seeking background information about the participant, her diagnosis, and her relevant experiences related to psychosocial adaptation to a chronic illness diagnosis and the related career impact as well as building rapport between interviewer and participant. The second meeting was the process of completing the Career Construction Interview. At the conclusion of this meeting, the participant was asked if she would like a copy of the Career Construction Interview notes and if requested, a copy was provided at the next meeting. For one participant, the first and second meetings were combined into one meeting because the participant knew me prior to the interview and was comfortable enough with me to participate in the Career Construction Interview during the first meeting. The third meeting was the presentation of the life portrait by the interviewer. After this meeting, the participant was asked to keep a journal from that time until the next meeting, recording thoughts about the experience and any possible career ideas or implications that come to mind. The fourth and final meeting was a follow up and wrap up of the entire experience and all of the meetings. The meetings took place in a location convenient for the participant. For two participants, the meetings were held in their homes. For one participants, the meetings were completed via FaceTime because the participant lived in a

different geographic location than the interviewer. The meetings lasted between twenty minutes and three hours and were audio recorded.

After each meeting, I transcribed the interviews verbatim. Each participant was assigned a number to keep her identity confidential. The list of participant numbers, along with the audio/video recordings, interview transcripts, and my notes, were kept in a locked cabinet in my office and on a password protected computer. The only people that will have access to this drawer, the key, and the computer will be the researcher. The consent forms and the data from the study will be retained until the completion of this dissertation, as required by the University of Arkansas IRB.

During the first interview, the following questions were addressed:

1. Tell me about your experience living with (insert illness).
2. What aspects of your chronic illness have impacted your career decision making process?
3. What type of career(s) have you explored? Have you found any barriers to those career choices because of your chronic illness?
4. Is there anything else you would like to tell me about?

After the first interview or first part of the interview was completed, participants engaged in the Career Construction Interview (CCI) activity. To conduct the Career Construction Interview, the following questions were addressed (Savickas, 2015, p. 28-36).

1. How can I be useful to you today?
2. Who did you admire when you were growing up? Who were your heroes/heroines? I am interested in learning about three people, other than your mother and father, who you admired when you were about three to six years old. They can be real people you knew or did not know personally, make-believe people like super-heroes and cartoon characters, or characters in books or the media.

3. Tell me about any magazines you read on a regular basis or subscribe to? Any television shows that you watch regularly? What about any websites that you visit frequently? (The goal is to get three of these or a combination of these)
4. Currently, what is your favorite book or movie? Tell me the story.
5. What is your favorite saying?
6. What are your earliest recollections (ER)? I am interested in hearing three stories about things that happened to you when you were three to six years old. When a client is finished communicating each ER, counselors ask, If you were to assign a feeling to that memory, what feeling would it be? If you had a photograph of the most vivid part of that memory, what would it show? Please give me a headline for each memory. The headline is like that used for a story in a newspaper or a title for a movie. A good headline has a verb in it.
7. After completing the CCI, counselors signal the end of the first session by asking clients if there is anything else that they want to mention. Counselors preview that next session by explaining to clients that during this first session they acted as a journalist trying to learn the client's story. Counselors inform clients that before the next session, they will study the collection of small stories and compose them into a large story to use in the client's decision making and planning.

The third meeting with the participant was what Mark Savickas calls delivering the life portrait. Between the second and third meetings, the researcher is tasked with constructing the life portrait. There are seven tasks that the researcher must complete to construct the life portrait: frame the perspective, describe the self, link ERs to role model attributes, name interests, script a role, apply advice, and unify the life portrait (Savickas, 2015).

To frame the perspective, one must “use early recollection to help clients comprehend and evaluate their analogies for the transition problem and to concentrate attention on issues they cannot ignore” (Savickas, 2015, p. 39). To describe the self, one uses the client’s words in describing the role models to help the client see that they also have or are developing those qualities. Linking ERs to role model attributes means to “trace the path from the perspective and preoccupations in ERs to solutions presented in the form of attributes engendered by role models” (Savickas, 2015, p. 49). Naming interests refers to naming the “type of occupations or academic majors that fit a client’s interests (Savickas, 2015, p. 52). Script a role refers to translating the “client’s current favorite story in terms of the transition problem” (Savickas, 2015, p. 58). Apply advice means to “pinpoint how the advice proffered in a client’s favorite saying could direct and propel the client’s initial action” (Savickas, 2015, p. 63). The final task is to unify the life portrait, which means to “assemble and edit the life portrait sentence into a verbal portrait that depicts the client’s career with continuity and coherence” (Savickas, 2015, p. 65).

On his website, [www.vocopher.com](http://www.vocopher.com), Mark Savickas provides a worksheet to help guide the counselor in constructing the life portrait. The early recollections lead to determining what the participant is preoccupied with or concerned about. The role models define the self and provide the characteristics that the participant has or is developing. The magazines, television shows, or websites describe the settings that the participant likes to be in and activities that he/she enjoys doing. The favorite story from a book or movie writes the script and describes what the participants likes to do. By combining the self, setting, and script, the participant’s success formula is created, which in its simplest form is “I will be most happy and successful when I am able to be \_\_\_\_\_ in places where people \_\_\_\_\_ so that I can \_\_\_\_\_” (Glavin, 2017).

Finally, the favorite saying or motto is the advice the participant should give to himself/herself. All of this information is then delivered to the participant during the third meeting. After the presentation of the life portrait, “clients then set goals that chart a direction through possibilities and constraints. Client and counselor co-construct a plan for strategic changes and deliberate actions that can test the provisional understandings generated during counseling” (Savickas, 2015, p. 72). To close this meeting, Savickas (2015) recommends that the researcher “read aloud the client’s response to the entry question of how counseling could be useful and then ask the client, *Have we done that?*” (p. 75).

The fourth meeting was a follow up and wrap up with the client. I collected the journal from the participant or asked the participant to email her a copy of the journal when it was completed. Only one participant actually completed the journal. The following questions were addressed in the fourth meeting:

1. Tell me about your experience participating in the Career Construction Interview and life portrait delivery?
2. Have your career plans changed at all from before the interview to after the interview?
3. What are your next steps?
4. Anything else you would like to share?

After the first interview with participant one, the idea of self-employment came up, so one additional question was added to this list.

5. If you were going to use vocational rehabilitation services for help in setting up self-employment, what services would you need or find helpful?

## Data Analysis

The audio recordings were initially run through the Dragon Naturally Speaking software to get an initial transcript and then I listened to each interview and edited the transcript as needed for clarity and accuracy. As the interviews were transcribed, data analysis was conducted continuously, although there was a time gap between the time of the interview and the time of transcription for two interview when I was recovering from a surgical procedure. I created Microsoft Word files for the interviews, as well as audio files and these files were saved on an external flash drive, and stored in a locked cabinet, to which only I had access. Constant comparative analysis was used to analyze the data and was an ongoing process as each transcript was completed (Boeije, 2002). Yin (2014) wrote,

In qualitative research, the originators of grounded theory... have provided much guidance over the years for following an inductive approach to data analysis. The procedures assign various codes to the data, each code representing a concept or abstraction of potential interest. The resulting guidance can be relevant to all case studies... (p. 138).

Boeije (2002) stated “By comparing, the researcher is able to do what is necessary to develop a theory more or less inductively, namely categorizing, coding, delineating categories and connecting them” (p. 393). This type of analysis involves first comparing within a single interview and summarizing the core of the interview (open coding). Open coding is defined by Strauss and Corbin (1990) as “the process of breaking down, examining, comparing, conceptualizing, and categorizing data” (p. 61). They go on to state “open coding is the part of analysis that pertains specifically to the naming and categorizing of phenomena through close examination of the data” (p.62). Strauss and Corbin (1990) also state:

Conceptualizing our data becomes the first step in analysis. By breaking down and conceptualizing, we mean taking apart an observation, a sentence, a paragraph, and giving each discrete incident, idea, or event, a name, something that stands for or represents a phenomenon (p. 63).

Essentially, the first step in open coding involved looking at and breaking apart the data in minute detail. Then the second step in open coding was grouping concepts together that seem to belong to the same phenomena and giving them a name. This is called categorizing (Strauss and Corbin, 1990).

After open coding, separate interviews were compared with each other to hypothesize about patterns and types (axial coding) (Boeije, 2002). Axial coding is defined by Strauss and Corbin (1990) as “a set of procedures whereby data is put back together in new ways after open coding, by making connections between categories. This is done by utilizing a coding paradigm involving conditions, context, action/interactional strategies and consequences” (p.96). Axial coding takes the data that was taken apart in open coding and puts it back together in a new way by making connections between the data categories (Strauss & Corbin, 1990). Although the purpose of my study was not to identify and create new theory, I was looking to identify central themes, which are the experiences of people facing a forced career transition due to chronic illness and the experiences of these individuals in participating in the Career Construction Interview process. Axial coding helped identify what these central experiences were and allowed me to explore the causal conditions that influence these barriers, as well as the causal conditions that impacted the effectiveness of the Career Construction Interview activity.



## **Validity and Trustworthiness**

Several validation strategies were used to give credibility to the research and findings of this study. These strategies were triangulation, member checking, peer review, and rich, thick description. The data was triangulated with the interviews and interview notes, the results of the Career Construction Interview, and the journal completed by one participant (Creswell, 2007). Rich, thick description was achieved by presenting the participants' voices and experiences in a detailed, honest and accurate manner (Creswell, 2015). This is an important component for my study because the population of individuals' with chronic illness does not have many opportunities to tell their story in an unfiltered way. Usually when this population is asked for their story, it is actually their medical history they are being asked to tell and so they are used to reporting facts, dates, diagnoses, and surgeries/hospitalizations. I gave them the important opportunity of being able to tell their whole story in the context of career exploration and hopefully helped them learn something new about themselves in the process of telling their stories.

Member checking was achieved by having the participants review the transcript of the interview and drafts of the findings and interpretation (Creswell, 2015). Participants reviewed the transcripts of their interviews to check for accuracy and any errors. Participants were also asked to review the codes and themes discovered during the data analysis phase. This was crucial for the effort to be honest and transparent about the data collected. I also hope that this will help with empowering the population of my study participants around the importance of their voice and their story. For individuals with chronic illness, it is not uncommon to find mistakes or false information when reviewing medical records. Therefore, I was aware that my participants may be concerned about this happening as a result of the inherent power that I as the researcher

automatically hold and wanted my participants to review the information they gave me in the interview and activity for accuracy to help reduce the power differential and ensure their confidence that I told their stories correctly.

Peer review was also used to provide an external check to the research process (Creswell, 2015). It is ethically important to have the data I collected peer reviewed by someone outside of my dissertation committee, as well as my interpretation of the data. As a person with multiple chronic illnesses myself, I wanted to be sure that my coding and interpretation of the data is accurate based on the data and not influenced in any way by own experience as a person with multiple chronic illnesses who has been through more than one career transition driven by the effects of chronic illness. Both peer review and member checking fall under what Maxwell (2012) called descriptive validity. Basically, was I as the researcher accurately reporting what was said in the interviews? Are the accounts that I am presenting factually accurate?

### **Researcher Reflexivity**

“Reflexivity is commonly viewed as the process of a continual internal dialogue and critical self-evaluation of researcher’s positionality as active acknowledgement and explicit that this process may affect the research process and outcome” (Berger, 2015, p. 220). To engage in the process of researcher reflexivity, I have disclosed my relevant beliefs and experiences in the researcher’s perspective section of this paper. I also completed reflective journal entries after each meeting with each participant. These journals and relevant experiences were discussed with the methodologist during meetings about data collection and analysis.

I did my best to go into this study without pre-conceived notions about the results and whether or not the Career Construction Interview would help my participants. However, I do not believe it is possible to be 100% objective, especially in a study with which I have personal

experience and can relate so much to the experiences of my participants. Going into the interviews, I did tell participants that I had completed the Career Construction Interview process myself, but I did not share my specific experiences with it until after we had completed all of the interviews, and then I only disclosed if they asked me about my experience. I did the same regarding my own experience with a forced career transition, only telling participants that I had also experienced a forced career transition, but keeping my stories to myself until after the interviews were completed. I do believe that my limited self-disclosure helped establish rapport with the participants and gain their trust.

### **Limitations**

There are limitations to this study. The Career Construction Interview has never been focused specifically on this population. There were purposely no age restrictions, other than being over 18, or chronic illness specifications on participants, but all of the participants were in their late 30's or middle to late 50's, so there were no younger ages represented in this sample. Generally, more women than men are diagnosed with chronic health conditions, and this is reflected in the fact that all three participants in this study were female. A definitely limitation to this study is that no males were represented. I extensively researched how to conduct a Career Construction Interview and deliver the life portrait, including attending a workshop conducted by Mark Savickas, and practiced the concept several times, but I am by no means an expert in the method and technique of career construction interviewing.

### **Summary**

The preceding chapter outlined the methods for this research study. The design for the study was instrumental multiple case study and data was collected through semi-structured interviews. Five participants were initially recruited for participation in the study, but only three

ended up being eligible for the study and completed all four interviews. The data collected was analyzed using constant comparative analysis and strategies for ensuring validity and trustworthiness such as triangulation, member checking, and researcher reflexivity were be implemented.

## **CHAPTER 4: PRESENTATION OF THE DATA**

This chapter involves a description of the data analysis process, and key findings and results of the study. Participants in the study are described and quotes from the participants related to each code are utilized.

### **Introduction**

This chapter will present key findings and interpretations of the data collected from interviewing the three participants in this study. First, the participants are discussed and each individual case is described. Then the open codes and categories of codes are presented. The axial codes or themes deduced from the open codes are briefly presented in this chapter, but will be explained in detail and elaborated upon in chapter five.

There were three participants involved in this study. Four interviews were conducted with two of the participants, and three interviews were conducted with one participant. This participant knew me prior to the interview and so an initial interview was not needed to establish trust and rapport with this participant as it was with the other two participants. Participants were asked standard questions in each interview, as detailed in chapter three, as well as relevant questions related to their answers to these standard questions. Responses were deduced to meaningful words, phrases, and sentences relative to the questions asked. No coding software was utilized; all data were hand coded. First, meaningful words, phrases, or sentences were identified in the participant's responses from the interviews. These excerpts were written down on sticky notes and then put on a white board. After looking at all the excerpts, they were grouped by similarities and then each grouping was named. This is how the open codes were identified.

After identifying the open codes, approval was sought for these codes from my methodologist. When discussing the open codes with a peer reviewer, it was decided that the open codes fit into two categories. Reviewing the transcripts again in a holistic manner, along with the codes, and talking with another peer reviewer, led to the conceptualization of the axial codes or themes. The “lightbulb” moment occurred, in relation to identifying these axial codes or themes, when I was asked to by a peer reviewer to tell her the story of the data and of the participants. After deciding on these axial codes or themes, I met again with my methodologist for approval of these codes. The purpose of this study and this approach to data analysis is to gain a deeper understanding of the experience of people facing a forced career transition due to onset or exacerbation of chronic illness and the experience of these people participating in the Career Construction Interview process.

### **Participants**

There were three participants in this study. All three participants were female, and their ages ranged from late 30’s to late 50’s. The participants were recruited from various Facebook support groups for people with chronic illness. Two participants live in Arkansas and one participant lives in Colorado. For the two participants living in Arkansas, the interviews were conducted in person at their homes. For the participant living in Colorado, the interviews were conducted via FaceTime.

### **Confidentiality**

Every effort was made to ensure that participant’s identities were kept confidential. Each participant was assigned a number and a pseudonym that is used when describing each participant’s individual case in the next section. The following case descriptions are designed to

help the reader gain insight into both the unique and common experiences of each individual participant.

### **Presentation of Cases**

In the following section, a brief description of each participant and her story is provided. This brief synopsis is intended to provide a glimpse into the lives and the journey of each participant.

#### **Participant #1: Stacy**

Stacy is a 58-year-old Caucasian female. She is single and has never been married. She lived and worked in another state for several years before moving to Arkansas to take care of her elderly mother several years ago. Her mother has since passed away. She has a bachelor's degree and a master's degree and practiced as a speech language pathologist in hospital settings and K-12 school settings for many years. She has many chronic illness diagnoses, including but not limited to Ehlers Danlos Syndrome, Chiari malformation, cranio-cervical instability (CCI), neuropathy, mast cell activation disorder (MCAD), and postural orthostatic tachycardia syndrome (POTS). She feels that she cannot work in a typical 9-5 job because her health is unreliable, so she has explored numerous online, self-employment business options. After the interviews were completed, she sent me an email to let me know that she had recently met with an attorney to discuss forming an LLC for a writing business.

#### **Participant #2: Lisa**

Lisa is a 39-year-old Hispanic female. She is married and has three teenage children. She has a bachelor's degree and was previously working on a master's degree in social work in a distance education format, but she had to stop the program. Her health issues caused her to have difficulty keeping up with coursework, and she did not receive the support or assistance she felt

she needed from the faculty or disability services office. She has been diagnosed with gastroparesis, fibromyalgia, Raynaud's, post-traumatic stress disorder (PTSD), anxiety, and is being evaluated for postural orthostatic tachycardia syndrome (POTS). Prior to finishing her bachelor's degree, Lisa worked in marketing within the arts and crafts industry. She had to leave this profession because it required a lot of travel and the stress of travel and having to be in certain places at certain times became too difficult for her to manage. She knows that she wants a master's degree and most likely a PhD, but has been struggling to find the right program for what she wants to do that will also accommodate her needs related to her health issues. After completing the interviews, she texted me to let me know that she had decided on a combined master's/PhD program at a local university in Colorado and is hoping to start Fall 2019 or Fall 2020. Unfortunately, not long after making this decision, she was involved in a car accident, which exacerbated her already existing health issues and suffered a concussion, which is leading to more health challenges. Her academic and career plans are currently on hold while she focuses on her recovery.

### **Participant #3: Mandy**

Mandy is a 56-year-old Caucasian female. She is currently married to her second husband and has two adult children and two grandchildren. She has both a bachelor's degree and a law degree. Mandy practiced as an attorney in different settings for many years and worked as an adjunct instructor at times for a local university. Mandy has been diagnosed with Ehlers Danlos Syndrome, postural orthostatic tachycardia syndrome (POTS), and neurocardiogenic syncope (NCS). She wanted to major in art as an undergraduate, but was told that was not a reliable profession, so she became an attorney instead. When her illnesses became severe and she could not work anymore, she started painting digitally on an iPad with a conductive brush. She initially



began painting to alleviate boredom and occupy her mind while spending many hours lying down due to her conditions, and was pleasantly surprised to find that people liked her art and expressed interest in purchasing it. She has recently set up an LLC and a website to sell her paintings. She has also had her art shown in galleries across the country and has a local gallery show that will run through the month of April in her community.

This section provided a brief description of each of the three participants in this study. The next section will describe the open codes from data analysis, as well as the categories under which these codes fall.

### **Presentation of Open Codes and Categories**

Through the process of hand coding the data that was collected, eight open codes were identified. These open codes divide into two categories. Six of these open codes correspond to research question one regarding the experience of a person facing a forced career transition due to chronic illness. One of these open codes corresponds to research question two regarding the experience of a person with chronic illness participating in the Career Construction Interview process. The eighth and final open code does not exactly fit with either research question, but illustrates an unexpected yet important finding relating to career options for people with chronic illness.

The open codes related to research question one were: diagnoses, employment issues, physical issues/symptoms interfering with work, life with chronic illness, employment options considered, and ways of coping. The open code related to research question two was Career Construction Interview experience, abbreviated to CCI experience. The final open code that does not exactly fit with either research question was vocational rehabilitation (VR) help for self-employment. Each of these open codes can be put into two categories: barriers and interventions.

Under the barriers category, there are four codes. These codes are diagnoses, employment issues, physical issues/symptoms interfering with work, and life with chronic illness. Under the interventions category, there are four codes. These codes are employment options considered, ways of coping, CCI experience, and VR help for self-employment. Each of these open codes are discussed in more detail in the following sections. Table 1 provides a visual representation of the open codes and categories.

### **Code One: Diagnoses**

Receiving a chronic illness diagnosis was the first step in the journey of the participants. As is common in the chronic illness community, participants had to wait for an extended period of time, sometimes years, for an accurate diagnosis. All three participants had at least two chronic illness diagnoses, including a chronic illness that causes chronic pain such as Ehlers Danlos Syndrome (EDS) or fibromyalgia. Stacy reported multiple health issues and had at least 23 chronic illnesses. Lisa and Mandy had two or more diagnoses. While the diagnoses provided anxiety and concern, there was also a sense of relief at finally being diagnosed properly. Stacy said, “I feel so validated [receiving the EDS diagnosis]; that has been the biggest plus.” Lisa is still in the process of getting officially diagnosed with one condition (POTS) that she is showing symptoms for, but is taking a break from dealing with doctors right now, after dealing with a few doctors with poor attitudes. She said:

I am in the process of trying to get screened for it, it's a matter of finding the right doctor...the doctor was kind of condescending, he was like treating me like a little lady. I just have to find another doctor to kind of go through the process and honestly the stress test really scares me...just being in his office, like freaked me out. So I'm taking it step by step.

While diagnosis may be the beginning of the journey, oftentimes for people with chronic illness, they received many more than just one diagnosis as they progress through their life, and it becomes a part of adjusting to life with chronic illness.

### **Code Two: Employment Issues**

As evidenced by published research, employment issues are common among the chronic illness population (Beatty, 2011; Beatty & Joffe, 2006; Charmaz, 1983; Henriksson et al., 2005; Kalsi et al.; Keponen & Kielhofner, 2006; Koch et al., 2013; Roessler et al., 2004). This experience was true for the participants in this study. Employment issues ranged from being discriminated against for asking for reasonable accommodations to worrying about how employers are going to treat them to working when advised to quit by a doctor to losing the dream job that had been worked toward for many years. Stacy's story about her career journey was intense and filled with mistreatment. When her health issues worsened, she tried to find a more accommodating position in her field. She ended up having to take an 80% job with less pay in order to have a job that provided group health insurance. She said, "I was desperate because I had to have health insurance." She took a less than ideal job and requested two reasonable accommodations, and the employer team immediately overreacted and repeatedly attempted to punish her for requesting accommodations. She said, "I was the first one, in the suburban schools in the entire county, to ever ask for a 504 at the time of hire. How large do you think the target was on my back?" She was told by someone when she first started in the position, "The district is going to find a way to fire you because they don't want anybody on their insurance that has a heart problem." Stacy stayed in that position for a couple of years until she could not put up with the mistreatment and bullying any more, plus her elderly mother's health was failing and she needed to come to Arkansas to help manage and coordinate care for her mother.

Another participant, Mandy, fought against a doctor telling her to stop working when she was initially diagnosed with POTS and NCS. “I worked 12 years beyond when I was told I could and should quit by a doctor.” She had just moved into her dream job when her condition got significantly worse. She said, “Career-wise, I lost, I did lose my dream job. I had only been in it a year, and I had planned for it to be my capstone.” She hoped to maybe work part-time, but even that turned out to be impossible. She said, “Initially, I rejected any notion of not working, of reducing my hours to part time or not working at all, and I rejected that notion for twelve years. Then when my body made it impossible suddenly to work at all, I have wished I could work part time.” She did not have to deal with unsupportive employers or co-workers, but she did lose her pension when she suddenly had to stop working.

Lisa’s biggest employment issue was worrying about the type of environment and co-workers she would face in finding a job. She worried that people would treat her differently when they found out she had chronic illnesses or when she requested accommodations. She said “My career decisions are probably also going to be based on what type of support I think that I would get from...where I work. Are they going to be treating me differently or are they going to be understanding?” She also voiced her biggest need from an employer as, “I need a compassionate, understanding person that’s willing to work with me.” For Lisa, while it was important to find a job or career that was interesting and meaningful to her, her biggest concern was finding a supportive and accommodating work environment.

### **Code Three: Physical Issues/Symptoms Interfering with Work**

While the specific physical issues varied from participant to participant, they all shared the unreliability of their symptoms and their bodies in common. Lisa said, “Day to day, it’s not reliable.” Mandy stated, “The reason I don’t think I can work a conventional job part time, is my

lack of ability to plan ahead or have reliable attendance.” Difficulties with driving was shared by all three participants. Lisa said, “Driving over 30 minutes I can maybe do that like once a month.” When Stacy was previously looking for a job, she had specific parameters related to how far from home the job could be, as well as the need to provide group health insurance. She said, “So then I had to narrow it [the job search] down close to home, public, over 50 employees, no more than 15 minutes away from home.”

Physical restrictions or limitations also played a large role in the ability to work at a traditional job. Lisa explained why she had to leave a previous job when she said, “The stress of travel was too much. I just didn’t have the physical capability to do the things I wanted to do.” The unpredictability of chronic illness and flares certainly impacted the ability to work. Mandy knew she had to stop working when this happened, “Overnight, I suddenly couldn’t walk more than five minutes at a time and couldn’t sit up for more than an hour unless my legs were elevated and then my limits were for three hours. So suddenly, I had to spend most of my time laying down.” Due to their conditions, planning ahead was difficult because they couldn’t rely on their bodies to do what they needed at the time they needed. For some, just planning a few hours ahead was all they could do. Mandy stated “I pass out unpredictably several times a week and have to lay down other times to bring my blood pressure down because it goes too high and then I pass out from it being too low and I can never plan more than two or three hours ahead.”

#### **Code Four: Life with Chronic Illness**

Day to day life with chronic illness varied from participant to participant, but there were some common elements. Concerns ranged from not being able to get health insurance to anxiety around managing the conditions to losing friends. Life with chronic illness prior to the Affordable Care Act meant that Stacy was denied private health insurance because she had pre-

existing health conditions. Stacy and Mandy went years without a proper diagnosis. Mandy said “My illness began 18 years ago and the onset was very gradual and that long ago, medical people didn’t know much about it. As a result, I went 12 years without a diagnosis.” Two participants lost relationships with friends because of their illnesses. Stacy described it as having a “social impact. You know, you lose friends. Well, we called you a couple times and you don’t want to go out, so we’re not going to call you again.” Lisa worried about how her illnesses might impact her friends and family. She said “The hardest part for me is letting people down.” Preparing or planning for the future was also a concern for participants. There is an emotional and mental toll that happens when living life with chronic illness. Lisa said, “There is such high anxiety when you’re dealing with your future, the ambiguity and the anxiety of being, having chronic illnesses as well as trying to figure out your next steps. It’s very heavy and it’s very hard.” All three participants also spoke about loss and acceptance as part of life with chronic illness. Mandy summarized the process when she said, “You go through a grieving process and there’s a sense of loss.”

### **Code Five: Ways of Coping**

While life with chronic illness has its challenges and obstacles, all three participants shared with me different ideas and strategies they use to cope with their chronic illnesses. Lisa tries to stay close to the supportive people in her life. Stacy advocated for trying to find balance when she said:

Putting life in balance - so that there is time for friends, for enjoyment, for some exercise, for doctor and bodywork appointments in addition to setting up a business. It certainly would go faster if I put in more time for a self-employed business, but I have to approach it as a long distance marathon not a dash.

Online support groups played an important role for all three participants. Mandy even saw herself becoming a mentor to others through online support groups. She said, “I feel a

responsibility that people my age need to help mentor the less experienced people, but particularly the younger people who are trying to find tools to cope.” Finding hope in everyday life came up too. Stacy shared one way that she does this by “Keeping a journal of inspirational quotes and short articles - they give me hope.” Participants tried to find ways to modify or adapt previous hobbies to work within the confines of their illnesses. Mandy shared one way she does this when she said, “I’ve started a little indoor garden. I can still have the fun and the hobby of gardening because I can sit on my little portable stool.” Most importantly, participants needed to find a way to do things that are important to them, even with their physical limitations. They need to find things they can still do, ways to stay engaged with life. Mandy summarized it well when she said “I have sought out proactively new things that I can do given my physical limitations because I think we always need dreams and we always need goals, however small or modest they may be.”

### **Code Six: Employment Options Considered**

Employment options varied by participant. But the common thread for all participants was needing some sort of flexibility with attendance or the ability to set their own schedule and work at their own pace. Having to be at a job for eight straight hours, five days a week was not going to be feasible for these participants, and may not be feasible for many people with chronic illness. Stacy explored a variety of options from house flipping to dog sitting to writing people’s ancestral stories. She said, “I’ve explored online businesses for a couple of decades. What I need is on my own hours and not Monday, Wednesday, Friday.” She has recently decided on establishing an online writing business, with the exact focus and purpose to be determined.

Mandy gave up dreams of being an artist early in her adult life, but when her health conditions forced her to lay down for a large portion of the day, she rekindled her interest and

passion for art. She said, “I took up digital painting because with a conductive brush and an iPad, I could paint laying down. And that has turned into a huge adventure.” Lisa’s passion lies in prevention and intervention science, ideally creating programming for families with adolescents, and she might even want to teach at a community college or university someday. Right now, her biggest obstacle is her education. She needs a master’s degree and possibly even a doctoral degree to pursue what she wants to do. But she has struggled to find a program that will support and accommodate her unique challenges related to her health. The last time we spoke, she had decided on a program and was taking steps to prepare for and take the GRE and apply for admission.

### **Code Seven: CCI Experience**

All three participants reported having a positive experience participating in the Career Construction Interview (CCI). Stacy appreciated the reflection component of the CCI, saying, “It’s been good to have somebody reflect back something. You’ve kind of been like my body double.” She also said that this experience gave her more impetus to get her mother’s estate taken care of, so that she can focus on deciding on and setting up her online business. Stacy also said that participating in the CCI made her feel better about her idea to pursue an online business, “I’ve always known I wanted income online for flexibility, but I feel more supported on that.”

Mandy had already decided on starting an online art website to sell her art before the CCI, but still found the CCI helpful. She said, “I thought it was very enlightening and I thought it made complete sense.” Lisa described hearing the results of her CCI as “I think it’s definitely right on. It’s exactly, like that’s totally me. It’s really good to hear that that’s still me.”

Completing the CCI helped her get closer to deciding to go back to school and decide on her



program, she made a final decision to apply to a local university for a graduate program just a week after completing our final interview. She described her experience with the CCI this way,

Having a holistic understanding of who you are and having it done in such a gentle assessment, I think it really helps to give that person a little bit of their power back and it really does, it just kind of sets it like gentle ripples into motion of my thoughts and themselves and seeing themselves rather than broken and half able. Really seeing them as, ok, these are the things I'm still capable of, that are still valuable in me.

The Career Construction Interview, as evidenced by the experiences of these participants, can be a useful tool for exploration of career options for people with chronic illness.

### **Code Eight: VR Help for Self-Employment**

Although my sample is certainly not a large sample with three participants, I think it is important to note that two out the three participants (Mandy and Stacy) have chosen to pursue self-employment through an online business. Stacy, when asked to review the codes and themes discovered through this study, said “Glad to see more light on how chronically ill want self-employment.” A question was added to the final interview for the two participants that had chosen self-employment, asking if they were to use VR services to help them set up their own business, what services would they find helpful? Having discovered firsthand how time consuming and challenging it could be to set up an online website and business, Mandy said this:

I am convinced that the way to help somebody who becomes disabled start an internet business...the best way is have the government or some organization pay an expert whose job it is to help them set it up. Now once it is set up, they run it themselves, and they need to know, that's not their support person to call every time they have a tech problem. But just to teach you, or bet yet, sit beside you in a chair physically and walk you through setting it up.

Mandy had to learn how to set up an LLC, how to charge sales tax, how to deal with selling outside her home state and even how to sell internationally. She learned how to use website analytics to determine better ways to advertise her art and how to bring more people to her website. Mandy also learned how to keep accurate accounting records and learned

accounting software, and she did all of this on her own. Stacy expressed an interest in learning similar concepts, specifically saying “I need to know more about bookkeeping. I need to know more about different tax structures. I don’t know what resources are out there.” The drive and willingness to learn as demonstrated by these two women provides a window in the desires of possible VR consumers that need to be considered.

### **Presentation of Axial Codes/Themes**

After open coding, the next step was axial coding. Although the purpose of my study was not to identify and create new theory, I was looking to identify central themes, which are the experiences of people facing a forced career transition due to chronic illness and the experiences of these individuals in participating in the Career Construction Interview process. Axial coding helped identify what these central experiences were and allowed me to explore the causal conditions that influence these barriers, as well as the causal conditions that impacted the effectiveness of the Career Construction Interview activity. Five themes were identified by comparing interviews to each other and attempting to look holistically at each participant’s individual experiences as well as common elements of each participant’s story. The “lightbulb” moment occurred, in relation to identifying these axial codes or themes, when I was asked by a peer reviewer to tell her the story of the data and of the participants. The story of the data led to the development of the following five themes.

1. The career construction journey of a person with chronic illness is a repetitive journey, like an upward spiral.
2. On this journey, people with chronic illness face and overcome obstacles by being creative, resilient, and realistic.

3. One of the goals of this journey is to find a career path that is meaningful and fulfilling, as part of their life design.
4. Giving up is not an option, because of financial, personal, and psychological reasons and responsibilities.
5. It is important to focus on what a person with chronic illness CAN do, rather than what they CANNOT do.

These themes will be discussed further in the next chapter. Figure one provides a visual representation of the codes, categories, and themes discovered during the data analysis process.

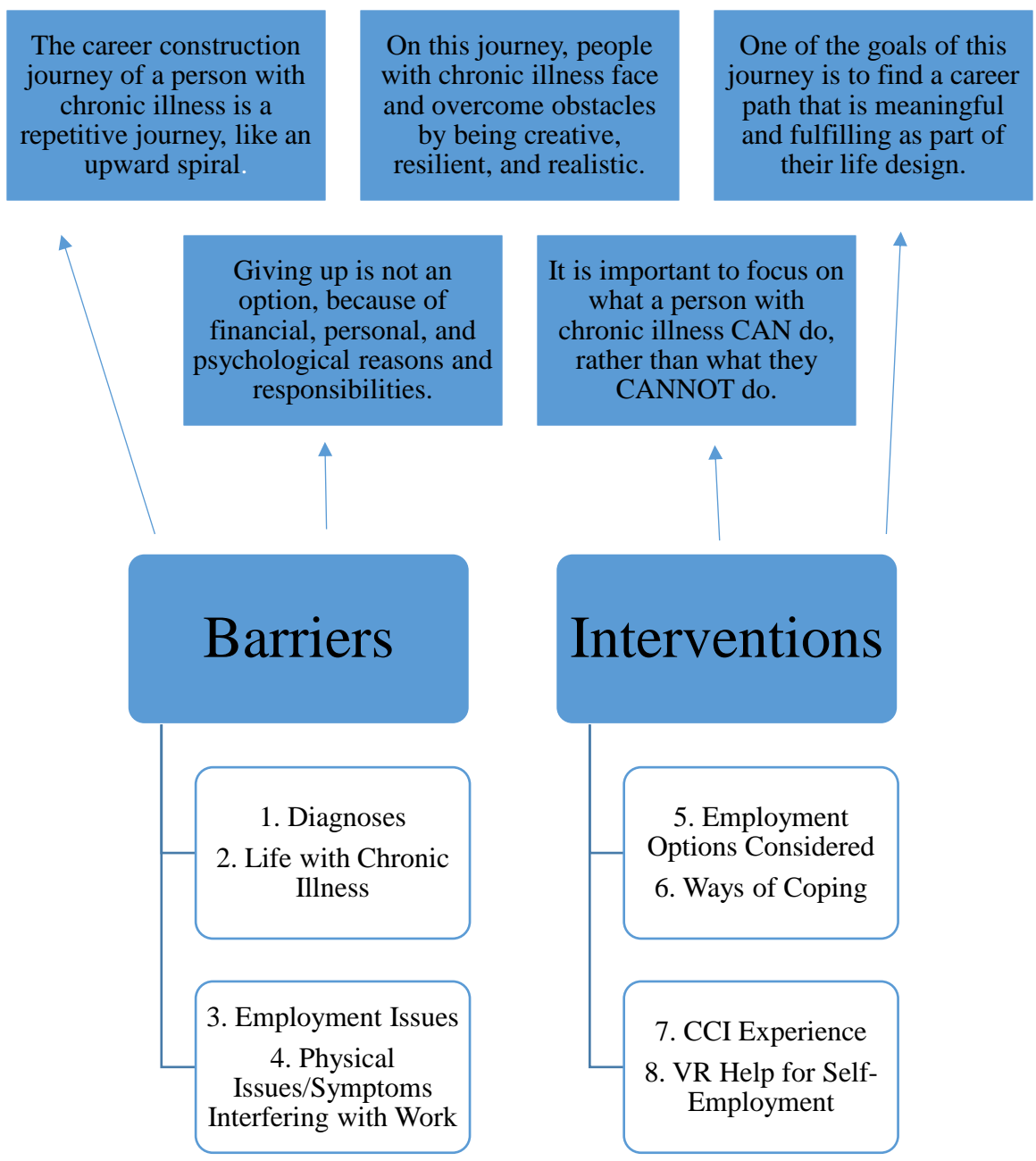


Figure 1: Codes, Categories, and Themes

**Conclusion**

Chapter four presented a detailed look at the results of this study, with findings presented in terms of codes, categories, and themes. Eight open codes were presented. The open codes

related to research question one were diagnoses, employment issues, physical issues/symptoms interfering with work, life with chronic illness, employment options considered, and ways of coping. The open code related to research question two was Career Construction Interview experience, abbreviated to CCI experience. The final open code that does not exactly fit with either research question was vocational rehabilitation (VR) help for self-employment. Each of these open codes can be put into two categories: barriers and interventions. Five themes were developed related to the open codes and holistically looking at the big picture of the participants' experiences and stories. In the next chapter, the themes will be elaborated upon and the results from this study will be connected to the current relevant literature. Implications for the field of rehabilitation counseling will be discussed, as well as recommendations for future research.

## **CHAPTER 5: DISCUSSION**

In this final chapter, the axial codes/themes are discussed in detail. At the conclusion of this chapter, the entire study is summarized.

### **Introduction**

This chapter describes and further explains the axial codes/themes presented in the previous chapter. Next, implications for the field of rehabilitation counseling are discussed. Finally, recommendations for future research are described.

### **Description and Explanation of Axial Codes/Themes**

There are five overarching themes that I discovered from completing this study, related to the overall experience of living with chronic illness, as well as related to the career development, career construction, and the career journey of people with chronic illness. While these themes are true for the participants in this study, and may be true for many others living with chronic illness, the themes may not be applicable to all people with chronic illness and should not be considered generalizable to all people with chronic illness. These themes are listed below.

1. The career construction journey of a person with chronic illness is a repetitive journey, like an upward spiral.
2. On this journey, people with chronic illness face and overcome obstacles by being creative, resilient, and realistic.
3. One of the goals of this journey is to find a career path that is meaningful and fulfilling, as part of their life design.
4. Giving up is not an option, because of financial, personal, and psychological reasons and responsibilities.

5. It is important to focus on what a person with chronic illness CAN do, rather than what they CANNOT do.

### **Theme One**

The first theme is the career construction journey of a person with chronic illness is a repetitive journey, like an upward spiral. For many people, with and without chronic illness, finding a job and a career is a journey. They do not stay in one job, or even one career path, for their entire lives. For the participants in this study, each job, each change, lead to trying to make it better the next stop along the journey. Experiences with employers and organizations and companies and higher education, positive and negative, all shape this journey. Each step and stop on this journey leads to new knowledge and new experiences, both positive and negative. Each step is a learning opportunity and each step leads to the next, shaping the journey into an upward spiral.

### **Stacy**

Stacy started her career as a speech language pathologist in a hospital setting. Eventually, her chronic conditions and symptoms made it too difficult to stay in this position. She said, “I just could not do hospitals anymore. Part of it was ethics but part of it was bedside evals. I just had so many problems bending over.” After leaving the hospital setting, she transitioned into working in schools for a school district. While this change had some positive aspects, it essentially closed the door on Stacy being able to go back into a hospital setting. She said

Unfortunately in that career, at that time, and I’m talking the 80’s and 90’s, it was like once you are in the school, then oh you must be one of the dumb speech pathologists, so we’re not going to hire you for the hospitals and you’ve missed out on all these in-services...you kind of lose track and then you’re pigeonholed.

So Stacy worked in the schools for a while and then her health issues worsened and she needed to go down to 80% time to try to manage her symptoms. She said,

The symptoms, before the diagnosis, were getting so strong that I had, by 35 years old, switched school districts and took an 80% job. It was supposed to be four days a week, but the problem is they give you a 100% caseload, then you have to do it in four days a week.

After working at 80% for one year, Stacy had the opportunity to work part time in another country, working on a special education team that provided services in rural areas in the home, and she took that opportunity for a year. At the end of that year, she wanted to stay there. But she could not get a green card, so she returned to the United States. She did not want to go back into the schools at that time, she could not go back into a hospital setting, so she explored other options and ended up at a community college in a grant-funded position, working in faculty recruitment and teaching classes as an instructor. “I was an instructor, but I had special needs populations and I loved it.”

Eventually that position ended, due to funding, right around the time that Stacy’s symptoms worsened. She did not yet have all of her proper diagnoses, and doctors did not know what to do with her without a diagnosis, and no one could come up with a diagnosis, so she was basically on her own for determining treatment options. Stacy said, “I just went home for months, I was out of the workplace for nine months... it was horrible and the stress.” She did not know how she was going to pay her bills or afford food. She ended up relying on the kindness of neighbors and friends. Eventually the symptoms subsided and she knew she had to go back to work, because she needed health insurance, since she had been denied private health insurance by a company that later had a class action suit brought against it. She could not drive long distances anymore because her shoulders would fall out of place when driving for longer periods of time.

Stacy described her search for a job, saying, “I had to find a public entity, with at least 50 employees, no more than 15 minutes away from home. Crap, crap crap!” The driving distance



was going to be difficult because she lived in a large city that was very spread out and did not have good public transportation. She said, “Looks like I’ll have to go through the K-12 environment again and it was November and most people will hire in March.” She found two positions that fit her requirements and applied. The first place that offered her a job, she decided to volunteer in the position for a week to see if she could do the job. After this, Stacy figured she could do the job, with a little help. She said, “Then they told me five other SLP’s had been there in a three month period. This is a red flag that this is not a good district, but I was desperate. Why? Because I had to have health insurance.” Stacy was offered the job, accepted, and then asked for two 504 accommodations, under the Americans with Disabilities Act. The employer then said they are not going to offer her a job if she needs accommodations. She pointed out her rights and the employer gave in and followed through on the job offer.

Stacy said, “Years later, I found out that I was the first one in [a specific large county in California] to ever ask for a 504 at the time of hire. How large do you think the target was on my back?” Before being hired officially, she had to go to a vocational and occupational medicine clinic to be cleared for work. Stacy had to jump through multiple hoops just to be able to start work. The employer fought back on her requested accommodations and technically complied with them, but did not make it easy or fair. She was told by a nurse with the school district, “The district is going to find a way to fire you because they don’t want anybody on their insurance that has a heart problem.” Stacy tried to build relationships with co-workers, but it was challenging and she ended up being betrayed and mistreated by several people. She said to me, “maybe you should put that down as a diagnosis, multiple stab wounds in the back.” The job got harder, and the district put more obstacles in her way, the longer she stayed. She stayed in the job for five years, because she needed the income and she needed the health insurance, despite the significant

mistreatment and incivility that she faced from her employer and her co-workers. Eventually, it got to the point that she could not do her job without proper accommodations and the employer refused to comply with those.

Around this time, Stacy's elderly mother's health started to decline and so she decided to take family medical leave (FMLA) and go to Arkansas to check on her mother. While she was in Arkansas, her employer contacted her and put additional demands and restrictions on her for when she came back. Stacy was on FMLA for two years, and eventually realized that she was not going to be able to leave her mother alone, even in a skilled nursing facility, and she resigned her position. She ended up taking care of her mother for nearly seven years, employed with a small allowance as her caregiver and personal assistant. As a self-employed person, she was able to buy her own health insurance in Arkansas, under the Affordable Care Act. Since her mother passed away, she has been trying to settle her estate and get her house ready to sell. Once this is done, she says she will have more time to devote to setting up her own online business. She said, "Now after I break down mom's house, I don't know what I'm going to do. But I've always realized, for 20 years, I have wanted to do an online business." Recently, Stacy met with an attorney to start the process of setting up an LLC for an online writing business.

Stacy's story was full of changes and challenges. With each change and challenge, she learned and her experiences formed her decisions. Her story exemplifies this theme. Next, I will share Lisa's story, in relation to theme one.

### **Lisa**

Lisa's career started out in the arts and crafts industry. She worked in marketing. She said, "I traveled and I taught and I came up with and developed educational programs, developed products, and worked with companies overseas." She enjoyed this work and was good at it. Her

services were in demand. Eventually, she said, “my chronic conditions got to the point where the stress of travel was too much.” She attempted to work remotely without traveling, but even that became too much. She said, “it just got to the point where I was again letting people down and that was really hard...I just didn’t have the physical capability to do the things I wanted to do.” Lisa had not finished her college degree yet, but had attended community college previously. She and her family moved to another state and she decided that she wanted to go back to school and obtain her bachelor’s degree. She said:

Going back to school became an outlet for me to still continue to go towards a path of preparing myself for some sort of a career in human services, to take the things I was somewhat good at, but not make it to where I had to travel. So it kind of re-routed my career I guess.

Lisa obtained her bachelor’s degree in Human Development and Family Studies. While she was working towards her degree, she worked in a research lab in the same department on campus. Working in this lab, as well as the site where she completed her internship, sparked her interest in intervention and prevention science, specifically working with adolescents and their families, developing programing for them. After taking a break from school, Lisa decided to go back to school again, this time for a master’ degree, and she chose a reputable online program in social work. However, the demands of going to graduate school full time, dealing with chronic health conditions, and homeschooling her teenage children became too much. She was not getting the support she needed from the disability services office or her professors. Lisa also figured out that she did not necessarily want an MSW degree and that this was not the right program for her. She said:

What I don’t like about the MSW, a lot of my cohort was very angry and mad at the world...and what I want to see in a program is hope, opportunity, and the idea that you have the power to go forward and create change in advocacy and policy.

Lisa knows that she needs a graduate degree in order to pursue the career she wants, but at the time of the interviews, she had not figured out where she wanted to go to school. She has learned from previous experience what kind of supports, in both school and work, she needs and now it is a matter of finding a place that is the right fit. She said, “My career decisions are probably going to be based on what type of support I think that I would get from that program, or that facility or where I work.” Based on past experience, she hopes to avoid being treated differently based on her chronic health conditions. She worries, “Are they going to be treating me differently or are they going to be understanding, matter of fact, this is the way that it is and these are the options we have.” Lisa has had a variety of types of work experience and has explored different career and job options. She has learned from each of these experiences and takes that knowledge gained with her into the future, as she tries to determine the best graduate program and career for her.

### **Mandy**

When she was first attending college, Mandy wanted to be an art major. Her parents and others in her life told her that would not be stable or reliable career option, so she decided on a different major and then went to law school. Mandy became a lawyer, working in several different positions, including at a university where she specialized in disability rights and worked as part of the EEOC office. She also taught as adjunct instructor for the university at times. Just prior to her conditions worsening, she started a new job, the job that would be her last job before retirement. She said:

I was at that time in my dream job, to me, my capstone job. The dream job I had wanted my whole life. I was making good money. My plans were to work six more years until I was 62 and then retire. I had it all worked out.

But all of a sudden, her health “suddenly went downhill literally overnight.” Since that cardiac event that changed her life, Mandy has not been able to work. She said, “Suddenly I couldn’t work anymore and lost a pension as a result because I wasn’t vested.” Mandy was not sure what to do next. She applied for Social Security Disability, and was approved on the first try, within three months, which is a very rare occurrence. However, she still needed something to do with her mind and with her time.

Mandy said, “I gave a lot of thought to what can I still do? You can only watch so many movies and TV.” She needed to be able to lay down as needed, and she passes out unpredictably several times a week. She said, “Given those parameters, I used to dabble in painting, and I could paint lying down, so I took up digital painting, because with a conductive brush and an iPad, I could paint laying down.” In a way, Mandy’s career and interests came full circle. At the beginning of her career, she wanted to be an artist, and when her dream career ended because of her chronic health conditions, she turned back to art again. She was able to use her knowledge as an attorney to set up her own online art business and established an LLC. Her art is beginning to be noticed and has been featured in gallery shows across the country, and people have started buying her art from galleries and from her online website. She has truly exemplified the ability to learn from her experiences, take a barrier and figure out a way around it. This concept will be further discussed in the next theme.

## **Theme Two**

The second theme is on this journey, people with chronic illness face and overcome obstacles by being creative, resilient, and realistic. The reality of life with chronic illness, especially multiple chronic illnesses, and the reality of life for the participants, is that life did not go the way they had planned or imagined. Chronic illness brought obstacles into their lives and

they had to figure out a way around or through those obstacles. Obstacles included, but are not limited to medical diagnoses, chronic illness symptoms, employers, co-workers, doctors, technology, health insurance, transportation, and others. For at least two participants, Mandy and Stacy, a significant obstacle was being told to stop working by a physician, even when this was not necessary, and the issues could have been resolved with a few simple accommodations. Each time an obstacle was faced, a decision had to be made. Am I going to overcome this or am I going to accept this? Sometimes the decision was made to overcome and sometimes the decision was made to accept. The decisions were approached with creativity and realism, and regardless of the outcome, participants emerged with resilience as their badge of honor.

### **Stacy**

As demonstrated by her story related to the previous theme, Stacy has faced many obstacles in her career. She faced obstacles related to her career and professional life, as well as obstacles related to getting diagnosed properly, and obstacles in her personal life, all related in some way to her chronic health conditions. In regards to her jobs, she faced numerous obstacles. Her employer did not want to hire her once she requested accommodations, the accommodations were never implemented properly, and she was mistreated by her co-workers. In order to conquer the obstacle of having adequate health insurance, she stayed in a position that was miserable for her. When I asked her what kept her going she said, “Money. I was desperate. I had to have health insurance.” Regarding all of the hoops her employer required her to jump through, including taking the certification exam again, she said, “They didn’t think I would stick it through and they didn’t think I would stay.”

It took until her mid 40’s for Stacy to get properly diagnosed with Ehlers Danlos Syndrome (EDS), and she is still getting new diagnoses now in her later 50’s. She said that one

of the worst obstacles that she has faced in her life, both from medical professionals and friends and family is not being believed about her symptoms and her conditions. She said, “The bad side is, the worst side is people not believing you. And that has impacted me greatly. Well. You look fine to me.” But, thanks to her persistence, when she did finally get a diagnosis, she said that it answered a lot of family questions. Stacy said:

I was not happy when my niece came up with hypermobility syndrome, officially, possibly Ehlers Danlos, it depends on what doctor puts her on what scale...But I feel the confidence as an aunt to say oh I know the answer to this, wait a minute, don't do this, do this, so that feels, that's the teaching part of me, that's the healer part of me. That's the good part. I'm not happy that she has it, but I'm happy I can help.

Stacy ended up using her professional knowledge and her personal medical knowledge to help with her mother's care and advocate for her mother's treatments with doctors. She exemplified this theme with the statement:

Sometimes there's reason for things, sometimes not, but I believe that maybe part of all of us connecting with EDS, maybe we were born at a specific time so that we can collaborate and help change the face of medicine. Not just for EDS, but truly hold their feet to the fire on the politics of medicine, the politics of insurance, the politics of vocational rights, if you have a disability.

Stacy faced many obstacles, and will most likely continue to face obstacles for the rest of her life, but she is truly an example of how to become creative, resilient, and realistic.

### **Lisa**

Lisa has also faced many obstacles, both personally and professionally. She summarized her current obstacle by saying, “I think right now the major barrier would be finishing my education and finding a program.” Both in relation to her employment and in her own personal life, driving and traveling has presented a challenge. Lisa had to stop working at one job, when the stress of travel became too much. When she tried to find a graduate program that would be a good fit, she said that she feels stuck in regards to her location.

I can't move and pick up and go to college across the United States. I can't apply for jobs outside of [the town she lives in]. I'm very limited especially in the wintertime. Driving long distances, even going to [a university 45 minutes away] wouldn't be an option for because driving over 30 minutes, I can maybe do that like once a month. But not multiple times a week under stress, having to make it to class on time, with requirements of, did I get this done? It's very difficult for me to plan because I really am stuck at home for the most part of I'm stuck going to [the local university], which isn't a bad option.

After completing her undergraduate degree, Lisa knew she needed and wanted a graduate degree to pursue her passions and goals for her career. She tried an online program at a university in another state, but faced challenges there. She said:

During spring semester, I had to drop down to, basically go on a leave of absence, because one, we were homeschooling, two, financially, we were strapped and that's a big stress for me, and three, like I was so spent from my first semester that I didn't even have the energy to figure it out and plan and that's the only way I can get through my semesters, if I have it structured and planned and understand what I have each week, then I can ration out my energy and it just got so hard to be able to keep up with it, especially without support from the school and teachers.

Even though there was a graduate program that would meet her professional needs at a local university, Lisa still felt like there was something standing in her way of going there, partly because of her experiences there as an undergraduate. She said:

As I look back to going back to school, I've also been stuck between a couple of different ones and ...there is a part of me that has not been wanting to go back to the department. And even though it might be the best choice for me, there has been something that has been holding me back and it's kind of trying to figure that out and such. I think because of the way that I left...when you look at it from an outside perspective, it really is like, wow, these people are coming together to support you...But going forward I think it was really great that they came together, but it also puts me in a position of feeling like, a different type of vulnerability, that was I guess maybe the pity part. And I know that they weren't pitying me, but there is a part that is like were they doing it out of pity, did they really think I was needed and belonged there? And so that's the kind of stuff I am processing right now.

In both her personal and professional life, Lisa worried that the challenges and unreliability of her chronic conditions will mean that she let people down. She said, "The hardest part for me is letting people down." To alleviate this, she does her best to explain her conditions and



limitations to others, especially her family. With her family, it can be especially hard. Regarding her children, she said, “they don’t even attempt to ask because they don’t want to get let down. Those are the things that are really hard to kind of juggle.” Some of Lisa’s obstacles are social-emotional, rather than obstacles related to employment or physical symptoms from her conditions. Even though these are a different type of obstacle, she still has to figure out a creative way around the problem it presents. After completing the Career Construction Interview and doing some more personal exploration on her own, Lisa was able to overcome her hesitation around returning to the local university and decided to apply to a combined masters/PhD graduate program for admission either Fall 2019 or Fall 2020. Unfortunately after making a decision about going back to school and finding the right program at the local university, Lisa was in a car accident that exacerbated her current conditions and also resulted in a concussion that has caused additional impairments. She now has new obstacles to face in her recovery and determining how those obstacles will impact her future and how she can get around or through them.

### **Mandy**

Mandy’s obstacles were mostly related to employment and then how to keep herself and her mind occupied once she was no longer able to work in her chosen career. One significant obstacle that she overcame was after finally getting a proper diagnosis of POTS and NCS, she was told by a doctor to quit working and go on disability. She said:

Fourteen years ago, I had a doctor tell me, well he thought I should go on disability then and he would fill out the paperwork. Well I fired him as my doctor and found a different doctor, because at the time, given my skills as an attorney, as long as I could use a computer and a phone, I could still work. So I worked twelve years beyond when I was told I could and should quit by a doctor.

Mandy worked until a sudden cardiac event dramatically worsened her condition and then she had to stop working. She said, “Initially I rejected any notion of not working, of reducing my hours to part time or not working at all ...then when my body made it impossible suddenly to work at all, I have wished I could work part time.” It took a while for Mandy’s life to stabilize after she had to stop working. But she had been through difficult times before and made it through, so she figured she could make it through this too. She said, “I’ve lived through some devastating life events before and I know I got through those, so I had every reason to have self-confidence that I could get through this.” At the time she had to stop working, she had been married to her husband for only two months and they had just bought a house that they had closed on only a week before her cardiac event. She said “He and I just sat down and rationally assessed things and figured out we’d still make it work. And we have made it work.”

One of the ways that Mandy adjusted to her new normal was that she started painting digitally to combat the boredom of not working and having to spend a lot of time laying down. She said, “I used to dabble painting, so I took up digital painting because with a conductive brush and an iPad, I could paint lying down. And that has turned into a huge adventure.” Mandy started posting pictures of her paintings in social media and was pleasantly surprised to find people interested in her art. She said, “To my surprise, some people have wanted to buy my art. I’ve had my art in art shows, and it’s opened up new horizons and social interactions.” Given the interest in her purchasing her art, she decided to try turning her art into an online business. She said during one of her interviews:

I decided, six months ago, that during this year, 2018, I would build up a portfolio, plus spend a year learning the ropes of the ins and outs of selling art online, because if I sold online, I wouldn’t be on a schedule. And I figure if I’m painting anyway and people are wanting to buy it anyway, if I were selling already, just to the people that have unsolicited asked to buy it, I’d be making two or three hundred dollars a month. So it’s not crazy talk to believe that if I actually made a proactive effort to sell, maybe I could

double that. Maybe I could make six or seven hundred dollars a month, just a little part time thing.

Mandy had initially planned to set up her business in January 2019 and launch her website in March 2019. She said, “next January, I’m going to form an LLC. Being a lawyer, I know how to do that.” However, she figured out and accomplished the necessary steps sooner than planned and she launched her business website in November 2018. She is still learning the best ways to advertise and pricing, but at our last interview, she said, “I’m happy to report that my art attracts a lot of traffic to my website.” Mandy has truly figured out the best way to conquer her obstacles through being creative, resilient, and realistic. The next section will discuss the third theme.

### **Theme Three**

The third theme is that one of the goals of this journey is to find a career path that is meaningful and fulfilling, as part of their life design. All three participants have had meaningful careers previously in their lives. Therefore, it makes sense that when those jobs or careers were no longer possible, that they would still want to find a job or career that they can find meaning and fulfillment in. All three participants have a passion for specific topics or activities and are working towards turning those passions into a career. In the following sections, the stories of each participants relating to theme three are described.

### **Stacy**

Stacy is working towards using her passion for writing to set up an online writing business. She said, “I want to write and not a novella, but like some kid’s books or other short books, thin books.” In her final interview, when she was still exploring her options, she said:

I’m going to take my inheritance and come up with an LLC company. But I also think I’m doing better writing about the family history and the services that are out there. Some

of them are incredible and others aren't. I'm like man, I think I can do that. And I could do it online.

She wants to be able to take her time and thoughtfully plan and set up her online business. She said she might have to "give myself permission to just learn for a year. I don't want to rush into something and fail." In a recent email to me, she wrote, "In meantime, still working on estate stuff but tax attorney and I have met on creating an LLC for a writing business, even if it isn't profitable at first. It's a step."

### **Lisa**

Lisa, once recovered from a car accident, is taking steps to pursue her passion for prevention science and will eventually obtain a graduate degree in this area. She has identified her passion, though. She said:

I want to work with families. What my passion is, is working with adolescents and teens. I love prevention science and I love teaching families ways of preventing, just helping families find correct patterns of communication within their teens to help grow their teens into responsible, respectful adults.

Even while trying to figure out the right path and program for her, Lisa is finding ways to use her passion in her everyday personal and family life. She said, "right now within our homeschool group, I manage our teen events for the teens and so I work with the teens as well as with their families and ... together we create events for our teens." After our final interview and doing some research and exploration on her own, Lisa sent me a text message telling me that she had explored different programs and decided on the graduate program at the local university. She wrote, "This gives me some good goals to work towards which allows me to feel as if I am investing I myself as I work on these items."

**Mandy**

As of April 2019<sup>1</sup>, Mandy has successfully turned her passion and talent for creating art into an online business and her art is being featured in gallery shows across the country and people are beginning to purchase her creations. She has definitely had a learning curve and had to figure certain aspects out through trial and error. In our last interview, after her online website had been active for about two months, she said,

I'm still working on my pricing. Because it's real guesswork with art, and I read a book about selling art online and it said start high and gradually bring it lower until you find that sweet spot. And I'm still at that point, I'm just now finding that sweet spot, because the computer analytics show me that a healthy amount of traffic goes to my art website and that's growing by the month, that's growing in leaps and bounds.

About three months after our last interview, Mandy sent me a message, telling me that her art is beginning to sell and she is even receiving pictures from people of her art hanging in their homes. Her art has been in several gallery shows across the country and one show is running in her town during April and May.

**Theme Four**

The fourth theme is that giving up is not an option, because of financial, personal, and psychological reasons and responsibilities. Each participant expressed different needs and desires around working. All expressed the desire to find something to do that brings meaning to their lives and helps others in some way, which is reflective of their previous careers.

**Stacy**

Stacy said she needs to work for financial reasons; she is single and must support herself and have decent health insurance coverage. She is still trying to figure out what level of income she needs to support herself. She is trying really hard to avoid going on Social Security Disability, mostly because she is worried about Medicaid health insurance. She said, "So if I

went on disability, would I have to take Medicaid, which is horrible in the state of Arkansas?”

One of the areas she still needs help with is knowing what resources are out there, which is where a VR counselor could help. This will be discussed later in the implications section. Stacy said, I really need a better resources than just my general knowledge or when I go online because there's just too much bad information.”

### **Lisa**

Lisa wants to still be able to put her passion and skills and education to good use, while also setting an example around working hard for her children and contributing financially to her family. She knows that going back to school will be hard on her, but she said:

It's hard to tell what I can handle and what I couldn't because when I was in school, I was full-time 50+ hours a week and I loved it. Working my internship...it was hard on my health, but I felt alive. It was just amazing how whole I felt.

As much as Lisa loves prevention science, she said that “I think the end goal for me is definitely going to be teaching. That's what I really just love.” She knows that she needs to go back to school to be able to accomplish these goals and put her passion to work and even said, “I still feel like I'm wanting to go on to a PhD.” The graduate program she has decided on is a combined masters/PhD program and hopefully Lisa will be able to find the support she needs to be able to realize her dreams.

### **Mandy**

Mandy eloquently stated the following about why working in some capacity is important to her, “People need goals and dreams and so there's intrinsic value in that above and beyond somebody becoming self-sufficient financially, although of course that's important.” She had to take the time to grieve the loss of her career and process the sense of loss. She was able to turn her skills and love of painting into more than just a hobby and is well on her way to turning her

art into a profitable venture. At this point in her life, she said, “I’m not better physically, but I have sought out proactively new things that I can do given my physical limitations because I think we always need dreams and we always need goals, however small or modest they may be.” Mandy also uses her platform as an artist to raise awareness about her chronic conditions. On her art website, she provides a brief description of why she started painting and how her chronic conditions influence her art.

### **Theme Five**

The fifth theme is it is important to focus on what a person with chronic illness CAN do, rather than what they CANNOT do. In my mind, this is the most important theme of all. People with chronic illnesses are constantly being told what they cannot do, and it becomes exhausting when that is all it feels like they hear. They hear it from employers, from doctors, from physical therapists or occupational therapists, and even from friends or family. It can even become an internal dialogue within the person with chronic illness. However, for many reasons, it is so important to focus on what they can do, instead of just focusing on what they cannot do. Yes, it is important to be aware of restrictions when it comes to using accommodations, structuring the workday, and pursuing new careers. However, in order to provide encouragement, hope, and perseverance, it is completely necessary to help the person with chronic illness figure out what they are still capable of doing and who they still are. This is one benefit to the Career Construction Interview experience. It reminds people of who they are, outside of their illness.

### **Stacy**

In response to her results from the Career Construction Interview, Stacy said, “It’s very true. I want to help change beliefs and I have never seen that in black and white before, so that was like oh yeah cool, that’s me.” Once she decided on an online writing business, she said, “I’m

doing better writing about the family history and the services out there, some of them are incredible and others aren't. I'm like man, I think I can do that." Once she had figured out what she can do and wants to do in regards to setting up an online business, she knew she would need some help. This will be addressed more in a later section regarding implications for the field.

### **Lisa**

Lisa is well aware of her limitations and what she cannot do, but she also knows what she can do. She recognizes that she may need some accommodations or support to do what she knows she can do. She said that she does not need much, "just a compassionate understanding person that's willing to work with me. Like help me get the job done and I'm able to, but physically I have limitations." In a previous position, she told the potential employer about her physical limitations and he said "We just want you for your mind." She needs support like that to continue to be able to focus on what she can do. She summarized her experience with the Career Construction Interview and thoughts relative to this theme when she said:

There is such high anxiety when you're dealing with your future, the ambiguity and the high anxiety of being, having chronic illness as well as trying to figure out your next steps. It's very heavy and it's very hard. And so having a holistic understanding of who you are and having it done in such a gentle assessment, I think it really helps to give that person a little bit of their power back and it really does, it just kind of sets it, like gentle ripples into motion of my thoughts and themselves and seeming themselves rather than broken and half able or whatever. Really seeing them as, ok, these are the things that I'm still capable of, that are still valuable in me.

### **Mandy**

Mandy is an amazing example of truly learning to focus on what she can do, rather than what she cannot do. In fact, focusing on what she can do is a coping mechanism that she uses. She said, "My biggest coping mechanism has been to seek out things I can still do and engage in, given my physical limitations. She used to enjoy gardening, but could no longer handle the heat of gardening outside, combined with all of the postural changes. Now she has a small indoor



container vegetable garden. She said, “I can still have the fun and the hobby of gardening because I can sit on my little portable stool.” Mandy summarized this theme, when she posted the following on social media and allowed me permission to use it here:

Don't allow the things you cannot do get in the way of things you CAN do! I began painting while lying down as a way to combat boredom when my Dysautonomia became severe (after 16 years). Now my paintings are beginning to be shown in art galleries. We may have to modify what we dream of doing, but don't let that stop you from dreaming. I'm living proof that anything is possible, including the improbable.

### **Implications for the Field**

There are a few important implications from this study that are relevant to the field of rehabilitation counseling and the world of vocational rehabilitation (VR). These implications essentially fall into two different categories: training for vocational rehabilitation counselors and best practices for delivering services to people living with chronic illness and disability. Implications for the field of vocational rehabilitation counseling and recommendations for improvement are described in relation to the five themes presented and explained in the previous section.

### **Theme One**

The career construction journey of a person with chronic illness is a repetitive journey, like an upward spiral. It is important for those training future VR counselors, as well as practicing VR counselors to be aware of this. In regards to service delivery, client cases are supposed to be closed within 90 days, at least in most state agencies, and this may not be feasible or realistic for cases of clients with chronic illness. They may need to go out and try a job or start a career and then come back to the VR counselor for support or accommodations. They may also have to go through a significant trial and error process to find out what type of job, in what location, and with what employer works best for them. They will most likely need the help of a

VR counselor in determining these options and may need to come back several times over a span of months or years to find the best fit or at least the best fit for that time, given the current state of their conditions and symptoms.

## **Theme Two**

On this journey, people with chronic illness face and overcome obstacles by being creative, resilient, and realistic. Some people with chronic illness have these traits on their own, but they may still need some assistance from a knowledgeable VR counselor, especially in regards to job accommodations and career exploration. Training programs already teach VR counselors the medical and psychosocial aspects of chronic illnesses, but VR agencies need to do a better job of reaching out to organizations and agencies related to chronic illness and letting this population know that they are there to help them and not just people with disabilities. This is important, because many people with chronic illness do not consider themselves as having a disability, unless they are on Social Security Disability.

Many career-related obstacles faced by people with chronic illness could be ameliorated with simple job accommodations and a conversation with the employer about limitations. People with chronic illness and disability are often fearful of disclosing their conditions and asking for accommodations due to the concern over retaliation or being let go. VR counselors can help alleviate these fears by speaking directly with the employer and educating them and providing recommendations for reasonable accommodations. They can also brainstorm with clients and practice having difficult conversations with employers before the client has a talk with the employer. Overall, it could take some burden off the person with a chronic illness to have assistance in tackling obstacles in their way and provide some emotional and psychological support to know they are not completely alone in this journey.

### **Theme Three**

One of the goals of this journey is to find a career path that is meaningful and fulfilling as part of their life design. This is where the Career Construction Interview (CCI) can be beneficial. Especially when combined with more structured assessments, like aptitude tests and interest inventories, the CCI could be a useful tool for VR counselors to use in the field when helping clients determine the best educational and career path. However, many graduate programs do not specifically teach this topic or how to conduct the CCI to their students. Practicing rehabilitation counselors may not know about this technique or may be hesitant to use an assessment that is not traditional or standardized. There are trainings available, but most VR agencies are not going to be able to pay for their counselors to travel to and attend these trainings and the counselors may not have the personal financial resources to pay for these trainings either.

Another important finding that has implications for the field of rehabilitation counseling and vocational rehabilitation (VR) agencies is around the concept of self-employment. Self-employment may be the best option for a career path that is meaningful and fulfilling for people with chronic illness. Research has shown that self-employment is considered a last resort for people with chronic illness. One researcher even wrote that self-employment is a sort of “‘opting out’ of the career game” (Beatty, 2011, p. 104). Many classes that train master’s level VR counselors teach that self-employment is the least desirable option for assisting clients with career exploration and readiness. However, given that two of the three participants in this study have purposely chosen self-employment because their conditions do not allow them to fit in a traditional employment environment, it might be time to reconsider the value of self-employment for people with chronic illness.

Stacy, when asked to review the codes and themes discovered through this study, said “Glad to see more light on how chronically ill want self-employment.” Self-employment allows for flexibility in hours, location, tasks, and abilities that make it an option conducive to the limitations of chronic illness. Mandy said the following about how VR agencies could help people with chronic illness set up an online business for self-employment:

I am convinced that the way to help somebody who becomes disabled start an internet business...the best way is have the government or some organization pay an expert whose job it is to help them set it up. Now once it is set up, they run it themselves, and they need to know, that's not their support person to call every time they have a tech problem. But just to teach you, or bet yet, sit beside you in a chair physically and walk you through setting it up. And I think if there is an organization out there that had a person like, their full time job is to help disabled people launch their online websites where there are selling something...and that person just goes around, like a traveling person, goes into their home, teaches them how to set it up, and I think it's better to teach them how to set it up than to set it up for them. Because then they'll feel like they are a part of it and I think they'll be less intimidated by it.

Self-employment has been growing in popularity in Europe for the past decade. One research study wrote, “In recent years an increase in self-employment has been one of the most significant changes in European labour markets. For the European Union (EU) as a whole the self-employment share of total employment was 15.6% in 2005” (Pagan, 2009, p. 217). The author went on to state, “self-employment can be used as a viable outcome for disabled people, especially those severe disabilities” (Pagan, 2009, p. 217). The author summarized his research by saying:

Self-employment provides flexibility and a better adjustment between disability status and working life. Moreover, the levels of satisfaction with job, type of job and working conditions of self-employed disabled people are higher than those reported by disabled people who are wage and salary earners. Policy-makers must encourage self-employment to increase levels of well-being and employment of people with disabilities in Europe.” (Pagan, 2009, p. 217).

In the United States, self-employment is growing in popularity as well. As of 2013, “the self-employment rate is growing at more than 20% annually, with microenterprise (businesses

employing one to five workers) generating 64% of all new jobs in the United States” (Griffin, Hammis, Keeton, & Sullivan, 2014, p. 2). Vocational rehabilitation agencies are starting to recognize the value in providing services to assist with self-employment for people with disabilities and chronic illness.

As of 2013, self-employment and business ownership are recognized across the country in newly revised state Vocational Rehabilitation (VR) agency policies...Because all people who are self-employed use, create, and purchase a variety of supports – ranging from accounting services to sales representatives – owning a business meshes well with the American dream and with the commitment of rehabilitation professionals, family members, friends, and neighbors to assist people with disabilities in achieving typical lives. Owning a business can be one of the least stigmatizing forms of employment for individuals with significant disabilities. (Griffin et al., 2014, p. 2)

Employment provides many benefits, physical, psychological, and financial, and VR counselors should be doing everything possible in partnership with the client to promote and prepare for employment. Self-employment is a valid option, especially for people with disabilities and chronic illness. A blog post from The Mighty demonstrates the reality of self-employment options for people with restrictions due to chronic illness. The author writes:

I was between a rock and a hard place. Not disabled enough not to work, but not healthy enough for people to want to hire me...It wasn't a free choice, it was a matter of necessity. Once I chose to work because I was able to, starting my own business became the only viable course of action in front of me. (Alessia, 2017, para 5-7)

More research in this area is needed. This and other recommendations for future research will be discussed in the next section.

#### **Theme Four**

Giving up is not an option, because of financial, personal, and psychological reasons and responsibilities. VR counselors are in a perfect position to help clients with this concept. I see people all of the time on my chronic illness support group sites posting that they are ready to give up, that they do not see a way around all of their obstacles and they have no one to help

them. This does not have to be the case! Help is available, but people need to know that it is out there. As stated previously, VR agencies need to do a better job of reaching out to organizations and agencies related to chronic illness and letting this population know that they are there to help them and not just people with disabilities. Employment and working, even part time, provides so many benefits, financially and psychologically. Many people with chronic illness feel they have no option other than Social Security Disability because they cannot see a way to work with their limitations, but VR counselors can help with that. They can also help someone currently on SSDI figure out how to work without losing their benefits, especially the healthcare benefit, which is crucial for people with chronic illness.

### **Theme Five**

It is important to focus on what a person with chronic illness CAN do, rather than what they CANNOT do. This task can be accomplished partially through the Career Construction Interview (CCI). Although the sample was small and limited to females, the Career Construction Interview was shown to be beneficial to the three participants in this study. Especially when combined with more structured assessments, like aptitude tests and interest inventories, the Career Construction Interview could be useful tool for VR counselors to use in the field when helping clients determine the best educational and career path. It does take time and practice to become proficient at conducting and interpreting the CCI, but the actual administration of the interview generally can be done in 20-30 minutes and typically only one follow up meeting to discuss and apply the results is needed.

### **Recommendations for Future Research**

Based on the results of this study and the deficiencies in the current research presented earlier in chapter two, there is a need for future research around both the Career Construction

Interview and interventions to promote career exploration and development for people with chronic illness, as well as additional studies looking at self-employment for people with chronic illness. Recommendations for future research will be discussed within the context of the themes discovered from this study.

### **Theme One**

The career construction journey of a person with chronic illness is a repetitive journey, like an upward spiral. Existing research has shown the patterns of employment and challenges faced by people with chronic illness (Beatty & Joffe, 2006; Beatty, 2011; Henriksson et al., 2005; Joffe, 2016; Keponen & Kielhoffer, 2006; Koch et al., 2013; Szymanski & Hershenson, 1998). Existing research has also shown that people do not stay in one job or one career for their entire lifetime and that careers can have stages to them (Barclay, Stoltz, & Chung, 2011; Bolles, 2015; Savickas, 2011). But this concept is not well communicated to the public, especially people with chronic illness and disability. There needs to be more research done that is aimed at educating the public, VR counselors and other practitioners, and consumers with chronic illness about this concept. Practitioners and consumers need to be shown how this concept plays out in real life and this can be done through further qualitative and quantitative research that is presented in a way that is easy to understand and available to the general public outside of academia.

### **Theme Two**

On this journey, people with chronic illness face and overcome obstacles by being creative, resilient, and realistic. Existing research has done an excellent job of identifying the barriers to employment and challenges related to employment faced by people with chronic illness (Beatty & Joffe, 2006; Beatty, 2011; Henriksson et al., 2005; Joffe, 2016; Keponen &

Kielhoffer, 2006; Koch et al., 2013; Szymanski & Hershenson, 1998). However, there is not enough research around how these obstacles are overcome or ways to encourage persistence, creativity, and resilience in this specific population. Specific interventions designed to help overcome the already established obstacles need to be explored so that they can be put into practice and help people.

### **Theme Three**

One of the goals of this journey is to find a career path that is meaningful and fulfilling as part of their life design. One of these paths might be self-employment. As initially presented in the previous section, more research is needed in the area of self-employment for people with chronic illness. Barriers and reasons why VR counselors do not recommend or encourage self-employment need to be explored, as well as possible ways to address these concerns. Barriers and assistance needed to pursue self-employment from the client perspective should also be explored and then ways to address these issues should also be addressed. While researching this topic, I found a good resource, a book titled *Making Self-Employment Work for People with Disabilities* by Griffin, Hammis, Keeton, and Sullivan (2014) that provides several practical solutions for people with disabilities and chronic illness tackling the steps to setting up self-employment. This guide might be a good place to start with pursuing this line of research. Partnering with researchers in European countries, where self-employment is more popular and encouraged might also be a good option for getting research started and bringing philosophies and strategies from other countries to the United States.

### **Theme Four**

Giving up is not an option, because of financial, personal, and psychological reasons and responsibilities. But there is not a lot of research available that shows strategies to put in place to



encourage people not to give up. More research is needed in this area, specifically for the population of people with chronic illness, because strategies for these people may be different than strategies for the general population. Research has shown the benefits of work, in general and for people with chronic illness. But this research is mostly known to researchers and academics, and not by people with chronic illness. There needs to be a way to communicate this information to this population, so that they will seek help from VR counselors and agencies to be able to gain and maintain satisfactory employment.

### **Theme Five**

It is important to focus on what a person with chronic illness CAN do, rather than what they CANNOT do. One of the ways we can help people focus on what they can do is through the Career Construction Interview (CCI). The limitations to the current study show there are definitely other populations to explore with the use of the Career Construction Interview as an intervention tool. Given that this study had no male participants, it would be good to see if similar results were found with all males with chronic illness. This could be challenging to find this population, since chronic illness affects females at a much higher rate than males. Another population to explore using the CCI with would be younger adults. Since this study's participants were all in middle age, it would be interesting to see if there are similarities or differences found when testing this experience with young adults in their late teens, 20's or 30's. It would also be interesting to test the CCI with groups of people with the same chronic condition, such as chronic pain, multiple sclerosis, etc., and see how the CCI works with these groups and if there are similarities and differences when compared to this current study.

## **Researcher's Experience**

Completing this dissertation was an interesting experience for me as the researcher. I chose this topic because losing my career due to chronic illness and having to figure out what to do next with my life was a huge event in my life and I could not have made it through this without the help of others. I see people posting on my chronic illness support groups all the time about losing their jobs or having to find a new job or career path due to issues related to their chronic illnesses. Completing the Career Construction Interview while I was in my master's program gave me a whole new perspective on who I was and what I wanted to do with my life. I was very mindful of this experience when I designed the study, and then also while I was conducting the interviews and analyzing the data. True objectivity is impossible, in my opinion, but I did my best not to let my experiences influence my participants or influence the way I analyzed or interpreted the data. I did end up sharing some of my own experiences with each participant, but only after we completed the entire interview process.

I saw pieces of myself in all three of my participants. I saw myself in Stacy when she said she could not give up and she kept fighting because she had to support herself. I saw myself in Lisa when she talked about it being very heavy and very hard dealing with the anxieties of having multiple chronic conditions. I saw myself in Mandy when she talked about it being important to her to seek out what she can still do and focus on that, instead of focusing on what she cannot do. I am grateful for the opportunity that I had to meet these women and get to know them and I take pride in the fact that my study was able to be a positive influence in their lives, even if it was just in a small way. Completing this study helped me understand myself as a person and a researcher. I am a pragmatist, I want to know what works for real people, and I will

take this experience and use it to help me design future studies, focusing on real, practical interventions and ideas that will make a difference in the lives of real people.

## **Conclusion**

This chapter presented and explained the qualitative themes associated with this research study and connected these themes to other current research. This section also discussed implications for the field of rehabilitation counseling and vocational rehabilitation agencies that provide services for people with chronic illness and disabilities. Finally, recommendations for future research were discussed, related to the Career Construction Interview and other interventions/research around career development and exploration for people with chronic illness and disabilities.

This overall dissertation study was an instrumental multiple case study design, specifically a collective case study with an explanatory design. The purpose of the study was to explore two research questions. The first research question was what is the experience of a person facing a forced career transition due to the onset or exacerbation of a chronic illness? The second research question was what is the experience of a person facing a forced career transition due to the onset or exacerbation of a chronic illness participating in the Career Construction Interview process? There were three participants involved in this study; each participant participated in four interviews. In answering the research questions, eight open codes fitting into two categories were discovered and five axial codes, also known as themes, were determined. The eight codes were: diagnoses, employment issues, physical issues/symptoms interfering with work, life with chronic illness, employment options considered, ways of coping, Career Construction Interview experience, abbreviated to CCI experience and vocational rehabilitation

(VR) help for self-employment. The two categories were barriers and interventions. The five themes are listed below:

1. The career construction journey of a person with chronic illness is a repetitive journey, like an upward spiral.
2. On this journey, people with chronic illness face and overcome obstacles by being creative, resilient, and realistic.
3. One of the goals of this journey is to find a career path that is meaningful and fulfilling, as part of their life design.
4. Giving up is not an option, because of financial, personal, and psychological reasons and responsibilities.
5. It is important to focus on what a person with chronic illness CAN do, rather than what they CANNOT do.

Peer review, member checking, and triangulation were all used to achieve validity and trustworthiness. Rich, thick description was achieved by presenting the participants' voices and experiences in a detailed, honest and accurate manner (Creswell, 2015).

From this study, I found that the Career Construction Interview was helpful to the participants in assisting them with making decisions about potential careers and options for employment. An unanticipated finding from the study was that people with chronic illness want options for self-employment, but need assistance in navigating the process of establishing self-employment. This is important for both future research and implications for practice, as VR counselors could certainly use more awareness and tools for helping with self-employment and more research is needed to establish the need for self-employment and the barriers and solutions to those barriers, as seen by both VR counselors and VR consumers. The use of the Career

Construction Interview also needs further study with different chronic illness populations. In general, more positive interventions are needed and wanted by people with chronic illness to assist them with exploring possible career options to allow them to find and engage in meaningful and fulfilling careers.

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## Appendix A: IRB Approval Letter



**To:** Julie C Hill  
 BELL 4188  
**From:** Douglas James Adams, Chair  
 IRB Committee  
**Date:** 04/16/2018  
**Action:** **Expedited Approval**  
**Action Date:** 04/16/2018  
**Protocol #:** 1803111794  
**Study Title:** Career Transitions Caused by Chronic Illness: A Career Construction Perspective  
**Expiration Date:** 04/05/2019  
**Last Approval Date:**

The above-referenced protocol has been approved following expedited review by the IRB Committee that oversees research with human subjects.

If the research involves collaboration with another institution then the research cannot commence until the Committee receives written notification of approval from the collaborating institution's IRB.

It is the Principal Investigator's responsibility to obtain review and continued approval before the expiration date.

Protocols are approved for a maximum period of one year. You may not continue any research activity beyond the expiration date without Committee approval. Please submit continuation requests early enough to allow sufficient time for review. Failure to receive approval for continuation before the expiration date will result in the automatic suspension of the approval of this protocol. Information collected following suspension is unapproved research and cannot be reported or published as research data. If you do not wish continued approval, please notify the Committee of the study closure.

**Adverse Events:** Any serious or unexpected adverse event must be reported to the IRB Committee within 48 hours. All other adverse events should be reported within 10 working days.

**Amendments:** If you wish to change any aspect of this study, such as the procedures, the consent forms, study personnel, or number of participants, please submit an amendment to the IRB. All changes must be approved by the IRB Committee before they can be initiated.

You must maintain a research file for at least 3 years after completion of the study. This file should include all correspondence with the IRB Committee, original signed consent forms, and study data.

cc: Kristin Kay Higgins, Investigator

## Appendix B: IRB Renewal Approval Letter




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**To:** Julie C Hill  
 BELL 4188  
**From:** Douglas James Adams, Chair  
 IRB Committee  
**Date:** 03/26/2019  
**Action:** **Expedited Approval**  
**Action Date:** 03/21/2019  
**Protocol #:** 1803111794R001  
**Study Title:** Career Transitions Caused by Chronic Illness: A Career Construction Perspective  
**Expiration Date:** 04/05/2020  
**Last Approval Date:** 04/06/2019

The above-referenced protocol has been approved following expedited review by the IRB Committee that oversees research with human subjects.

If the research involves collaboration with another institution then the research cannot commence until the Committee receives written notification of approval from the collaborating institution's IRB.

It is the Principal Investigator's responsibility to obtain review and continued approval before the expiration date.

Protocols are approved for a maximum period of one year. You may not continue any research activity beyond the expiration date without Committee approval. Please submit continuation requests early enough to allow sufficient time for review. Failure to receive approval for continuation before the expiration date will result in the automatic suspension of the approval of this protocol. Information collected following suspension is unapproved research and cannot be reported or published as research data. If you do not wish continued approval, please notify the Committee of the study closure.

**Adverse Events:** Any serious or unexpected adverse event must be reported to the IRB Committee within 48 hours. All other adverse events should be reported within 10 working days.

**Amendments:** If you wish to change any aspect of this study, such as the procedures, the consent forms, study personnel, or number of participants, please submit an amendment to the IRB. All changes must be approved by the IRB Committee before they can be initiated.

You must maintain a research file for at least 3 years after completion of the study. This file should include all correspondence with the IRB Committee, original signed consent forms, and study data.

cc: Kristin Kay Higgins, Investigator