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Quality of Life Among Entrepreneurs With Chronic Fatigue Syndrome

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2018

Abstract

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Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy
Psychology

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Abstract

The impacts of chronic fatigue syndrome (CFS) are far reaching, resulting in many burdens in the individual lives of CFS patients. One notable challenge lies in the inability to participate in the workforce due to associated physical, mental, and emotional symptoms. Previous research indicates that alternative employment options may help to overcome work related barriers presented with various types of chronic illness. Entrepreneurship is one path to working that offers many benefits, including autonomy, flexibility of work schedule, choice of work environment, and control. Questions though remain as to whether entrepreneurship enhances QOL or exacerbates symptoms among individuals with CFS. This interpretive descriptive study investigated the lived experiences of individuals diagnosed with CFS who have pursued a path of entrepreneurship. A semistructured interview was used to gather the 12 participants' descriptions of their history of living with CFS while working as entrepreneurs. The interviews were coded and analyzed to extract overarching themes. Results included the ways in which participants were transformed as a result of having CFS, their experiences of living with CFS and being self-employed, and the interpersonal factors that arose in connection with these experiences. This study served to shed light on the challenges involved in being self-employed while living with CFS, how being self-employed affected participants' quality of life both positively and negatively, and how participants interpret these changes. The findings of this study have the potential to set the stage for future qualitative and quantitative research that would provide more support in terms of tangible action when it comes to employment options for individuals living with CFS.

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Dedication

I dedicate this research to my family. To my mother Barbara, who introduced me to the world of psychology and has been my guidance in life. To my father Randy, who always provides encouragement and reminds me to never give up. To my brother Bran, who helps me find the humor in life. It was especially appreciated during this process. To my late grandfather Michael, who is my inspiration and motivation to be a positive, generous, and genuine person. And finally, to my angel watching over me. I am forever grateful for all of your unconditional love and support in accomplishing my life goals.

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Chapter 1: Introduction to the Study

According to the Institute of Medicine (2015), between 836,000 and 2.5 million people in the United States are diagnosed with chronic fatigue syndrome (CFS). Of that number, at least 25% have been home or bed-bound during the course of their illness (Institute of Medicine, 2015). Living with chronic illness adversely impacts an individual's quality of life (QOL) across many dimensions (Lam & Lauder, 2000), including professional life (Saarni, Saarni, & Saarni, 2007).

Living with CFS can make it difficult for an individual to participate in the workforce (Beatty, 2012). Billions of dollars are lost nationwide each year due to diminished productivity and medical costs correlated with this illness (Arnett, Alleva, Korossy-Horwood, & Clark, 2011; Lin et al., 2011; The Institute of Medicine, 2015). CFS is associated with physical, mental, and emotional symptoms that make it challenging to work in a typical, full-time job (Barker & Nussbaum, 2011). In addition to the financial struggles that result, a lack of employability and job security may have psychological consequences that can affect a person's wellbeing and QOL (Asbring, 2001).

QOL has historically been defined in terms of wealth-related constructs, whereas in contemporary QOL research, subjective, objective, and existential factors are taken into account (Ventegodt, Merrick, & Anderson, 2003). However, this emergent conceptualization of QoL can be difficult to operationalize using one approach, measurement, or dimension (Theofilou, 2013). There has been research on QOL in the workplace (Kawambe et al., 2015; Reilly, Sirgy, & Gorman, 2012; Sirgy, Reilly, Wu, &

Efraty, 2012). An individual's employment situation must be considered when measuring QOL, and satisfying employment experiences enhance QOL (Arnold & Seekins, 2002).

For individuals living with CFS, or any sort of disability that impairs a person's ability to work full time, entrepreneurship/self-employment is one potential solution (Pagán, 2008). Entrepreneurship offers many benefits including autonomy, flexibility with schedule and environment, and a greater locus of control (Pagán, 2008). The Global Entrepreneurship Monitor Report found that entrepreneurs exhibited higher levels of wellbeing as compared with nonentrepreneurs in several countries (as cited in Amorós, Bosma, & GERA).

Background of the Study

CFS, often known as myalgic encephalomyelitis (ME), is described by the Centers for Disease Control and Prevention (CDC, 2012) as a complex and disabling illness that affects over a million people in the United States. The CDC reported that the main symptom of this illness is persistent fatigue, which impairs day-to-day functioning. The CDC outlined physical symptoms (fever, soar throat, swollen lymph nodes, etc.), cognitive symptoms (impaired memory, attention deficits, decreased motor speed, etc.), and emotional symptoms (depression and anxiety). Anderson, Jason, Hlavaty, and Porter (2013) examined the impact of CFS symptoms to understand the effects on various domains of individuals' lives and they indicated that a diagnosis of CFS influenced identity and coping and led to reductions in functioning. Anderson et al. stated that the fatigue, and other symptoms associated with CFS, result in a reduction of personal, educational, social, and occupational activities.

Martin, Student, and Alonzo (2013) concluded that it is critical that individuals living with this illness seek the lifestyle modifications they need. Martin et al. recommended that CFS patients maintain flexibility with their environment, along with schedules that do not exacerbate their symptoms but instead help to alleviate them. Individuals diagnosed with CFS should develop innovative ways of navigating and balancing activities of daily living, as well as familial, social, and occupational responsibilities.

Christley, Duffy, Everall, and Martin (2013) and Hopstaken, van der Linden, Bakker, and Kompier (2015) found that maintaining employment is a challenge for CFS patients, as symptoms limit work proficiency and overall wellbeing. CFS patients struggle day-to-day within the professional domain, and maintaining regular employment, and the accompanying financial instability, are ongoing challenges. In addition, several researchers have explored the impact of CFS on the nationwide economy. Lin et al. (2011) found that the debilitating effects of CFS have a measured consequence on the national economy. The Institute of Medicine (2015) estimated that 17 to 24 billion dollars are spent annually related to CFS/ME. These estimates are based on health care costs as well as diminished productivity.

Avenues to address the employment struggles associated with living with CFS have yet to be studied. However, Parker Harris, Caldwell, and Renko (2014) researched the experiences of entrepreneurs with various types of chronic illness and concluded that entrepreneurship can empowerment a person to become financially self-sufficient while overcoming the physical, emotional, and mental barriers presented with various types of disabilities or chronic illness. This path presents an opportunity to achieve a sense of passion and purpose and make a meaningful contribution to society. The broader study of entrepreneurship has been recognized from an academic standpoint for decades (Carlsson et al., 2013). Ali and Topping (2011) found that entrepreneurship has impacted the U.S. economy by providing product and market innovation, employment expansion, and contributing to national wealth. Okwiet (2013), and Parker Harris et al. (2014) found that entrepreneurship and self-employment offer benefits, including autonomy, flexibility of work schedule, choice of work environment, and control over business strategies.

Problem Statement

The impacts of CFS are far reaching, resulting in many burdens in the individual lives of CFS patients, as well as negatively affecting the national economy due to lost productivity (Arnett et al., 2011; Beatty, 2012; Lam & Lauder, 2000; Saarni et al., 2007). The professional dimensions of QOL have been researched, including studies on entrepreneurs, as well as studies on chronic illness and QOL (Kawabe et al., 2015; Reilly et al., 2012; Sirgy et al., 2012; Yamamoto, Unruh, & Bullis, 2011). Yet, there is a gap in the literature on assessing QOL dimensions among entrepreneurs living CFS. Although scholars have suggested that employment among individuals with various types of chronic illness typically can lead to greater life satisfaction (Dahalan, Jaafar, & Mohd Rosdi, 2013; Strine et al., 2008), entrepreneurship and self-employment can hinder health and negatively impact QOL due to the associated high levels of stress, loneliness, and lack of job security (Luyten et al., 2011; Rietveld, Kippersluis, & Thurik, 2014). Questions remain regarding whether entrepreneurship and self-employment enhance

QOL among individuals with CFS (rather than general chronic illness) by accommodating their illness, or whether negative aspects of self-employment outweigh the positives, potentially exacerbating symptoms.

It was important to explore the experiences of individuals living with CFS rather than general chronic illness. CFS comes with its own onset of physical, emotional, cognitive, and neurological symptoms, whereas most chronic illness are solely physical or psychological in nature (Barker & Nussbaum, 2011). The numbers of individuals diagnosed with CFS have been increasing (CDC, 2016). As these numbers grow, there will be an increased need for solutions to address problems of employment and financial security among the CFS population (Morris, Berk, Galecki, & Maes, 2014).

Purpose of the Study

The intent of the study was to explore the experiences of individuals with CFS who were working or have attempted to work as entrepreneurs (Backstrom, 2002). The results of this study may provide insight into how these experiences have affected participants' QOL (Vickers, 2002). A qualitative approach was used to explore the challenges faced by participants, as well as factors that have brought about success and improved QOL. I examined how participants interpreted, perceived, and described their experiences working in an entrepreneurial/or self-employed capacity and how these experiences impacted their QOL and overall wellbeing. The knowledge from this study might fill the gap in literature regarding this intersection of experiences in a manner that will build upon the existing research.

Research Questions

I sought to understand and explore the experiences of individuals diagnosed with CFS who are working or have attempted to work as entrepreneurs. I aimed to shed light on this phenomenon by inquiring about the experience itself, as well as exploring QOL factors that I objectively determined and the participants subjectively determined. The research questions were grounded in a review of the literature. The following questions served as a guide to this qualitative study:

RQ1. How do participants with CFS describe their QOL/overall wellbeing when working in an entrepreneurial or self-employed capacity?

RQ2. What challenges do participants with CFS experience when working in an entrepreneurial or self-employed capacity?

RQ3. How do individuals with CFS who are working or have attempted to work in an entrepreneurial or self-employed capacity describe, comprehend, and interpret changes in their QOL?

Framework

Research regarding the topic of meaningful work has become more prevalent (Burger, Crous, & Roodt, 2013; Dik, Byrne, Zinta, & Steger, 2013; Wong & Wong, 2013). Theorists of all disciplines have attempted to observe this connection and its importance to an individual’s well-being. Within the existential psychology perspective, this topic was viewed as critical to a person’s life purpose. Frankl’s existential analysis and logotherapy are known for its focus on human’s search for meaning as the primary motivation for life (Reitinger, 2015).

Most individuals spend the majority of their lives working. Working can be viewed in a positive light as a process and a journey, rather than an end product (Moroz & Hindle, 2012). A meaning-centered approach includes recognition of the correlation of meaning with job satisfaction and productivity (Pryce-Jones, 2010; Wong, 2011). From this view it is seen as a person's commitment to doing or creating something (creative values), experiencing something or encountering someone (experiential values), and choosing one's attitude toward suffering (attitudinal values). Creating a meaningful work experience is critical in producing personal purpose and wellbeing.

The concepts mentioned helped to build a foundation for this study, as they are applicable to both traditional work practices along with those who pursue entrepreneurship. Traditional work practices and environments do not provide necessary value to a person's being. An entrepreneurial endeavor is an opportunity for an individual to bring personal meaning and fulfillment not only to his or her work but also into his or her lives (Geldhof et al., 2014). Connecting self to a greater purpose was shown to decrease negative thoughts, symptoms, and stressors associated with CFS, overall enhancing QOL within this population. This theoretical framework was integrated throughout the dissertation.

Nature of the Study

I employed a qualitative design in order to examine the lived experiences of individuals diagnosed with CFS who have taken an entrepreneurial path. I explored the ways in which this experience has impacted- objectively and subjectively- QOL factors. Within this mode of inquiry, I captured the underlying meanings of participants' experiences in a broader context (Creswell, 2013). By gaining a deeper understanding of this intersection of experiences, I was able to shed light on how working in entrepreneurship has impacted QOL for those living with CFS. A semistructured interview of open-ended questions was used to gather the participants' descriptions of their symptoms and experience with CFS in relationship with their entrepreneurial endeavors. A small, purposeful sample of 12 participants were asked to describe their experiences, and the interviews were coded and analyzed to extract overarching themes.

The participants of the study consisted of individuals living with CFS who were entrepreneurs or who were self-employed. Criterion-based and snowball sampling techniques were used to find and contact 12 participants who met the inclusion criteria of the study. Criterion-based sampling involved contacting groups that met certain participant criteria, such as CFS support groups, and inquiring about whether members fulfilled the criteria of the study and were interested in participating. The snowball sampling technique entailed asking participants if they knew of any other individuals who might be appropriate for the study. This technique enabled me to recruit a sufficient number of participants from a population that was elusive to study.

Selection criteria for the participants were as follows: (a) self-identify as entrepreneur and/or self-employed, (b) diagnosed with CFS by a medical professional, (c) were working in an entrepreneurial/ self-employed capacity or have worked or attempted to work in an entrepreneurial/ self-employed capacity in the past, and (d) fluent in the English language. Recruitment was conducted by reaching out to organizations, support groups, and networks geared towards individuals diagnosed with CFS. The interviews were conducted by phone, and they lasted roughly 1 hour. The approach was used to address the research questions and to identify core patterns. In the data analysis phase, interviews were transcribed and coded to identify emergent themes across participant experiences.

Following the approval of the Walden University Institutional Review Board (IRB), recruitment began and continued until the sample size of 12 had been met and interviews were scheduled. For studies that use the in-depth interview approach to interviewing, a sample size of 10 or more is recommended (Creswell, 2013). During the initial phone contact, I briefed potential participants on the purpose of the study, research questions, methods, procedures, and consent form. The participants were also informed that they were welcome to withdraw from the study at any stage, for any reason. Only participants who met the inclusion criteria, accepted the conditions of the consent form, and were willing to participate in the study were included.

Operational Definitions

CFS/ ME: A chronic, flu-like illness (Farrar, Locke, & Kantrowitz, 1995) characterized by debilitating fatigue and a combination of symptoms as musculoskeletal pain, mental impairments, and sleep disturbances (Fukuda et al., 1994).

Chronic illnesses: A persistent disease that does not resolve spontaneously and cannot be prevented or cured. Chronic illnesses are responsible for an estimated 80% of the global disease burden worldwide (Nieman & Cheng, 2011).

Entrepreneur: An individual who discovers, creates, or invents a business, organization, or enterprise with the aim of providing products or services to an individual or society as a whole (Schmitt-Rodermund, 2004).

QOL: The ways in which health, illness, and medical treatment influence an individual's wellbeing and ability to function (Eren, Erdi, & Sahin, 2008).

Self-employment: Yamamoto et al. (2011) proposed that self-employment, microenterprise, and entrepreneurship are often interchangeable terms. According to Le (1999), self-employment is defined as carrying out work for personal profit rather than for wages paid by other individuals.

Assumptions

The following were my assumptions:

1. An interpretive description orientation and semistructured interview method would be effective approaches to collect data to thoroughly address the research questions.
2. With a complete understanding of the study, the participants would be willing to provide both honest and accurate responses. The assurances of anonymity, confidential data management, and freedom to withdraw from the study at any time would help to ensure that participants would be comfortable speaking openly.
3. The criteria I used to screen for both CFS and entrepreneur/self-employed would successfully recruit participants who were in alignment with the given definitions.

Limitations

The present study was subject to the following limitations:

1. The participants' level of comfort in answering the interview questions may vary, ultimately affecting their willingness to provide honest responses.
2. There is a range of definitions for the term entrepreneur, and the study may end up including participants with varying degrees of entrepreneurial experience.
3. There is no diagnostic test that establishes a diagnosis of CFS; rather, the illness is identified based on elimination of alternative illnesses.

Delimitations

The study was confined based upon the following:

1. Those who fit the parameters of an entrepreneur or self-employed individual (as defined by the definitions stated)
2. Individuals who have been diagnosed with CFS
3. I was interested in the experiences of entrepreneurs and self-employed individuals, rather than those who worked in the business sector.

Rationale and Significance

My intent was to showcase the experiences of CFS patients working as entrepreneurs, with an emphasis on QOL factors. I explored the challenges the subjects faced as entrepreneurs, how they have coped with those challenges, the types of help or support they could have used, and any helpful reflections they could share for the CFS community. This qualitative research was designed as a pilot study to explore the intersection of living with CFS and working as an entrepreneur. The findings of this study have the potential to set the stage for further research, perhaps quantitative, that builds upon this study and to delineate action steps in support of individuals with CFS, regarding employment options. The percentage of individuals diagnosed with CFS has risen in recent years (CDC, 2016), and CFS patients themselves frequently express a need for increased support (de Lourdes Drachler, 2009).

I allowed individuals with CFS to gain insight into the benefits and challenges that arise with taking on entrepreneurial endeavors. The research design allowed for an organic dialogue, where an entrepreneur could tell his or her story using an open-ended, qualitative approach. In the analysis of the study data, I identified key themes that arose across the subjects participating in the study, as well as highlighted differences. Exploring the lived experience of the entrepreneur not only provided a depth of understanding and insights not previously realized, but helped to compile a more holistic look of the entrepreneur and identify contributing factors to effective entrepreneurial pursuits.

Entrepreneurs may benefit from an understanding of the lived experience of the research participants, as this knowledge can help them recognize and assess their ability, strengths, and possible deficiencies as an entrepreneur. This may guide the individual to make more effective decisions with entrepreneurial pursuits. Given the importance of self-management with this illness (Martin et al., 2013), this information may enhance support to the community, ultimately providing value to the approach, thoughts, and understanding of entrepreneurship.

Summary

As the number of individuals diagnosed with CFS increases, it was important to find alternative avenues that lead to productive, healthy, and meaningful lifestyle options for this population. Although few scholars have looked at the effect of CFS upon QOL, no considerable research had thus far been conducted. In this chapter, I described a qualitative study designed to investigate individuals living with CFS who have pursued entrepreneurship. In Chapter 2, relevant literature on CFS, entrepreneurship, and the research question are discussed. In Chapter 3, I describe the methodology used to conduct the research. In Chapter 4, I summarize the research findings of the study, while in Chapter 5, I interpret the findings and discusses recommendations for future research.

Chapter 2: Literature Review

Introduction

According to the Institute of Medicine (2015), CFS is a medical condition characterized mainly by an ongoing state of extreme fatigue. CFS includes a feeling of fatigue that is exacerbated by physical as well as mental activity, and unlike other illnesses, symptoms do not improve with rest (CDC, 2012; Christley et al., 2012). CFS is also known as ME, postinfectious or postviral fatigue syndrome, royal free disease, Epstein Barr virus, and chronic mononucleosis (Anderson et al., 2013; Wojcik, Armstrong, & Kanaan, 2011). The most commonly used terms to describe this illness are CFS and ME (Anderson et al., 2016; Institute of Medicine, 2015; Wojcik et al., 2011).

The medical community views CFS as a highly complex condition, due to its effects across several major bodily systems (Anderson, Jason, & Hllavaty, 2016). CFS causes an array of immunological, neurological, hormonal, gastrointestinal, and musculoskeletal problems (Jason, Corradi, Gress, Williams, & Torres-Harding, 2006). Individuals living with CFS function at a lower activity rate than prior to the onset of the disorder, which impacts QOL (CDC, 2012; Institute of Medicine, 2015).

In the 1980s, CFS begin attracting attention from the fields of medicine and science (Fukuda et al., 1994). CFS was first named and established as a diagnosis in 1988 (Arnett et al., 2011; Brurberg, Fønhus, Larun, Flottorp, & Malterud, 2014; Komaroff & Cho, 2011). The CDC (2012) estimated that there are approximately 4 million people in the United States diagnosed with CFS. The illness is diagnosed across all ages, ethnicities, and socioeconomic groups (Komaroff & Cho, 2011). However, there are significant gender differences when it comes to the prevalence of CFS, with women being more frequently diagnosed than men (Jason et al., 2006; Kerr et al., 2007). CFS is more than twice as common in females as it is in males (Arnett et al., 2011; Christley et al., 2012). Health care workers are more likely to be diagnosed with CFS than any other occupational group (Christley et al., 2012). Juster et al. (2011) suggested that the underlying cause of CFS may be hormonal imbalances resulting from chronic stress or burnout, accompanied by frequent exposure to viruses.

At present, the underlying causes of CFS have yet to be determined. It is not possible to diagnose CFS using brain scans, blood work, or any sort of medical test, and no cause has been identified that accounts for all cases of CFS. Holgate et al. (2011) explained that no neurologic test exists that has the necessary levels of sensitivity and specificity to constitute a diagnostic test for CFS. This has led scholars to believe that CFS may be triggered by extreme physical or emotional stress.

Yancey and Thomas (2012) found that the onset of this illness may involve dysfunction of the immune or adrenal systems, an association with certain genetic markers, or a history of childhood trauma. Carruthers et al. (2011) confirmed that CFS is frequently triggered by bodily stressors, such as a virus or serious medical issues. However, the ability of psychological factors such as trauma, emotional stress, and mental health issues to trigger the onset of CFS remains up for debate. These factors, in combination with others, create the perfect storm under which CFS is initially triggered (Viner & Hotopf, 2004). However, Speigel (2003) reported, the CFS of a child was not predicted by the mother, which contradicts other findings that both parents and their children may both have CFS. The CDC (2012) claimed that CFS is the result of a convergence of several factors, including viruses or infections, brain abnormalities, stress-related hormonal abnormalities, and an overactive immune system.

The purpose of this study was to understand the ways in which the QOL of CFS patients has been affected by their engagement in work that provides some degree of financial stability and/or personal fulfillment. I sought to explore the benefits that entrepreneurs living with CFS have experienced and to uncover the struggles associated with this path. I interviewed individuals with CFS who have attempted, with or without success, to work as entrepreneurs. Whereas some research has been conducted on the experiences of entrepreneurs living with physical disabilities or various types of chronic illness, there is an absence of research on the prevalence and experiences of entrepreneurship among the CFS population. Given that CFS comes with an array of physical, psychological, and neuropsychological symptoms, it is unique from other chronic illnesses and disabilities (CDC, 2012). Scholars have sought to offer research on the experience of living with CFS, focusing on diagnosis, symptomatology, and the complexity of CFS, rather than exploring different occupational avenues for life enhancement. Much remained to be explored regarding the experiences of individuals diagnosed with CFS who have pursued entrepreneurship, specifically the benefits and struggles of this pursuit, as well as coping mechanisms adopted and outside supports.

In this chapter, I provide a critical review of the existing literature on CFS, entrepreneurship, and self-employed individuals living with CFS. Initially, CFS is explored in-depth, including a discussion of the diagnostic process; etiology of the illness; physical, psychological, and neuropsychological symptoms; impact of stress; treatment options; and impact on work, financial stability, and other elements having to do with QOL.

The following section delves into entrepreneurship, defining entrepreneurship/self-employment and exploring the personal and cultural advantages, both economic and relating to lifestyle. I also highlight the challenges associated with entrepreneurship. In the final section, I explore the phenomenon of disabled individuals working as entrepreneurs and the ways in which this experience impacts QOL factors. Because there is a scarcity of research on entrepreneurs with CFS, I sought to investigate the most similar population. The chapter culminates with the introduction of the research question.

Literature Search Strategy

I present results from an extensive review of related literature, as well as discussion pertaining to the phenomena being studied. I referred to the Academic Search Premier Database within Walden University's library, including EBSCOhost, PsycInfo, and ProQuest. References from other appropriate Internet online search engines and public libraries were used. Article selection was initiated by searching for peer-reviewed studies on the following key terms and combinations of terms: *CFS, ME/CFS, chronic illness, disability, entrepreneurship, business owner, self-employment, flexible work schedule, workplace fatigue, QOL, qualitative,* and *lived experience.* All articles were published in English. Upon reading each article, I analyzed the articles based upon the population of interest, themes of findings, theoretical composition, and implications and recommendations.

Chronic Fatigue Syndrome

Diagnosis

At present, a valid diagnostic test to establish the existence of CFS has not been developed (Institute of Medicine, 2015). Komaroff and Cho (2011) delineated the diagnosis process used to determine whether an individual has CFS. Medical professionals diagnose based on a set of symptoms, which must include profound fatigue, impaired concentration and memory, muscle and joint pain, and headaches. Funk and Wagnalls (2016) added that other diseases that cause fatigue, such as hypothyroidism, cancer, chronic mononucleosis, and certain psychiatric disorders, must be ruled out prior to establishing a CFS diagnosis.

The CDC (2012) provided a more in-depth explanation of the symptomatology that leads to a definitive diagnosis of CFS. The CDC speculated that three overarching diagnostic criteria must be experienced continually over the course of at least 6 consecutive months. Firstly, the individual has to have been experiencing severe and chronic fatigue that is not attributable to persistent exertion or another medical condition. Secondly, the fatigue must significantly interfere with work and/or daily activities. Finally, the individual must display four of the following eight symptoms: postexertional malaise lasting more than 24 hours, unrefreshing sleep, significant impairment of short-term memory, significant impairment of concentration, muscle and joint pain, tender lymph nodes, and a recurring sore throat.

Morris et al. (2014) explained that among individuals diagnosed with CFS, the course and progression of the illness varies. Morris et al. argued that although some individuals recover completely, others get progressively worse. Funk and Wagnalls (2016) found that in some cases the illness stabilizes early on, then later cycles through periods in which symptoms improve, then worsen. Patients may suffer from unpredictable relapses throughout their lives, resulting in malaise for days, weeks, months, or even years (Morris et al., 2014).

Etiology

The root cause of CFS remains unknown. Scientists have hypothesized that it involves interactions between the nervous and immune systems, which might be triggered initially by infections, immune disorders, trauma, stress, or even environmental toxins (CDC, 2012; Funk & Wagnalls, 2016). Researchers have not yet been able to confirm a link between CFS and any single infection. Christley et al. (2012) and determined that no single infection or pathogen causes CFS; rather, it can be triggered by several viruses and infections, most of which are neuropathogens and have debilitating effects on the central nervous system. Christley et al. concluded that the absence of diagnostic tests in CFS has necessitated that clinicians and researchers rely on case definitions as a method of establishing the presence of CFS, explaining that case definitions are frequently comprised of essential clinical, laboratory, and/or epidemiological indicators; such benchmarks are used as confirmation of the presence of a disease or health complaint. The CDC (2012) was in agreement with this assessment.

Arnett et al. (2011) conducted a meta-analysis of a large body of CFS research, outlining some examples of viruses, infections, and neuropathogens that have been found to trigger CFS. Their list includes Epstein-Barr, Ross River, Coxiella Burnett, cytomegalovirus, human herpesvirus 6 (HHV6), enteroviruses, retroviruses, and Borrelia burgdorferi (Mawle, Reyes, & Schmid, 1994). Among individuals diagnosed with these pathogens, approximately 10-12% of them will eventually meet the criteria for CFS. These findings are corroborated by research by the CDC (2012), as well as Komaroff and Cho (2011). Most of these illnesses produce a persistent infection that continually provokes the immune system, resulting in the symptoms of CFS (Komaroff & Cho, 2011). The CDC found that several viral infections, as well as extreme levels of stress, lead to the chronic production of cytokines, which are cells involved in the communication and response of the immune system. This repetitive action results in abnormalities within the central and autonomic nervous systems, triggering the ongoing symptoms of the illness (Komaroff & Cho, 2011).

Physical Symptoms

CFS is accompanied by an array of physical symptoms. Keech et al. (2015) sought to gain an understanding of the physical symptoms of CFS in the words of CFS patients and found that the common descriptors included exhaustion, tiredness, drained of energy, heaviness in the limbs. The physical symptoms most closely associated with fatigue include weakness, lack of energy, muscle pain, and insomnia. Keech et al. also concluded that the fatigue element of the disease reduces stamina and is worsened by both physical activity and mental exertion.

Haney et al. (2015) explored a different set of physical symptoms associated with CFS and found that participants in their study reported additional symptoms including abdominal and chest pain, bloating, chronic cough, dizziness, digestive problems, earaches, stiffness, nausea, night sweats, shortness of breath, tingling and other skin sensations, weight loss, brain fog, visual disturbances, and food sensitivities. Patients often experience flu-like symptoms, including frequent sore throat and swollen lymph nodes (Keech et al., 2015). Stringer et al. (2013) concluded that individuals with CFS typically experience hyperalgesia; a heightened sensitivity to pain; as well as hyper-sensitivity to light, sound, touch, and medications. Komaroff and Cho (2011) found that hyperalgesia is likely the result of central sensitization or augmented sensory processing, making physical symptoms all the more difficult to cope with.

Neuropsychological Symptoms

Because CFS is connected with the central nervous system, individuals with CFS also experience neuropsychological symptoms including pain and cognitive problems (Komaroff et al., 2011). Tanaka et al. (2006) conducted MRIs to monitor the central nervous system activity of six CFS patients as compared with seven controls, confirming the neuropsychological component of CFS. However, Tanaka et al. acknowledged that the sample size was small, and studies with larger number of subjects would need to be conducted in order to generalize the findings.

Other researchers have estimated that 50-80% of CFS patients experience cognitive impairments in the areas of attention, concentration, reaction time, and memory (CDC, 2012; Christley et al., 2013). The most frequently recognized cognitive difficulty displayed in CFS patients is impairment in information-processing speed and efficiency, on both simple and complex tasks (Tanaka et al., 2006). Many neuropsychological scholars have explored deficits in reaction time among CFS patients (Tanaka et al., 2006). CFS patients display impairments on activities that require subjects to manage large amounts of information, and on complex and time-limited tasks, as compared with healthy control groups (Christley et al., 2013). Majer et al. (2008) added that individuals with CFS exhibit impairments in motor speed.

Caseras et al. (2016) investigated memory impairments among CFS patients using functional magnetic resonance imaging. Caseras et al. showed that patients who were diagnosed with CFS showed differences, both quantitative and qualitative, in working memory network activation compared with healthy control subjects. In tasks that required participants to concentrate over extended periods, CFS patients performed poorly on tasks involving working memory. However, Caseras et al. found that they were able to compensate for these deficits by using strategies to offset their struggles.

Tierksy et al. (2003) explored the memory impairments among CFS patients and found that the sample displayed difficulties in remembering verbal information. As compared with healthy control participants, individuals diagnosed with CFS needed more turns to learn a word list. Tierksy et al. found that the memory impairments experienced by CFS patients are stemmed in their compromised ability to recall and encode verbal information. This range of neurological deficits in CFS patients, in addition to other symptoms, result in a diminished ability to engage in normal daily activities, as well as fulfill social and occupational expectations (CDC, 2012; Christley et al., 2013; Masaaki, Akira, & Yasuyoshi, 2013). Tierksy et al. stated that CFS patients deal with chronic physical debilitation, reduced neuropsychological functioning, and changes in emotional well-being; such difficulties detract from QOL. The impact of CFS on QOL factors will be more explored in a later section of this literature review.

Psychological Symptoms

The neuropsychological difficulties commonly seen in CFS patients are also linked to mood disorders and behavior (Christley et al., 2013). Between 60-70% of individuals diagnosed with CFS suffer from comorbid psychological problems, such as depression, anxiety, panic attacks, and irritability (CDC, 2012; Fuller-Thompson & Nimigon, 2008). Fuller-Thompson and Nimigon (2008) screened a community sample of CFS patients for depressive symptoms. Fuller-Thompson and Nimigon found that 36% of participants met the *DSM-IV* symptoms for depression, concluding that clinicians should assess depression and suicidal ideation among their patients with CFS. This showed to be particularly true for females who reported moderate to severe pain, low incomes, and inadequate social support. Fuller-Thompson and Nimigon found that the aforementioned factors were most commonly experienced by depressed participants.

Major depressive disorder often cooccurs with CFS, affecting 15-40% of CFS patients (Van Houdenhove, Kempke, & Luyten, 2010). The symptoms of CFS and major depressive disorder overlap, and at times it can be difficult to discern whether particular symptoms are attributable to CFS, major depressive disorder, or both (Christley et al., 2013). Some researchers argued that depression is the most common cause of the fatigue associated with CFS. Komaroff and Cho (2011) attempted to separate the symptoms of mental health issues and CFS, finding that 30-50% of CFS patients do not suffer from any comorbid psychological disorders. Komaroff and Cho confirmed that most CFS patients who are diagnosed with a mental health disorder developed the disorder only after the symptoms of CFS set in. Maes, Twisk, and Ringel (2012), however, saw depression and CFS as comorbid, suggesting that inflammation may play a role in the pathophysiology that underpins both disorders. Major depressive disorder is not a precursor to CFS because neurological testing reveals abnormalities in patients with CFS that cannot be explained by a preexisting depression (Komaroff & Cho, 2011). The deficits seen in attention, memory, and reaction time among CFS patients were not found in comparison groups of healthy individuals and individuals with major depressive disorder.

Scholars have explored the intersection of major depressive disorder and CFS. Using the Beck Depression Inventory II (BDI-II), Brown, Kaplan, and Jason (2013) concluded that CFS patients were more likely to endorse the BDI-II items related to somatic-affective symptoms than the items that touched upon cognitive symptoms. Brown et al. acknowledged that their sample size was low, and the results would have been increasingly replicable and generalizable with a greater sample size. The cognitive model of depression includes the onset of depression as the product of negative cognitions, such as feeling worthless or useless, lacking in motivation, or becoming withdrawn and avoidant (Young, Weinberger, & Beck, 2001). The perceived low social status sometimes experienced by CFS patients leads to shame and embarrassment, which can result in depression (Cella, White, Sharpe, & Chalder, 2013; Gilbert, 2000). A potential causal relationship between CFS and depression remains a mystery to researchers.

Treatment

At present, there are no definitive treatments for CFS (Fukuda et al., 1994). No specific cures or prescription drugs have been developed for CFS, and since symptoms tend to evolve over time, managing CFS can be complex (CDC, 2012). Nonetheless, CFS patients have a variety of options to help address symptoms and improve QOL. Treatment begins by addressing the most predominant symptoms, namely fatigue, sleep issues, pain, memory and concentration problems, and comorbid mental health disorders (CDC, 2012). These symptoms are typically addressed through pharmaceuticals, as well as herbal supplements. Physicians can prescribe medicines to relieve pain, sleeping problems, and depression. Some patients with CFS have low blood pressure, and see improvements when given drugs to treat this condition (Rowe et al., 2001).

Developing a realistic activity and graded exercise plan also lends support to manage the symptoms of CFS, and in some cases, to help patients to approach or return to former activity levels (Cella, et al., 2011; Nater, Maloney, Heim, & Reeves, 2011). Núñez et al. (2011) found that the combination of cognitive behavioral therapy and graded exercise is not effective and not evidence-based; instead, it may be harmful in some patients. They indicated that some degree of CBT therapy and graded exercise therapy can be useful; but, the intensity of each should be analyzed regularly on an individual basis to determine the effects on symptoms and well-being. They explored health-related QOL factors and found that CFS may produce physical and neurocognitive disabilities that significantly affects health-related QOL.

As a general rule, CFS patients are told to avoid extremes in terms of the amount and intensity of daily activity, being cognizant to refrain from being overly active or inactive (CDC, 2012). In regards to improving health and QOL, recommendations include psychological interventions such as cognitive-behavioral therapy and support groups (Arnett et al., 2011; CDC, 2012). In individual and group therapy, CFS patients learn to redirect their energy into physical activities within their limits, and to replace negative thoughts with positive ones (Cella et al., 2011). Fernández et al. (2009) advocated for a multidisciplinary management approach, concluding based on their findings that CFS patients benefit most from a combination of medical interventions, psychological interventions, and social supports.

Personal Impact

Taken together, the existing research and case studies indicated that living with CFS is profoundly difficult (CDC, 2012). Similar to other chronic illnesses, CFS has a highly disabling effect on an individual’s life (Fernández et al., 2009; Nunez et al., 2011). Each day presents challenges, and patients must learn to adapt to major lifestyle changes and acknowledge many new limitations (CDC, 2012). Living with CFS is all the more complicated due to the fact that symptoms occur in unpredictable cycles, and patients tend to experience periods of illness followed by periods of improvement (Anderson et al., 2013). In some cases, temporary remission may occur. However, symptoms can return at a later date. This ever-changing symptom pattern makes CFS difficult to manage in the long-term. Yet, despite patients in remission feeling well enough at times to participate in activities, overexertion may trigger a relapse (CDC, 2012: Fernandez et al., 2009; Morris et al., 2014).

The most commonly cited difficulties for CFS patients include the inability to cope with unpredictable symptoms, decrease in stamina, memory and concentration issues, mounting reliance on outside supports, and negative modifications to livelihood and financial security (Anderson et al., 2013; CDC, 2012). Other difficulties include changes in relationships with loved ones, as well as concerns about one's ability to raise children (CDC, 2012). There is a lack of current literature specifying the effects of CFS on personal relationships, and its disruptive nature.

Feelings including anger, guilt, anxiety, frustration, and isolation are also frequently experienced among individuals with CFS (Brown et al., 2013; Christley et al., 2013; Luyten et al., 2011). Whereas these responses are only natural, emotional stress can exacerbate symptoms, affect the efficacy of prescription drugs, and complicate recovery (CDC, 2012). Individuals diagnosed with CFS experience many personal losses, and disruptions in all domains of life (Anderson et al., 2013). Lin et al. (2011) calculated that the average annual direct medical costs to CFS patients amount to $3286. CFS accounted for $8,554 annually in lost household earnings, and the average household income for CFS patients was $23,076. The researchers concluded that CFS leads to increases in health care costs and a decrease in the individual earnings of the diagnosed.

Chronic Fatigue Syndrome and Work Life

Disability. Due to its persistent and debilitating symptoms, CFS is classified as a disability (Cella et al. 2011). The World Health Organization (2016) defined disability as impairments in body structure or function, limitations in activities, and lessened ability to participate in activities of daily living. As described in prior sections, the symptoms of CFS have a significant impact on work, as well as personal, social, and educational realms of life. For most CFS patients, the illness significantly limits one's ability to participate in typical life activities for extended periods (Arnett et al., 2011). Symptoms vary across each individual; however, all CFS patients are limited in these realms to some extent (CDC, 2012). Most workplaces are not aware of these health challenges, and operate with the assumption that their employees are perfectly capable of job completion without any physical or mental interference (Beatty, 2012).

Taylor and Kielhofner (2005) speculated that very few studies exist which seek to explore work-related impairment and work-focused rehabilitation among CFS patients. Their research sought to explore the impact of the physical and mental challenges associated with CFS, and the rates at which they lead to unemployment or underemployment. In their results, they found that unemployment rates ranged from 35% to 69%; job loss rates ranged from 26% to 89% within the CFS population sampled. They concluded that CFS is associated with work-related disability ant that there is a need for rehabilitative programs for CFS patients.

Broader impact. Cairns and Hoptof, (2005) conducted a meta-study to analyze the prognosis and occupational outcomes of CFS patients. They reported that between

27%- 65% of individuals with CFS are unable to work, and an estimated 8%-30% of untreated individuals are able to continue working after diagnosis. Future studies should seek to more deeply understand the workplace limitations resulting from CFS, and provide job-related insights and supports for employers as well as CFS patients. Correspondingly, rates of unemployment among individuals diagnosed with CFS ranged from 35%–69%. Among the participants in the study, 26%-89% of individuals lost jobs due to their CFS symptoms (Taylor & Kielhofner, 2005). A third study found that among 61 percent of participants with CFS, many were able to complete only an hour of work per day at certain points due to heightened symptoms (Wilson et al., 2001).

Due to reduced earnings and increased medical costs, the individual financial burden of CFS is estimated to be $11,780 annually (Lin et al., 2011). Eighty-two percent of these costs occur due to unemployment or underemployment and wage reductions due to job modifications that were put in place to accommodate CFS symptoms (Lin et al., 2011). In terms of the nationwide economic costs of CFS, Komaroff and Cho (2011) found that due to lowered productivity, the condition costs the U.S. economy approximately 9 billion dollars each year. Another study conducted in the early 1990s in Australia by Lloyd and Pender (1992) found that the direct and indirect costs of CFS resulted in an economic impact amounting to approximately 59 million dollars annually.

Decreased work performance. Among CFS patients who are able to continue working as a result of controlling and managing their symptoms, several studies have found that their productivity and work performance decreases significantly. In a meta-analysis of several studies, it was concluded that work performance decreased among

22%–62% of participants (Bombardier & Buchwald, 1995, 1996; Vercoulen et al., 1994). Rates of unemployment among individuals diagnosed with CFS ranged from 35%–69%, and rates of job loss specifically due to CFS ranged from 26%-89% (Taylor & Kielhofner, 2005).

Other researchers who have sought to explore specific performance difficulties found that most common were difficulties surrounding scheduling, deadlines, memory impairments, making mistakes, transportation, attendance, falling asleep during work, and burden on coworkers (Schweitzer, Kelly, Foran, Terry, & Whiting, 1995; Ware, 1998). Taylor and Kielhofner (2005) cited participant memory loss, problems with concentration and attention, difficulty reading, extreme fatigue, and pain as the factors that most interfered with ability to perform a previous job. Barrows (1995) tried to understand the impact of CFS and its symptoms on activities of daily living (ADL). The participants reported that continuing to work had exacerbated their physical and cognitive symptoms, and their work responsibilities grew too difficult for them to perform. The majority of these individuals reported that they quit or were fired from their jobs as a result of their impaired ability to work.

Fatigue. According to Barker and Nussbaum (2011), fatigue is "a multi-causal, multidimensional, non-specific and subjective phenomenon resulting from prolonged activity and psychological, socioeconomic and environmental factors that affect both the mind and the body" (p.1371). Fatigue pertains to both physical and mental classifications. While physical fatigue results from repetition in muscular action, mental fatigue is the result of engaging in a cognitive task over an extended amount of time, leaving one tired, unmotivated, and unable to focus. Sharpe et al. (1991) added that fatigue is subjective sensation that often can result in a lack of motivation, alertness, and strength.

Physical and mental fatigue. CFS patients must be careful to avoid over-exertion, as it can bring upon physical fatigue, which lowers immunity and exacerbates symptoms (Christley et al., 2012). A 30% increase in activity may trigger a relapse in individuals living with CFS (CDC, 2012). Postexertional malaise resulting from over-exercise exacerbates patients' symptoms and weakens the immune system (Keech et al., 2015). The physical symptoms of CFS such as fatigue and postexertional malaise make it very difficult for CFS patients to be physically active (Nijs et al., 2011). Mental Fatigue is often the cause of impaired performance on a cognitively demanding task (Hopstaken et al., 2015). Ocon (2013) defined mental fatigue as a state characterized by changes in motivation and mood, as well as challenges with information processing among the healthy population, mental fatigue levels may fluctuate during everyday activities, explaining that for individuals with CFS, mental fatigue is pervasive and debilitating.

Hopstaken et al. (2015) found that as individuals grow fatigued, they tend to disengage from a task due to onset experiences with diminished focus and attention, while feeling less motivated. The study may be limited in its generalizability due to their sample size of 20 undergraduate students. Eighty-five percent of individuals diagnosed with CFS are suffering from cognitive impairments (Komaroff, 1993; Ocon, 2013). Mizuno et al. (2011) demonstrated that among CFS patients, symptoms of mental fatigue pose the greatest challenge when it comes to ability to continue working.

The cognitive impairments that accompany CFS are quite disruptive. In their research, Joyce et al. (1996) found that the attention spans of CFS patients are severely impaired, which also interferes with efficiency and information processing, resulting in difficulty planning and organizing. In their conclusions, they stated that CFS patients seem to struggle most with tasks that require planned or self-ordered generation of responses from memory. CFS patients colloquially describe the aforementioned cognitive impairments as “brain fog.” Descriptions of brain fog include slowness and difficulty thinking, focusing and concentration problems, and forgetfulness. Some have identified brain fog as the most debilitating aspect of CFS (Ocon, 2013). With this stated, it is important for individuals with CFS to pace daily activities. Moreover, they must recognize and accept the physical and mental limitations inherent to CFS in order to avoid bringing about postexertion malaise (Nijs et al., 2011).

Depression. Depression frequently occurs comorbidly with CFS, and is another significant factor that negatively affects CFS patients’ ability to work (Ross et al., 2004). Olesen et al. (2013) explored the reciprocal relationship between participation in the workforce, and mental health, arguing that participation in the workforce is a feature of the mental health of the public, global social inclusion policies, and often a therapeutic goal in treatment settings. Poor mental health among the unemployed is a compounded effect of existing mental health problems and the distress associated with being unemployed. However, there are some limits to the study’s generalizability, namely the fact that participants ranged in age from 20-55, and presence of a mental health disorder was established based on a survey rather than diagnosis by a healthcare professional.

Beck et al. (2011) indicated that depression and dysthymia are associated with impaired work performance, reporting that minor levels of depression are associated with a loss of productivity. Considerably greater productivity loss was found among those employed full time vs. part time. Future research head in the direction of improving treatment for depression to restore QOL, ability to work, and psychosocial function. Building upon the research of Beck et al., researchers Lawrence et al. (2013) found that depression impacts several cognitive domains including attention, memory, psychomotor speed, and executive functioning. These deficits compound the brain fog that accompanies CFS. The researchers used a survey measure to determine degree of depression among participants: no depression, mild depression, moderate depression, and severe depression. Independent of antidepressant use, perceived cognitive functioning worsened with increasing severity of depression symptoms. These impairments translated to limitations in the workplace such as reduced productivity, increased work errors, increased risk of injury, inability to meet required deadlines, interpersonal conflicts, or reduced ability to cope with stressful situations.

Workplace stress. The stress that is endemic to many contemporary work environments is another factor that frequently precludes CFS patients from participating in the workforce. There is mounting evidence that CFS may arise due to chronic stress that results in the dysregulation of the hypothalamic-pituitary–adrenal (HPA) axis for an extended period of time (Johnson, Kempke & Claes, 2015). After the onset of CFS, stressors and emotional distress typically exacerbate symptoms, contributing to the disease process of the illness (Kennedy et al., 2005). Lattie et al. (2013) found that perceived stress-management skills led to lower emotional distress, which in turn resulted in less social and fatigue-related illness burden. This indicates that stress management skills have the potential to lower the impact of CFS symptoms. One drawback of the study, however, is that it relied on self-report measures rather than objective assessments, so the results are based on participants' subjective experiences. Other authors reported that the changes in immune response described in CFS patients are modulated by the effect of stress on the endocrine system (Glaser, & Kiecolt-Glaser, 1998).

As a result, many individuals with CFS have a low stress tolerance, which increases the likelihood that they will be unemployed (Löfgren, Shult, Öhman, Julin, & Ekholm, 2016). Coping skills may impact the relationship between the severity of illness and the overall burden of the illness because such skills may mitigate the stress associated with managing the illness (Luyten et al., 2011). Those with more adequate coping skills to manage such challenges may show better adaptation to illness and a greater ability to engage in some sort of work (Lattie et al., 2014).

Education

There is a relationship between CFS and educational attainment (Lin, 2011; Rusu, Gee, Lagac, & Parlor, 2015). Early onset of CFS makes it extremely difficult for an individual to attain a higher education, which affects earnings and employment. According to Lin et al. (2011), early onset of CFS reduces a person's likelihood of completing college by 50%, which is quite detrimental as a college education adds significantly to earning potential. The researchers found that a great portion of the economic burden of CFS may derive from the interruption of education or the impairment of an individual's ability to attain higher education.

Individual Economic Burden

For many people, work is a central element that affects well-being and quality of life (Taylor & Kielhofner, 2005). It is clear, however, that due to the aforementioned factors, individuals living with CFS experience significant workplace challenges, and struggle to remain employed (Taylor & Kielhofner, 2005). Individuals with CFS tend to experiences a series of losses involving their ability to work, employment status, and finances, which can drastically disrupt their lives (Anderson et al., 2013). McCrone, Darbishire, Ridsdale, and Seed (2003) found that many of the economic burdens imposed upon CFS patients directly relate to unemployment or underemployment, as well as costs of both health care and informal care. The researchers suggested that treatments be developed to address these impacts, which result in substantial economic costs to society. Lin et al. (2011) found that the amount of burdens significantly rise on these employers and family members as their earning fall.

Effects on Well-Being

In addition to resulting in tremendous lifestyle changes, CFS frequently leads to disruptions in self-perception and identity (Anderson et al., 2013). Whitehead (2006) found that a diagnosis of chronic fatigue syndrome leads to a severe disruption in identity, and a need for identity reconstruction. This can include a loss of self-esteem and self-confidence among CFS patients. Whitehead concluded that it is critical that health professionals seek to understand the impact of CFS on patients' well-being and quality of life in order to provide the best treatment.

Researchers have defined three main phases in identity reconstruction (Anderson et al., 2013). The first is an early phase where an initial shift in identity occurs, and one typically adopts the sick role. The next phase is the medium term, where the individual has acceptance in terms of being ill. Lastly is the long term phase in which the individual develops coping strategies and develops a new identity that integrates chronic illness. The search for self-renewal among CFS patients is perpetual, as they will experience the pattern of loss, healing, and evolution regularly. Providing CFS patients with more opportunities to engage in the workforce has the potential to facilitate self-renewal and identity reconstruction (Anderson et al., 2013).

Workplace Accommodations

Chronic illness threatens an individual's sense of control, which in turn, requires them to make accommodations in all areas of life, including the workplace (Beatty, 2012). Although organizations often feature policies that address certain illnesses and disabilities, many policies fail to account for the unique symptoms and patterns of chronic illness. Workplace illness policies "are mostly designed for acute illnesses, which typically follow a pattern of relatively quick onset of noticeable symptoms, a brief period of illness, and subsequent recovery to normal" (Beatty, 2012, p. 93). Chronic illnesses can take several years to diagnose and properly address, and may have patterns including progressively worsening, or cycling through ups and downs. Beatty (2012) argued that typical workplace illness policies do not provide the flexibility required to manage chronic illness, as they are not aligned with essential features. Thus, many individuals may often fall in the “space between” and are left entirely without support (Beatty, 2012).

Researchers have found that illness diminishes an individual’s ability to acquire human and social capital; therefore, putting them on a trajectory of reduced wealth and health over the course of one’s lifetime (Lin et al., 2011). However, there are helpful interventions such as cognitive behavioral therapy and graded exercise therapy, and these supports tend to make it easier for individuals with chronic illness to work (Cella et al., 2011). It is clear that there are many benefits, both individual and societal, to facilitating CFS patients’ ability to work. There is a need for workplace accommodations that are better attuned to the needs of individuals with CFS, as well as support for CFS patients who choose to work from home or become entrepreneurs.

This section overviewing CFS highlighted many elements of the illness, as well as its impacts on all areas of life. Whereas there is a wide body of research exploring the etiology and impact of CFS, there remains many gaps in the research. In terms of strengths within the research, several studies have confirmed that particular demographics are more likely to be diagnosed with CFS, particularly women and health care workers. The research has also reached a consensus when it comes to identifying and defining the physical, neuropsychological, and psychological symptoms of CFS. For example, multiple researchers have confirmed that fatigue and depression often accompany CFS, and have explored the interaction between the diagnoses. More macrolevel studies have sought to understand the broader impact of CFS, exploring the individual and societal economic burden that results, as well as viewing other factors that tend to be associated with a CFS diagnosis, such as a discontinuation of education.

In terms of limitations in the general body of CFS research, scholars have been unable to reach a consensus as to what single factor or combination of factors triggers CFS. There are several compelling hypotheses, some quite well supported by research, yet medical and mental health specialists have yet to propose a cohesive theory that accounts for all cases of CFS. Similarly, there remains debate in determining the best treatment for CFS, with much of the research in this area contradicting itself. For example, some studies have found graduated exercise to be extremely helpful to CFS patients, whereas other researchers declare it is too risky and exacerbates symptoms of fatigue. Some researchers have concluded that CFS must be dealt with on a case-by-case basis, which leaves much to be desired when it comes to generalizable results. In the aforementioned areas, the vast majority of research has used various quantitative methodologies, which has led to some helpful broad-stroke conclusions, but in some cases has failed to capture the nuanced experiences and struggles of individuals living with CFS.

Research within the particular sub area of CFS and occupational outcomes, impairments, and rehabilitation is starkly lacking. It seems that most of the research remains focused on understanding and addressing CFS from the medical and mental health perspective, as many aspects of CFS still remain a mystery to researchers and professionals. The organic next steps in the evolution of CFS research seem to be to focus more specifically on areas of challenge, and seek to develop helpful interventions.

Entrepreneurship

Definition

Entrepreneurship is often synonymous with self-employment (Naudé, 2012). While there is no universal definition of the two terms, self-employment is often correlated with necessity (Naudé, 2012) and personal profit (Parker-Harris et al., 2014), and entrepreneurship refers to opportunity (Naudé, 2012) and providing innovation to society (Webb, Bruton, Tihanyi, & Ireland, 2013). Webb et al. (2013) asserted that self-employment is an informal form of entrepreneurship. Both terms have been used interchangeably in the literature (Parker Harris et al., 2014). Nevertheless, entrepreneurs are uniquely involved in the complex and intricate process of identifying opportunities while undertaking both human and monetary risks in order to create a business, organization, or enterprise that provides goods or services. An entrepreneur and self-employed person may act alone, as part of a team, or some other form of collective (Schonfeld & Mazzola, 2015; Webb et al., 2013). Entrepreneurs must develop a new knowledge set in a context substantially different than established firms rather than use pre-existing routines set by others. Given these commitments, it is clear that entrepreneurs are devoted to putting in the necessary time and effort along with the risks and rewards involved (Maziriri & Madinga, 2016).

Economic Impact

Entrepreneurship is seen as a vehicle to economic growth, success, and prosperity, and has been recognized as a tool that drives the economy (Maziriri & Madinga, 2016). Researchers both past and present have found that entrepreneurial pursuits contribute significantly to U.S. economic growth (Pena, Jamilena, & Molina, 2011; Poudyal, Siry, & Bowker, 2012). Carlsson et al. (2013) highlighted the tremendous potential for nationwide economic growth as increased numbers of people pursue entrepreneurship. They argued that increased research is needed to fully understand the effect of entrepreneurial activity on economic growth and human welfare.

Entrepreneurship, both high impact and small and medium enterprises (SMEs), helps increase national productivity and alleviates poverty (Fairlie & Holleran, 2011). According to Schonfeld and Mazzola (2015), in 2009, approximately 15.3 million people were self-employed, lending it to be a significant source of work for many Americans. Rietvel, van Kippersluis, and Thurik (2014) found that entrepreneurs are often reported to be healthier than wage workers; however, they did not explore or identify the cause of this health difference. The consensus among scholars is that the rise in entrepreneurial presence has made a tremendously positive impact by providing product and market innovation, employment expansion, and increasing national wealth (International Labour Organization, 2013). Ali and Topping (2011) studied business students and found that university students hold generally positive attitudes toward entrepreneurship and are interested in taking coursework in entrepreneurship, indicating a rowing level of interest among the next generation of businesspeople.

Advantages of Entrepreneurship

Entrepreneurs experience higher levels of job satisfaction than individuals who work for an employer (Schonfeld & Mazola, 2015). This may be attributed to several factors including autonomy, flexibility in schedule and environment, having control and freedom, and participating in selling a product or service in which one is interested in or passionate about. Entrepreneurship can be a difficult and risky path, and the research indicates that individuals who choose this route tend to be very passionate about their work, and are willing to incur the risks involved because they are driven by a desire to follow their dreams, improve the world in some way, or innovate a novel item or service (Auwalu Ibrahim & Mas, 2016).

Autonomy and freedom. Individuals who are self-employed tend to obtain satisfaction from autonomy and freedom (Feldman & Bolino, 2000; Schonfeld & Mazola, 2015). As presented in the psychology literature, autonomy is understood as a wish to define one's own goals, and choose how time is spent (Croson & Minniti, 2012). British researchers Binder and Coad (2013) found that even when their income is lower, the self-employed consistently report higher satisfaction with their jobs and overall quality of life, as was measured by several dimensions of life satisfaction. By leading an independent lifestyle, entrepreneurs benefit from greater flexibility, skill utilization, and job security (Binder & Coad, 2013). With this independence, people are more intrinsically motivated than wage workers (Croson & Minniti, 2012). Schonfeld and Mazzola (2015) explained that from a job-characteristic perspective, greater autonomy brings increased personal satisfaction, as well as lessened psychological distress.

Job control and schedule flexibility. Entrepreneurs hold complete control over personal and professional decisions, and the associated factors. This applies to the management of different tasks, allocation of resources, and scheduling (Rietvel et al., 2016). Feldman and Bolino (2000) suggested that the ability of entrepreneurs to work where and when best suited is a major attraction of self-employment. In a more specific study, Lim (2015) found that self-employed individuals were drawn to the path of entrepreneurship in order to have the ability to work from any environment, along with choosing the number of hours to work. This study focused on mothers of young children who had pursued entrepreneurship specifically for the degree of flexibility it offers.

Within this mode of inquiry, Feldman and Bolino (2000) found that self-employed individuals experience a greater sense of control over their lives as compared with wage workers. In a study on entrepreneurship among disabled individuals, Hagner and Davies (2002) asserted that self-employment is now a viable employment option for individuals with disabilities; this includes individuals with cognitive disabilities. They found that control over one’s own workspace and work methods help to ensure ultimate job accommodation. From this perspective, individuals with CFS may find it advantageous to be self-employed and potentially work from home, as well as choose how many hours are worked each day in accordance with how capable they feel physically, emotionally, and mentally.

Passion and purpose. Feldman and Bolino (2000) found that self-employment provides an opportunity for individuals to express their skills and abilities through creative outlets. Benz and Frey (2008) built upon the work of prior researchers who found that the self-employed derive higher satisfaction from work than those employed in organizations, irrespective of income gained or hours worked. Looking at several factors underpinning this phenomenon, the researchers concluded that entrepreneur’s value being independent rather than being subject to decisions made by others. They also found that their subjects valued outcomes and the processes leading to outcomes.

Taken together, these findings indicate that in a scenario where individuals value the end result as well as the process of working toward it, a higher measure of satisfaction will be felt. Many individuals have chosen a path of entrepreneurship because it is a means by which they can follow their passion, and make a meaningful contribution that is in alignment with their talents.

Challenges of Entrepreneurship

Often times, entrepreneurship is seen through an alluring lens. Although entrepreneurship can indeed provide potential advantages, it is important to also discuss the drawbacks of entrepreneurship, which are potentially harmful to individuals living with CFS. The risk and stress that accompany entrepreneurship, the stigma of chronic illness, and the potential lack of skills are factors to be aware of and address so that they do not outweigh the benefits of entrepreneurship.

Stress. Entrepreneurship and self-employment are undoubtedly accompanied by stressors. Creating and running a new venture is typically unpredictable and strenuous (Schonfeld & Mazola, 2015). The types of stressors vary depending on many factors, including the type of business, and individuals involved. They can include economic and income security, difficult clients, threats to reputation, uncertainty of business, lack of knowledge or skill, onerous workloads, and lack of support (Schonfeld & Mazola, 2015). Baron, Franklin, and Hmieleski (2013) acknowledged that entrepreneurs face significant stress due to unpredictability when faced with high levels of risk, work overload, and great responsibility. However, they found that individuals who pursue entrepreneurship seem to be relatively high in the capacity to tolerate or effectively manage stress, and in fact, reported experiencing low rather than high levels of stress while running new ventures. One limitation of this study is the inability of the researchers to determine whether the results are due to individuals with a higher stress tolerance being drawn to entrepreneurship in the first place.

The stress that is endemic to entrepreneurship must be taken into account when exploring or promoting self-employment among CFS patients. As explained in the prior section, individuals living with CFS tend to have elevated levels of stress related to their medical condition and logistical barriers such as obtaining adequate health coverage and managing personal responsibilities. High levels of stress may not only consume these individuals' basic ability to function (Baron et al., 2013), but may have a psychological, physical, and behavioral impact as well (Schonfeld & Mazola, 2015).

Disability discrimination. Parker Harris et al. (2014) reported that there are approximately 54 million individuals in the Unites States with disabilities, a group that has suffered a long history of oppression and segregation. Fewer than half of this group are able to participate in the labor market, even when their symptoms don't preclude them from doing so. Marumoagae (2012) asserted that disability discrimination is one of the worst stigmas society has yet to overcome. Many individuals with disabilities who are willing and able to work experience tremendous difficult in securing and keeping a full or part-time job, which results in lower income and diminished financial stability (Parker

Harris et al., 2014). Disability discrimination is common among the workplace due to negative attitudes and lack of knowledge/ awareness (Maziriri & Madinga, 2016).

Individuals with a disability, such as CFS, are viewed as inferior and considered marginally able to contribute to the workforce (Maziriri & Madinga, 2016). They are often assessed as mentally and physically weak (Maziriri & Madinga, 2016) and employers are found to often discriminate in the job selection procedure (Rietvel et al., 2016). For some individuals with a chronic illness or disability, self-employment is the only option. The exclusion on a structural and cultural level can affect many aspects of employment and even self-employment (Parker Harris et al., 2014). Chronic illness can also preclude entrepreneurs from receiving funding, as health is considered by investors in calculating investment risk (Rietvel et al., 2016). As a result, it seems that the ability of this group to participate in the workforce will continue to be limited, which unfortunately is very disempowering (Parker Harris et al., 2014).

Lack of skill set/qualifications. Auwalu Ibrahim and Mas (2016) emphasized the need to obtain or acquire certain skills is imperative to an entrepreneur's success. An entrepreneur must be a "jack-of-all-trades" and have the skills to dedicate tangible and intangible time, effort, and ability to take risks. They argued that increased support would help these individuals to build characteristics such as boldness, tenacity, and readiness, which are often required to achieve certain objectives with their entrepreneurial endeavors.

Due to the lack of opportunity in the workforce and education realms for disabled people, they often are not able to gain experiences such as business management, and legal/ financial expertise (Maziriri & Madinga, 2016). Hagner and Davies (2002) stated that it may be difficult for people with physical and cognitive disabilities to acquire the complex skills needed to run and manage a business, which consequently creates a barrier to achieve self-employment. However, they found that when given support, individuals were able to be successful as business owners and derived great meaning from this experience. The researchers suggested that supports be made increasingly available to individuals with disabilities who would like to pursue self-employment.

Full responsibility. Rietvel et al. (2016) sought to understand the pressures experienced by entrepreneurs due to bearing the full burden of keeping their business afloat. With this responsibility comes increased job demands and workloads as compared with wage workers, and this is a factor that must be taken into account when promoting entrepreneurship among CFS patients or the disabled population at large. The researchers pointed out that factors including income, job security, and personal assets are all at stake. As a result, entrepreneurs can feel burdened by work challenges such as potential uncertainties, failures, and frustrations that can come with starting a business.

Loneliness. Although entrepreneurs and self-employed individuals are autonomous, this can frequently be accompanied by a loss of social interaction and social support. Feldman and Bolino (2000) reported that self-employed individuals stated the following complaints:

- I definitely feel more isolated in self-employment and this is my biggest source of dissatisfaction. I came from an aerospace company where I was surrounded by interesting, well-educated people ... the difference is immense.

- The loneliness of working out of home and lack of social contact at work is a major challenge. Social isolation is a real problem.
- The thing I miss most is the corporate family we had. Just about all our friends and things we did were within that family. It's taken a long time to replace that.

These factors are used to help understand the challenges people who are self-employed are faced with in terms of isolation.

Fernet, Torrès, Austin, and St-Pierre (2016) pointed out that the topic of loneliness among entrepreneurs has been largely ignored. The topic attention because it may contribute to psychological issues, given that prior research findings support the notion that connectedness is an essential ingredient for psychological health. Fernet et al. sampled 337 entrepreneurs, the results showed that occupational loneliness can indeed lead to burnout. By utilizing a survey of over 54 entrepreneurs, Schonfeld and Mazola (2015) found that the most common stressors experienced included uncertainty about income, dramatic slow- downs in business, reputational threat, betrayal, unreasonable customers, and medical problems. In terms of coping mechanisms, they found that the most effective strategies employed coworker and supervisor support. They recommended that entrepreneurs who work alone lean on family and friends for support.

This section explored the body of research dedicated to investigating and understanding all elements of entrepreneurship. There seems to be much consensus within this area. Several researchers confirmed that there are quite a few advantages to working as an entrepreneur, such as contributing to the nationwide economy, experiencing feelings of purpose and job satisfaction, and liberties such as autonomy and a flexible schedule. Researchers are also in agreement about the challenges of entrepreneurship. In particular, they find across the board that entrepreneurship can be stressful due to the high stakes and widespread responsibilities that typically fall on an entrepreneur's shoulders. Multiple studies also cited loneliness as a central challenge of entrepreneurship. Within these areas, many of the studies conducted appear to be quite strong, with appropriate methodology and high generalizability, leading to a solid consensus between studies. Entrepreneurship is an area that has been researched for several decades now, and the findings seem to be clear and conclusive.

Disability and Entrepreneurship

At present, there is a lack of research investigating the lived experiences of individuals with CFS who work as entrepreneurs. There is existing research on the experiences of individuals with various disabilities who are self-employed and working from home. Due to the daily challenges they face, individuals with disabilities often provide unique insight into the unmet needs of this particular population (Parker Harris et al., 2014). In understanding their experiences, they are in an ideal position to innovate new solutions. Zahra, Gedajlovic, Neubaum, and Shulman (2009) have paved the way when it comes to exploring specifically how opportunities are created that lead to social entrepreneurship, in some cases due to personal struggles or limitations such as disability. Historically, some of the most successful entrepreneurs have solved problems that are personal to them (Shaw & Carter, 2007). For the purposes of this study, it is constructive to turn to individuals with disabilities to more intensely learn about the ways in which they have creatively found opportunities to participate in the workforce in spite of the significant barriers previously discussed.

According to Martin et al. (2013), "living with a chronic illness is a self-management process that includes tasks and skills related to coping with the illness and growing as a person, as well as transitioning from a focus on the illness needs to integrating the illness into the context of the individual's life" (p. 5). A major shift faced by individuals diagnosed with chronic illness is the lowering of career expectations. Individuals in demanding, high-stress jobs are typically unable to continue performing at that level, and often seek easier jobs with lower career potential. For many individuals, realizing and accepting this particular limitation is one of the more difficult aspects of living with a chronic illness (Beatty & Joffe, 2006). Beatty and Joffe (2006) suggested, "Career dreams are so closely associated with a person's identity" (p. 187), which in one way, highlights the importance between work and individuality.

There are numerous reasons as to why it's preferable for individuals with CFS to have the option to work. Anderson et al. (2013) found that many disabled participants chose to continue working due to difficulties obtaining disability income, a desire to participate in the work force, and for the sake of keeping health insurance. The results of this study are limited in their generalizability due to the qualitative approach used by the researchers, however it sheds light on this very unique phenomenon. Olesen et al (2013) affirmed that "Workforce participation is a key feature of public mental health and social inclusion policies across the globe, and often a therapeutic goal in treatment settings" (para 1). The researchers collected data from an extremely high number of participants (*n*=7176), lending credibility to the generalizability of the study.

In addition to the logistic benefits to providing work opportunities for disabled individuals, there are a score of psychological and emotional gains as well. It is supported that participation in the workforce shows positive mental health outcomes (Baron et al., 2013). Psychological outcomes include "social role and status, access to social networks and support, and a sense of purpose and achievement" (Olesen et al., 2013, para 2). Similarly, other studies have speculated quality of life to be linked to many aspects of work, such as productivity, social relationships, income, career success, and job satisfaction (Pinquart & Sorensen, 2000; Wright & Cropanzano, 2000).

One study discovered that most disabled people who pursued entrepreneurship chose this path because their traditional employment opportunities were limited. The second most influential factor was the promise of a flexible schedule (Parker Harris et al., 2014). Some individuals with diseases such as CFS or multiple sclerosis have been able to arrange a telecommuting agreement with their employer, enabling them to continue working from home, often with a more flexible schedule (Ahmadi, Alamzadeh, Daraei, & Akbari, 2012). Pagán (2009) pointed to the many benefits that self-employment offers individuals living with disabilities, including flexibility and ease in adjusting to disability. However, he made the argument that the barriers to employment that many disabled people face should not be the main reason for disabled people to pursue entrepreneurship. Disabled individuals who are self-employed are more satisfied with their work and experience better working conditions as compared with disabled wage workers. At present, there is a need for additional research seeking to understand the ways in which entrepreneurship can enhance the well-being of individuals living specifically with CFS.

Benefits and Challenges

Medical professionals, mental health workers, and researchers across fields encourage both disabled individuals and individuals with chronic illness to work to the extent possible. There are many benefits associated with participating in the workforce (Joffe & Friedlander, 2008; Pinder 1995; Register 1987). It is essential for disabled individuals and their families to be empowered in their ability to care for their needs in each sphere of their lives (The World Health Organization, 2016). Researchers have found that workplace schedules and structures are profoundly helpful in maintaining a daily routine, and by providing a distraction from the challenges of living with chronic illness (Beatty, 2012; Pinder, 1995).

Whatever the case, adjusting to a chronic illness involves acceptance of an altered life and identity. In order to integrate the illness into daily life, one must modify lifestyles and routines. This can be achieved by being attentive to symptoms while also partaking in enjoyable and meaningful activities. Meaning-making helps an individual to find a sense of meaning and purpose in life, and strive for personal growth (Martin et al., 2013). In spite of being disabled, some of the positive health effects associated with working include giving structure to the day, developing new skills, interacting with others, financial security, personal achievement, and working toward life goals. As one research participant articulated, “I had a title at the office, I had things to do at the office. I had things to do with people, with work, and I was busy. I was doing something. Suddenly, I'm doing nothing and I am nothing because you feel like your identity is gone" (Anderson et al., 2014, p. 7).

Arnold and Seekins (2002) concurred with health care professionals and researchers who have suggested that entrepreneurship be used as a possible tool for rehabilitation among individuals with disabilities, to achieve faster and better integration into the labor market. Based on the results of their study, these researchers developed a Self-Employment Process for Vocational Rehabilitation that agencies can use to aid disabled individuals in becoming successful entrepreneurs. For disabled individuals seeking to participate in the workforce, their most important needs have to do with flexibility. "The physical changes of illness require a flexible career path so that people can adjust their participation over time" (Beatty & Joffe, 2006, p. 190). Self-employment offers many benefits to individuals with disabilities or chronic illness, including independence, a flexible schedule, and ability to work from home (Office of Disability Employment Policy, 2001; Parker Harris et al., 2014).

In general, the existing literature has suggested that entrepreneurship can empower people with disabilities and chronic illness to be less reliant upon disability services, and become financially independent (Parker Harris et al., 2014). In addition to research within the U.S., multiple researchers have explored the same phenomenon in the developing world, and arrived at similar conclusions (Maziriri & Madinga, 2016; Rahim et al., 2014). Falch and Hernaes (2012) conducted research seeking to understand the experiences of disabled entrepreneurs in Uganda, and found that disabled entrepreneurs tend to encounter prejudice, but entrepreneurship has the potential to alleviate poverty and empower individuals with chronic illness or disabilities. Similarly, Mpofu and Shumba (2013) conducted a mixed-methods study seeking that explored the experiences of disabled entrepreneurs in Zimbabwe. They concluded that entrepreneurship is a beneficial avenue of employment for individuals with disabilities; however, they face more discrimination than their non-disabled counterparts. Boylan and Burchard (2002) asserted that whereas governments have focused some attention on combating discrimination against disabled people, support in becoming self-employed has not yet been provided. In their qualitative study with 12 established and aspiring entrepreneurs, they shed light on the complex picture of barriers and opportunities faced by this population. The barriers they cite include difficulty accessing start-up capital, receiving helpful advice and accessing training opportunities.

Pagán (2009) illuminated the specific needs of disabled individuals seeking to become self-employed, highlighting a need for grants and loans at reduced interest rates, some sort of security system that would ensure that individuals will no lose disability benefits, and ongoing support, guidance, and training via employment services and vocational rehabilitation agencies. He argued that people with chronic illness or disability must feel that entrepreneurship is a practical option that provides steady income while affording flexibility, autonomy, and job satisfaction. “Policy-makers should encourage self-employment among disabled people in order to improve their employment opportunities. This would help to prevent their social and labour exclusion and reduce the employment gap between the disabled and non-disabled populations” (p. 227). There is a need for increased support and resources to enable disabled individuals to move forward in entrepreneurial pursuits.

Within entrepreneurial research, there are limitations in the subarea of researching disabled entrepreneurs. Some research has found that individuals with disability or chronic illness are more likely to experience discrimination in the workplace, and thus often turn to a path of entrepreneurship to resolve the issue of needing to work yet being unable to find or maintain wage-an-hour jobs. The research is starkly lacking in this area, with only a few studies (many of which have actually been conducted outside of the U.S.) having sought to more deeply understand the experiences of disabled entrepreneurs.

Some of these studies are qualitative which has shed light on the phenomenology of the matter, and others are quantitative which have led to some narrowly generalizable results. The qualitative studies have concluded that there are benefits to being a disabled entrepreneur, such as having income and a flexible schedule, whereas there are also significant challenges, such as the high level of stress associated with entrepreneurship. The research is heading in the direction of more deeply understanding the phenomenon of individuals with disabilities working as entrepreneurs. There is a need for increased research exploring the experiences of individuals diagnosed specifically with CFS, given its unique set of symptoms, in their pursuit of entrepreneurial endeavors.

Quality of Life

Definition

The scholarship pertaining to QOL is significant and wide-ranging. On the one hand, quite a few scholars have sought to offer definitions of QOL that offer objective clarity. Theofilou (2013) stated that such a definition is difficult given the multidimensional nature of the underlying idea. Yet despite this complexity, definitions of QOL commonly emphasize self-perception, even if it is an inherently subjective foundation on which to base scientific inquiry. Due to this inherent subjectivity, many scholars have used QOL interchangeably with *subjective well-being,* although this terminology does not necessarily clarify the underlying idea.

In response, some scholars have deviated from definitional clarity by presenting intuitive conceptions concerning a good life. In this reconceptualization, it is less important to define what QOL is, and more important to clarify three principle perspectives from which the good life might be viewed. With regard to its subjective quality, researchers can pay attention to the individual's self- perception. In its existential quality, researchers look at deeper levels of meaning and fulfillment. And finally, in its objective quality, a researcher can observe a life as others perceive it, in the outside world (Ventegodt et al., 2003).

Scholars have also viewed tangible factors which make QOL manifest. As indicated, some have characterized QOL as a kind of physical well-being. Along these lines, scholars have sought to demonstrate that physical illnesses — ranging from cardiovascular disease to respiratory infections — can be predicted rather accurately by

QOL ratings (Anderson, Kiecolt-Glaser, & Glaser, 1994; Vitaliano, Dougherty, & Siegler, 1994). Likewise, low QOL may introduce clinical depression and suicide (Gonzales, Lewinsohn, & Clarke, 1985; Koivumaa-Honkanen, Honkanen, Viinamaki, Kaprio, & Koskenvuo, 2001). For this reason, measures, which enables the assessment of QOL, may assist in forecasting an individual's unique risk of depression, illness, and suicide, which in turn may result in more effective prevention and treatment programs.

QOL and CFS

Closely related to the specific physical conditions in this paper, is the scholarship of Schweitzer et al. (1995), who developed a sickness impact profile to measure the effects of CFS on patients' QOL. CFS patients experienced significantly impaired QOL, something that was most apparent in areas of social functioning. Similarly, another study utilized health-related quality of life, an increasingly important measurement, to demonstrate that the disabilities of CFS patients were striking, especially in the realms of vitality, social functioning, and role functioning. These findings were consistent whether the patients were living in the United States, the United Kingdom, or Germany (Hardt et al., 2001).

While few studies have specifically looked at the effect of CFS upon QOL, there have been some that investigated related constructs, such as impairment. In particular, one notable paper demonstrated just how psychologically debilitating CFS can be. By utilizing a battery of symptom and mood questionnaires, researchers determined that subjective quality of life was markedly low among CFS patients, even when compared to other patients with mental disorders. Therefore, the comorbidity of depression and CFS calls out for interventions which address the emotionally devastation of CFS, which affects QOL in a negative manner (Rakib et al., 2005).

Hvindberg et al. (2015) looked at health-related QOL among patients who had been diagnosed with both myalgic encephalomyelitis and CFS (Hvindberg, et al, 2015). Such ME/CFS patients featured an even more disabled and socially marginalized group of individuals due to the severity of their diseases. While this study was limited by its use of self-reported conditions, it nevertheless demonstrated negative effects on patients' HRQOL.

The Effects of QOL on Work

While the scholarship pertaining either to the particular effect of CFS or to the general effect of physical illness is not yet complete, the wide-ranging benefits of high QOL is well-attested. Myers and Jeeves (1987) pointed out that when people experience elevated QOL, they tend to see the rest of the world as non-threatening and generally pleasant. Correspondingly, people with high QOL tend to make decisions more readily. And while low QOL levels among business employees can predict accidents on the job, high levels may forecast profitability and productivity (Harter et al., 2002).

Individuals who exhibit high levels of subjective wellbeing, which is another way to denote QOL, tend to be more generous, and they display greater compassion for those around them (Myers & Jeeves, 1987). These benefits are not only social; instead, the positive characteristics of generosity, gratitude, and other-directed service are correlated with greater leadership ability and follower acceptance (Bordas, 2007; Newman et al., 2009; Van Vugt, 2006). High QOL is vitally important to the development of collaborative decision-making and conflict resolution skills (Isen & Labroo, 2003). Much of this may explain why an individual's QOL can predict his or her ability to function effectively in the workplace (Diener et al., 1999; Frisch et al., 2005). A person's overall QOL may indicate future job performance and work satisfaction up to 5 years in advance (Wright & Staw, 1999).

Larsen and Eid (2008) found that people with higher levels of QOL are "more sociable and creative, live longer, have stronger immune systems, make more money, are better leaders, and are better citizens in the workplace" (p. 11). With such positive implications for life, work, and leadership, QOL holds a central place in any analysis of human capital.

Factors That Determine QOL

While many scholars have sought to demonstrate the importance of QOL as a determinant of external outcomes, others have attempted to research the underlying parts of QOL in the first place. At the outset, one must freely admit that attempts to define QOL using a basis of income and poverty require troublesome value judgments about money and well-being (Kingdon & Knight, 2006). Nevertheless, researchers have long explored the impact of poverty upon one's perception of well-being. For instance, several authors have shown that poverty engenders feelings of unhappiness, which in turn have been linked to lower QOL levels. But these findings have largely been associated with people living in undeveloped countries (Ahuvia, 2002; Ahuvia & Friedman, 1998; Cummins, 2000; Veenhoven, 1999). By comparison, the correlation between income and subjective well-being is moderate-to-low for those in the developed world (Ahuvia, 2002; Diener & Oishi, 2000).

Income differences seem only to account for two to three percent of the variance in QOL within developed nations (Ahuvia & Friedman, 1998; Andrews & Withey, 1976; Argyle, 2001; Campbell, Converse, & Rogers, 1976; Clark & Oswald, 1994; Schyns, 2001). When controlling for access to basic necessities such as shelter and adequate nutrition, less than 1% of the variance can be attributed to income per se (Ahuvia & Friedman, 1998; Cummins, 2000; Diener & Oishi, 2000). Moreover, surveys indicated that although real income per capita has doubled in the United States since 1950, the percentage of people who rate themselves as “happy” or “satisfied” with life has not increased correspondingly (Lee, 1999). Significantly, the access to public goods and to quality education has a greater effect on QOL than does personal income (Argyle, 2001). Taken together, all of these findings reflect Maslow’s conceptualization, which argues that higher-level needs emerge and become dominant only when basic ones like food and shelter have been satisfied (Maslow, 1970). Given this theoretical framework, it is not difficult to see why income would play a larger role in determining the QOL of those who struggle to meet their basic needs, and a smaller role for those who have already acquired a job, a home, and food (Ahuvia & Friedman, 1998; Cummins, 2000; Diener & Oishi, 2000).

QOL Among Entrepreneurs

Closely related to research about job and life satisfaction is the scholarship looking at the nexus of entrepreneurship and well-being. One study researched levels of job satisfaction among the self-employed, and found that satisfaction levels were higher among such entrepreneurs than among those who worked in environments characterized by a strict division of labor and hierarchical controls. Hundley (2001) found that the greater job autonomy endemic to entrepreneurial pursuits resulted in a more satisfying work experience. But not all studies have been so clear. Saarni et al. (2008) looked at QOL and HRQOL among three groups: entrepreneurs, farmers, and salary earners. While farmers scored lowest on each measure, entrepreneurs and salary earners showed no differences in QOL or HRQOL.

While some scholars have investigated kinds of professions, others have focused on the HRQOL effects of working hours among the professions themselves. For example, Kawambe et al. (2015) measured the effects of four work types: nighttime work, shift work, day to night work, and daytime work. The two most detrimental types of work were day-to-night work and shift work. Both were broadly correlated to negative impacts upon health related QOL.

Personality Factors and QOL

Shifting focus, some scholars have attempted to look at QOL through the lens of personality. Personality traits like extraversion, neuroticism, and sociability can predict a significant percentage of an individual’s subjective well-being (Ayyash-Abdo & Alamuddin, 2007; DeNeve, 1999; Heady & Wearing, 1991; Sagiv & Schwartz, 2000). Extraversion is positively correlated with QOL (Costa & McCrae, 1980; Diener & Lucas, 1999). By contrast, in more than a few studies the diminished emotional stability of neuroticism — often associated with pessimism, conscientiousness, guilt, or anxiety —

seems to be inversely correlated with subjective well-being and QOL (Bostic & Ptacek, 2001; Costa & McCrae, 1980; DeNeve, 1999; Hottard, McFatter, McWirter, & Stegall, 1989).

QOL and Demographic Differences

Demographic factors have also been a theme in the QOL literature. Gender and marital status have a complicated relationship with QOL. Factors such as education and marital status account only for a small percentage of an individual's QOL (Andrews & Withey, 1976). But more recent studies indicate that marriage is uniquely potent as an influence on QOL, although other close relationships can have a significant impact (Argyle, 2001). While marriage is strongly correlated with high QOL, the research has provided no conclusive evidence regarding causation. Some found that people with higher QOL are more likely to get married in the first place, while others have argued that marriage actually causes individuals to find greater satisfaction in their lives (Diener & McGavran, 2008; Diener & Seligman, 2002).

Life satisfaction does not seem to decline with age, nor are there significant differences in overall QOL for men and women (DeNeve, 1999; DeNeve & Cooper, 1998). Nevertheless, effects may differ between the genders. For example, Nolen-Hoeksema and Rusting (1999) speculated that relational effects may affect males differently because they are generally "socialized not to experience or express affect as intensely as females" (p. 344).

The educational attainment of a given individual is a complex factor in QOL as well. The effect of education is weakest in the United States and has become increasingly weaker (Argyle, 1999; Campbell, 1981). When controlling for occupational status and income, the effect of education is particularly small (Glenn & Weaver, 1981). In some cases, higher levels of education actually seem to yield negative effects on QOL, particularly when income does not increase along with education (Clark & Oswald, 1994).

As demographic characteristics seem to have little correlation to QOL, researchers have looked at other factors such as stress, goal-setting, personal values, social support, and spirituality. Quantity and perceived quality of relationship factors greatly affect QOL (Feiring & Lewis, 1991; Jones, Rapport, Hanks, Lichtenberg, & Telmet, 2003; Spira & Kenemore, 2002; Veenhoven, 2004). One study that looked at well-being among young adults found that QOL correlated with a number of social support dimensions, including the size of one's social network, the frequency of social contact, the satisfaction with friendships, the instrumental support manifest in those friendships, and the capacity to provide aid and support (Chou, 1999).

Relatedly, those who were active members among clubs, churches, and associations featured greater levels of subjective well-being (Veenhoven, 2006). It is important to note that social support systems vary widely among individuals of different ethnicities (Kim & McKenry, 1998). Although different cultures may expect differing levels or categories of social support (depending upon whether those are more communal or more individualistic) in almost all there is an underlying conviction that a sense of belonging is essential to one's cultivation of high QOL (Ng, Ho, Wong, & Smith, 2003; Veenhoven, 2004).

The opposite rather has rather predictable effects as poor quality relationships are linked to low levels of subjective well-being, most notably in unhappy marriages (Hawkins & Booth, 2005). Individuals with disabilities likewise indicate that low levels of social support or negative social support (such as the underestimation of capabilities) correlates with lower levels of fulfillment and poor QOL (Cimarolli & Boerner, 2005). Cultural mistrust and lack of social support also yield lower QOL levels for members of minority groups (Bell & Tracey, 2006; Gee et al., 2006). Negative relationships and a lack of community in work environments are associated with low levels of life satisfaction (Hill, Leinbaugh, Bradley, & Hazler, 2005). These scholars find that the items which are most discouraging to workers in academic settings are those related to social relationships — such as being controlled by others on the job or having to work alongside less skilled or less knowledgeable colleagues. The absence of a mentoring relationship, along with the presence of office gossip and politics also contributes to a mentor, office gossip and office politics also contributes to one's sense of discouragement. Each of these negative social experiences in work environments correlates to a lower QOL (Hill et al., 2005).

Factors That Diminish QOL

Some scholars have concentrated upon elements that may be uniquely detrimental to QOL. Stressful life events negatively correlate with measures of subjective wellbeing (Karlsen, Dybdahl, & Vitterso, 2006). The chronic stress of daily hassles and interpersonal conflicts more negatively affects well-being than major life events, even traumatic ones (Bolger & Schilling, 1991). Despite the real correlation between income and overall QOL, middle-age and older adults in the U.S. reported in one study that money and financial stressors are among the most damaging forms of anxiety for subjective well-being. Other anxieties causing a negative effect includes interpersonal conflicts, marriage difficulties, and work, family, or child anxieties (Cacioppo et al., 2008). The larger impact upon QOL by daily stressors may be a consequence of our utilization of coping mechanisms during stressful life events (Karlsen et al., 2006).

Although stress may negatively correlate with well-being, stressful events can sometimes prompt personal and emotional growth, which ultimately increases one's QOL and well-being (Blascovich, Mendes, Hunter, & Salomon, 1999; Linley & Joseph, 2004). This potential for growth often manifests as individuals' face stressful life events and perceive that those events may prompt new forms of growth, changes in life philosophy, or strengthened social relationships (Tedeschi, Park, & Calhoun, 1998). In this way, one's capacity to see stressful events in light of a larger purpose is a powerful step to well-being. This larger purpose may, in turn, be related to a number of individual attributes ranging from spiritual beliefs and values to life goals.

Goals, Values, and QOL

Within this mode of inquiry, some scholars have highlighted the importance of values as components of subjective well-being. Schwartz (1996) attempted to make the case for a universal system of values. But he is in the minority as researchers disagree widely about which values are important in generating high QOL, particularly because values vary so markedly from one individual to the next (Braithwaite & Scott, 1991; Schwartz, 1996). Yet values often determine which goals an individual chooses to pursue

(Schwartz, 1996). Even before studies related such goals to QOL, the pursuit of significant goals was considered key to one's healthy psychological functioning (Cantor & Blanton, 1996; Oishi, Schummack, & Diener, 2001). Recent theories of subjective well-being regard goal-setting as a foundational component in subjective well-being (Emmons, 1996).

Wiese (2007) argued that the difficulty understanding the relationship between goal attainment and QOL arises from the fact that many people set goals that are directly related to improving their own well-being. Nevertheless, a number of researchers explain that self-determination theory indicates that the secret to subjective wellbeing is meeting one's intrinsic needs by pursuing intrinsic goals (Ahuvia, 2002; Csikszentmihalyi & LeFevre, 1989; Klonowicz, 2001). Csikszentmihalyi (1999) expanded this concept, speaking of it as being in "flow" or as a "flow" experience. In flow, not only are the goals intrinsic, but they are also pursued via intrinsic motivation. Further, a number of studies confirm that higher levels of subjective well-being can be maintained through a dual process of reducing emphasis upon extrinsic goals (such as wealth acquisition and body modification) while placing greater emphasis upon intrinsic goals (such as personal improvement, strong relationships, and serving the community; Carver & Baird, 1998; Kasser & Ryan, 2001). To be clear, flow experiences can certainly include leisure activities. After all, many scholars note that participation in pleasurable life events has long been associated with a higher QOL (Argyle, 2001).

The link between intrinsic goal-seeking and QOL is further illustrated in research on extrinsic goals. The preoccupation with such goals, particularly materialistic ones, is positively correlated with both low QOL and poor physical health (Kasser, 2002). Although goals oriented toward financial success may be intended to augment well-being, they rarely lead to higher QOL in the literature. This observation corroborates Kasser's (2002) assumption that when people are preoccupied with materialistic values, they essentially waste their time. By concentrating on such profitless ends, they leave themselves little opportunity to pursue the kind of intrinsic goals which would improve their QOL (p.47).

Work and its Effects on QOL

Work has a direct impact on QOL for many people precisely because of its relationship to goal-setting and its capacity to provide meaning. Cantor and Sanderson (1999) argued that an individual's participation in work that is both personally and culturally valued has QOL benefits that extend beyond the direct effects of personality traits and income. Broadly speaking, scholars agreed that work that is personally valued provides both structure and meaning to daily life (Csikszentmihalyi, 1997). Other factors which seem to influence the nature of one's work life include the sense of autonomy, personal growth, intellectual challenge, altruistic orientation, job demands, skill use, variety, and opportunities for contact with other people (Warr, 1999). It was found that pay only has a limited impact upon the quality of working life (Argyle, 2001; Warr, 1999).

Work satisfaction is strongly correlated with overall life satisfaction, with a correlation of .44 reported by a meta-analysis (Tait, Padgett & Baldwin, 1989). Lu, Gilmour, and Kao (2001) explained that this correlation is not surprising because it is culturally ubiquitous, whereas the “Protestant work ethic” is endemic to many Western countries, the Confucian work dynamism pervades throughout the East with much the same effect. In the research to determine causality between work satisfaction and global life satisfaction, patterns seem to indicate mutual influence. That having been said, the effect of life satisfaction upon work satisfaction is much more salient than the reverse (Warr, 1999).

Judge and Klinger (2008) concluded that no research on subjective well-being could willfully ignore quality of work life given the fact that over half the non-retired adult population of the U.S. spend the majority of their time at work. For this reason, researchers have called for more comprehensive investigations into the nature of well-being in the workplace. Chief among the questions pertinent to such an investigation are the influence of socio-demographic factors and the role of job features in shaping QOL (Warr, 1999).

The body of research on QOL is quite extensive, as this is an area that has been of interest within the research field for several decades. In early QOL studies, researchers debated whether QOL should be measured according to objective or subjective criteria. This debate led to some inconsistencies in the research approaches and methodology. Over time researchers created rating systems to measure QOL based on both subjective and objective criteria. These criteria have evolved quite a bit over time – for example, in initial QOL research, the main determinant was income. However, additional studies found that given a person’s basic needs such as shelter and adequate nutrition are addressed, QOL is not affected by income. The QOL research has investigated many factors that have been theorized to affect QOL, such as demographics, personality traits, and goals and values. The body of research is extensive and contains both quantitative and qualitative studies, which is a strength. Measuring QOL remains elusive in some regards, but the research transcended.

In viewing specifically how working as an entrepreneur affects quality of life, the studies are less conclusive, which is a limitation in this area of inquiry. Some studies have found that entrepreneurship enhances quality of life quite significantly, whereas other studies have found no difference in the quality of life of an entrepreneur vs. a wage-an-hour employee. However, studies consistently show that performing work that is personally and culturally valuable, leads to a greater QOL.

Research Question

Taylor (2004) sought to measure work-related impairment of CFS patients via a meta-study. Findings stated that rates of unemployment ranged from 35%–69% and rates of job loss ranged from 26%–89%. Taylor concluded that there is a lack of support systems in place for individuals with CFS, leading to poor prognosis. There is a need for comprehensive rehabilitative programs focused on volitional, functional, social, and environmental aspects of re-employment.

Ross et al. (2004) conducted an extensive meta-study that explored evidence in the published literature on how best to measure, monitor, and treat disability in patients with CFS. The number of societal supports in place are increasing, however, relatively few programs have directed their attention towards addressing employment concerns. They concluded that increased research is needed to understand characteristics associated with inability to work among CFS patients, as well as interventions that are effective in restoring the ability to work in the CFS population.

Health care professionals agreed that there is a need for increased support around issues of work and employment among disabled individuals (Taylor & Kielhofner, 2005; Uslan, 2003). Mounstephen and Sharpe (1997) acknowledged that there is ongoing controversy about the etiology and ideal management of CFS, and argued that regardless of this debate, there is much more that can be done to support the well-being of CFS patients. In their conclusions, they stated that education and rehabilitation for employment are among the most urgent needs.

Put simply, the next step in supporting individuals with disabilities entails engaging directly with disabled individuals who are currently working as entrepreneurs, “to truly explore how people with disabilities are participating in entrepreneurship and to what extent that is similar or differs from people without disabilities who are starting enterprises” (Parker Harris et al., 2014, p. 335). I sought to do exactly that, with a specific focus on individuals diagnosed with CFS.

Entrepreneurship is a path by which individuals with CFS can partake meaningful work that aligns with their career dreams, ideally in a manner that contributes to their well-being without exacerbating the symptoms of their illness. There is a lack of research exploring specifically how this is being accomplished at present by individuals living with CFS. Utilizing an interpretive descriptive approach to explore the nuanced experiences of CFS patients who work as entrepreneurs, this study explored and answered the following overarching question: How do participants with CFS describe their quality of life/overall well- being when working in an entrepreneurial or self-employed capacity?

This question covered a number of considerations: What are the challenges and rewards experienced by entrepreneurs with CFS? Do they feel fulfilled by the work they’re doing, or feel a sense of meaning and purpose in their work? How do they manage their schedule and balance the demands of their work? Are there times when their symptoms have been exacerbated due to their entrepreneurial pursuits, and if so, how was this handled? What are the ways in which their entrepreneurial pursuits have added stress to their lives, and how have they coped or failed to cope with stress? What type of support could they use at present, or have they needed in the past? The research methodology is explained in detail in the following chapter.

Summary

Existing research exploring the experiences of individuals diagnosed with CFS and who are working as entrepreneurs is extremely limited. Only a handful of existing researchers explored this intersection, and frequently adopt a quantitative approach. There appears to be a need for additional quantitative research, perhaps preceded by qualitative research that would first capture the unmet needs and challenges faced by CFS patients who work as entrepreneurs.

Although there are some social supports accommodating individuals living with CFS, there are virtually no employment specific supports. Researchers have found that CFS patients are very much in need of support in reentering the workplace, and of finding creative solutions to the problem of needing to work while living with this chronic illness. A qualitative study that seeks to shed light on the experiences, needs, struggles, and rewards experienced by entrepreneurs with CFS was just one intuitive next step.

Chapter 3: Research Method

Introduction

Individuals diagnosed with CFS tend to experience a diminished QOL, due to newly arising symptoms and limitations associated with the illness. One challenge associated with QOL that CFS patients face is the reduced ability to participate in the workforce. For CFS patients, the inability to work and associated financial burdens are some of the most difficult aspects of living with CFS (Taylor & Kielhofner, 2005).

The number of individuals diagnosed with CFS is growing, and the effects of this illness are far-reaching, not only personally but also societally and economically (Komaroff & Cho, 2011). Society must provide more avenues to accommodate individuals diagnosed with CFS. Many individuals living with CFS have found creative solutions that help them to live well, including pursuing entrepreneurship as a way to participate in the workforce and generate income while allowing for a flexible schedule and the ability to work from home. Although some scholars, mainly in Europe, have attempted to shed light on how self-employment can be advantageous for those living with a chronic illness (Binder & Coad, 2013; Pagán, 2009), the lived experiences of CFS patients who have had success working as entrepreneurs have yet to be explored.

Using an interpretive descriptive research design, I sought to understand the factors that lead CFS patients to be successful entrepreneurs. The intention of this study was to see what would emerge from participants' stories, rather than to collect quantitative data. In the research question, I sought to define and explore theories about the experience of living with CFS and working as an entrepreneur.

Qualitative research is an appropriate method for exploring a human experience, and the qualitative method of interpretive description is defined as noncategorical methodological approach used to develop clinical understanding (Hunt, 2009). The intention of this study was to understand the experiences of individuals living with CFS who have established a career path in entrepreneurship or self-employment. I explored the experiences of individuals diagnosed with CFS working as entrepreneurs. I aimed to garner a basic understanding of the experiences common to CFS patients working as entrepreneurs and to shed light on several factors, such as the supports that have been helpful to them, challenges they have encountered, and changes in QOL.

The research may lead to positive social change by supporting individuals living with CFS. Individuals with CFS who are currently working as entrepreneurs are the experts in this area, and they provide many insights for those who might want to pursue entrepreneurship or self-employment. I also sought to understand the emotional and psychological responses to pain and suffering from the illness and how they have interfered with the ability to be self-employed, as well as coping mechanisms that have improved QOL. Lastly, participating in this project gave subjects the opportunity to share their narratives and speak to the advantages and disadvantages of the path they have chosen.

In Chapter 3, I provide justification and rationale for the research methodological framework; describe the research design, role of the researcher, data analysis, and sample strategy and size; and provide a description of the process that were used for data procedures. This chapter will conclude by addressing issues of trustworthiness with the data and procedures, along with ethical considerations of the study.

Research Design and Rationale

The interpretive, descriptive approach was initially developed by nursing researchers. Borrowing from other approaches including grounded theory, phenomenology, and ethnography, they sought to fit the objects and methodological rules of sociology, philosophy, and anthropology to a study of health and clinical issues (Morse & Chung, 2003). Their goal was to create a methodology that would meet nursing science needs; however, since its development, this approach has been used in research in all applied health disciplines (Hunt, 2009). The interpretive descriptive approach provides an approach to research design and analysis that is geared toward clinical practice. It is suited to smaller qualitative studies that aim to capture themes within subjective experiences (Thorne, 2000).

In establishing the interpretive descriptive method as the most appropriate approach for this project, I reviewed several studies that employed this approach, as well as considered alternative approaches including phenomenological, narrative, and grounded theory. Existing research on chronic illness and self-employment have used a variety of qualitative approaches (Arroll & Senior, 2008; Dickson, Knussen, & Flowers, 2008; Reynolds, Vivat, & Prior, 2008; Winger, Ekstedt, Wyller, & Helseth, 2014).

Interpretive description is a useful methodological approach when seeking to explore topics related to health and medical issues. CFS is debilitating across several areas of functioning, including a person’s ability to work. The experiences associated with this condition can be articulated through the lives of CFS patients, and they can be understood through an interpretive descriptive approach to research design and analysis. In this study, I aimed to explore how participants conceptualized their personal experiences of living with CFS while pursuing an entrepreneurship/self-employment path. From this, I interpreted themes and meanings as they arose from participant narratives.

The research question was as follows: How do participants with CFS describe their QOL/overall wellbeing when working in an entrepreneurial or self-employed capacity? The interpretive descriptive approach was designed to examine the shared experiences of individuals living with CFS who have pursued a path of self-employment. In the research question, I focused on the nuanced experiences of this distinct population.

The design of this inquiry was motivated by a desire to understand the intersection between self-employment and wellbeing/QOL among this population. This approach allowed me to explore how participants were able to assume entrepreneurship and self-employment in spite of their medical condition; I also distinguished which of the factors embedded in this experience have enhanced their wellbeing and which have exacerbated stress. Factors explored included workload, coping strategies, QOL, scheduling, and burdens, with room for participants to introduce additional elements that organically arose during the interview process.

Role of the Researcher

I will serve as the role of researcher. I was responsible for considering the influences of bias, judgment, and personal beliefs in relation to the subject matter being studied. I sought to control these factors as much as possible to minimize their outcome on the research procedures, analysis, and findings. In order to best control for these influences, the researcher must bracket his or her own personal knowledge, reality, and conceptions of the experience being studied in order to dedicate his or her attention to the research and to capture the true essence of the subject matter (Giorgi, 2006, p. 355).

It was my responsibility to set aside assumptions and make observations based upon the data presented. Drawing from the suggestion of Tuffor and Newman (2012), I began the data collection process with a self-reflection to identify preexisting beliefs, in order to avoid any assumptions while interviewing participants. This reflection process helped me to define and bracket existing biases and assumptions, allowing the research process to move forward without interference from preconceived ideas (Tufford & Newman, 2012).

Methodology

The population of the study consisted of individuals living with CFS who were entrepreneurs or were self-employed. Criterion-based and snowball sampling techniques were used to find and contact 12 participants who met the inclusion criteria of the study. Criterion-based sampling involved contacting groups that met participant criteria, such as CFS support groups, and inquiring about whether members met the criteria of the study and were interested in participating. The snowball sampling technique entailed asking participants if they knew of any other individuals who might be appropriate for the study. This technique enabled me to recruit a sufficient number of participants from a population that could be elusive to study.

Following the approval of the Walden University IRB, recruitment began and continued until the sample size of 12 had been met and interviews were scheduled. For studies that use the in-depth interview approach to interviewing, a sample size of 10 or more is recommended (Creswell, 2013). During the initial phone contact, I briefed potential participants on the purpose of the study, research questions, methods, procedures, and consent form. The participants were also informed that they were welcome to withdraw from the study at any stage, for any reason. Only participants who met the inclusion criteria, accepted the conditions of the consent form, and were willing to participate in the study were included.

Participant Selection

In this study, I focused on individuals living with CFS who had successfully founded a small business and/or entrepreneurial endeavor. Participants were selected based on meeting the inclusion criteria: (a) participants had been diagnosed by a medical professional with CFS; (b) participants had started a business, or were self-employed in some manner; and (c) participants were literate in English so as to be able to participate in the interview, and must be willing to allow the interview (with all identifying information removed) to be used for the study. In order to fulfill the third criterion, the participants were forwarded the informed consent prior to the initial phone screening.

Participation in the study was on a voluntary basis, with no compensation or incentive offered. I hoped that participants would find participating a positive experience, during which they would have an opportunity to share their stories and contribute to the wellbeing of the greater CFS community. Expressing experiences help to make meaning and integrate experiences. Participation in the research had the potential to benefit participants (Mehl-Madrona, 2005).

Recruitment

Once the IRB granted me permission to move forward with the study, the recruitment process began. Criterion-based sampling and snowball sampling were used to recruit study participants, which involved screening participants based on inclusion criteria (Creswell, 2013). For the purposes of this study, criterion-based sampling entailed distributing a recruitment e-mail online among networks that included potential participants, specifically among CFS support groups and communities, as well as shared on Facebook. Once several participants had been recruited, snowball or chain sampling was employed. During the initial phone screening, I asked the potential participants if they knew of other individuals who might like to participate in the study. These individuals were contacted by phone, and if interested in the study and they met the eligibility requirements, they were invited to serve as participants (Atkinson & Flint, 2001).

Each potential participant was notified that, throughout the recruitment process, they were welcome to inquire about the rationale of the study, my qualifications, and any other questions relevant to the research project. Recruitment was complete once interviews were scheduled with the appropriate number of participants. Creswell (2013) recommended an average size of five to 25 participants used in a qualitative study. The population size for this study was decided based on similar and relevant studies, as well as with guidance from the dissertation committee members.

The recruitment e-mail included information regarding the purpose of the study, process, participation requirements, and my contact information. Upon contacting me via e-mail to confirm their interest in participating in this study, I contacted the participants by telephone to confirm their interest, remind them of their rights to free and voluntary participation, as well as confidentiality and anonymity, and ensured that they met the inclusion criteria. After confirming that they had been medically diagnosed with CFS and were also are working as an entrepreneur or were self-employed, the participant and I scheduled an interview time, and I e-mailed the participant the informed consent form.

Data Collection

Once participants had been recruited, the data collection process began. Each participant completed an in-depth, semistructured phone interview, which is the approach typically used in an interpretive design study. The interview questions had been designed to provide the basic framework for a semistructured interview. A semistructured interview allows the researcher to plan to ask questions, with the flexibility to ask clarifying questions and let participant narratives emerge organically (Patton, 2002). Both preplanned questions and spontaneous questions were permissible, based on my judgment (Creswell, 20013). This ensured that the same general lines of enquiry were used with each participant, establishing consistency of questions across all participants (Jacob & Fergerson, 2012). This approach provided a focus for the data collection process, while allowing the interview to be conversational (Patton, 2002).

Before the interview process began, the participants were asked to sign the informed consent form. I informed all of the participants of the purpose of the study, the length of time that the interview was expected to take (30 minutes to 1 hour), and reminded them that they had the choice to withdraw from the study at any time. The minimal risk factors involved were addressed, and they were also reminded that their identities and information were protected.

In the interview questions, I sought to understand the experience of living with CFS and working as an entrepreneur. They helped to elicit a storytelling process during the interviews, and provide me with the opportunities to address issues that the participants may not have brought to attention on their own. The interviews were intended to collect data on the participants' lived experiences, while still maintaining a focus on the guided research question of wellbeing and QOL.

The participant interviews were conducted over the telephone, and each participant was interviewed separately. I ensured that the participants felt comfortable throughout the interview process. The interviews were expected to range from 30 minutes to an hour, and they were conducted in English. All interviews were audiotaped using my computer digital recorder.

I transcribed each interview within 2 weeks of the phone interviews, and any information that might have identified the participant was deleted or altered from the written record to preserve confidentiality. The audio recording files and transcript files were securely stored, and they will remain securely stored for 1 year. Once the data collection phase was complete, the analysis phase began. Data collection and analysis influenced one another, leaving the analytic process open to evolution as the study progressed. Thorne (2000) explained that an analyst must remain skeptical of what is apparent, and must create challenging data collection pathways that do more than reinforce earlier conceptualizations.

Data Analysis

In accordance with the interpretive descriptive approach, data collection and analysis occurred simultaneously. Hunt (2009) explained the analytic process is characterized by a concurrent and responsive relationship between data collection and analysis. Based on his recommendations, the interviews in this study were immediately transcribed and read, so that any insights that might have arose could be brought into the ongoing data collection (Hunt, 2009).

I used the main research questions of the study to inform the data analysis and interpretation. The interview questions were designed with the intention to gain insight into the research question, exploring subareas including how participants decided to take up entrepreneurship, what types of challenges they have encountered, and how this path has enhanced their wellbeing.

Gibson et al. (2013) recommended that the audio be transcribed and interviews be reviewed first as a whole to identify and interpret broad, overarching narratives describing the phenomenon. The data were then analyzed using a process of thematic analysis. This approach to analyzing qualitative research allows common elements among participant interviews to emerge organically (Creswell, 2013). To organize the common themes that presented themselves across participant interviews, I used a multiphasic coding process (Whittemore, Chase, & Mandle 2001). As research on the interpretive descriptive method recommended, the main goal of coding is to identify connections in the data and establish categories, patterns, and relationships between participant experiences. In the initial stages of data analysis, it is advisable for the researcher to focus on broader questions and seek to maintain a wide-angle view, rather than narrow in on minute details of the data (Hunt, 2009).

In Phase 1, I reread each interview two to three times, beginning to formulate codes. In Phase 2, the codes were grouped into labels to create categories. Then preliminary codes were combined and renamed to more accurately represent the data of the entire group. Phase 3 entailed the process of more deeply interpreting codes and combining them into themes that captured the data. I also made note of outliers. In the next phase, I took a second look over the data to determine whether the themes fully captured them and told an accurate story about them. Lastly, I prepared the themes for presentation to the readers by naming and defining the themes, assigning participant quotes for each theme, and explaining significance of the themes (Braun & Clarke, 2006).

The final step in the analysis involved explaining the codes and themes to a doctoral-level colleague who served as a second reader. This individual examined the data and the analysis process and pointed out potential blind spots in the coding and theme development. Once the analysis was complete and the final chapters of the dissertation are finished, the original interview transcripts may be deleted.

Issues of Trustworthiness

Credibility

Credibility refers to the internal validity of the research, determining if the study measures what it was designed to measure, and whether the results are honest (Creswell, 2013). The study has been designed to ensure that the methods used for data collection and analysis were as airtight as possible. The interpretive descriptive approach suggests that multiple sources of data analysis are employed to provide triangulation of the analysis, which leads the findings to be more credible. Allowing for a second reader to assess the efficacy of the codes and themes were set to accomplish this objective. This element of the analysis was hoping to provide a fresh perspective, and provide more validity to the coding approach.

Transferability

Transferability involves the degree in which the research may be transferred or generalized within other contexts or settings; in other words, that the descriptions of these experiences are understood by others who read the study. This study was not intended to provide measured results that might be generalized or transferred to the population of individuals living with CFS. Due to the fact that this study's topic has been so sparsely explored, the purpose of this research project was to serve as a pilot study that will deeply explore the experiences of individuals living with CFS and working as entrepreneurs. It is my hope that the study would lead to additional research, qualitative or quantitative, that will continue to seek to understand the lived experiences of individuals diagnosed with CFS, and what avenues might allow them to participate in the workforce, achieve financial stability, and experience enhanced QOL.

Dependability

Dependability refers to the reliability of the study - the stability or consistency of the study design as used over time. To ensure the dependability of this study, the dissertation committee members checked to see whether the researcher has made any errors in conceptualizing and designing the study. I attempted to be as transparent as possible in explaining how and why each element of the study was designed as it was. The second reader served to determine that the analysis and interpretation, as well as the findings and results, were reported thoroughly and accurately. I planned to increase the dependability by implementing the use of audit trails. All notes and records relating to thoughts, actions, and what is heard will be securely kept.

Confirmability

Confirmability is ensured through the researcher's ability to demonstrate neutrality as it applies to the study design and analysis. To achieve confirmability, the researcher must show that results originate from the data and not their own predispositions. The practice built into the study of the researcher becoming clear about assumptions and biases before conducting the data collection lends confirmability to the research. Patton (2002) recommended using triangulation in analysis as a means to lessen bias and ensure confirmability.

Ethical Procedures

The researcher is responsible for controlling for all ethical issues that might arise during the course of the study (Carey, Shaw, & Shiu, 2008; Creswell, 2013). Researchers must create an atmosphere of trust and ease, conduct the research with integrity, guard against misconduct, and address any challenges that might come up (Creswell, 2013). I conformed to all ethical guidelines as outlined in the Walden University Ethics Code Handbook.

Before each interview took place, participants were given copies of the informed consent. Any questions they had about these forms, the research, my credentials, or any other relevant topics were addressed. For the sake of maintaining confidentiality, all identifying information was modified and the data was used solely for the purposes of this study.

Summary

Chapter 3 was a detailed overview of the interpretive descriptive approach to qualitative research, a rationale for choosing this method, and a detailed overview of the design of the study. Once recruitment through criterion-based sampling and snowball sampling was complete, participants took part in a semi-structured interview that sought to collect data that will address the research question: How do participants with Chronic Fatigue Syndrome describe their quality of life/overall well-being when working in an entrepreneurial or self-employed capacity? The rationale for using a thematic analysis was given, and the steps that were taken were described. Also addressed were issues of trustworthiness, and ethical considerations.

Chapter 4: Results

Introduction

In this study, self-employed individuals with CFS participated in one-on-one interviews in order to share how they interpreted, perceived, and described their experiences working in an entrepreneurial or self-employed capacity, and how these experiences impact their QOL and overall wellbeing. The guiding research questions for this interpretive descriptive study were as follows:

RQ1. How do participants with CFS describe their QOL/overall well-being when working in an entrepreneurial or self-employed capacity?

RQ2. What challenges do participants with CFS experience when working in an entrepreneurial or self-employed capacity?

RQ3. How do individuals with CFS who are working or have attempted to work in an entrepreneurial or self-employed capacity describe, comprehend, and interpret changes in their QOL?

This chapter includes research procedures for the in-depth interviews that were conducted; demographics of the study participants; and the study's emerging findings as it relates to three main discussion topics: (a) personal transformation as a result of having CFS, (b) the experience of being self-employed with CFS, and (c) interpersonal factors that organically arose in participants' stories.

Research Procedures

All participants were recruited via recruitment flyers that were e-mailed to administrators of CFS organizations to either post to their bulletin board or to forward to their networks through member-direct e-mails.

The data collection involved a telephone interview protocol. The 12 interviews were audio-recorded to facilitate accurate transcription of responses. Each participant read and signed the informed consent form (ICF) prior to the one-on-one interviews. The ICF disclosed the purpose of the study, my responsibilities, and the rights of the participants. The participants were reminded that the interviews would be recorded from beginning to end. In building a rapport with the participants, I hoped that they would feel more comfortable in sharing their experiences and perceptions. Interviews were conducted from August 29, 2017 to October 16, 2017.

The data analysis phase first required listening to and transcribing the audio recordings from the one-on-one interviews. I first reviewed each audio recording as a whole, then listened and transcribed each interview into a Microsoft Word document. The data were then analyzed using a process of thematic analysis in order to enable common elements among participant interviews to emerge organically. A multiphasic coding process was implemented to help organize the common themes that presented themselves across participant interviews.

First, I read over each transcript several times, and codes were created to capture the critical elements of each sentence. The codes were then grouped into labels in order to create categories. The following step entailed combining preliminary codes and renaming them to more accurately represent the data of the entire group. The codes were then compiled into overarching themes that captured the data. I allowed codes and themes to emerge that most naturally captured participant experiences, rather than attempt to align the responses with the interview questions. A doctoral-level colleague served as a second coder and reviewer who helped examine all connections in the data and established categories, patterns, and relationships between participant experiences.

Participant Demographics

Twelve individuals participated in this study. At the time of data collection, each participant completed a demographic questionnaire prior to the interview questions. Demographic information including age, gender, ethnicity, and CFS diagnosis date were collected from each participant. The ages of the participants ranged from 26 to 65 years. The mode age was 57 years. The median age was 56 years. The mean age was 50 years. All participants (100%) were female. As mentioned in the study prior, there are significant gender differences when it comes to the prevalence of CFS, with women far more frequently being diagnosed than men (Jason et al., 2006; Kerr et al., 2007). CFS is more than twice as common in females as it is in males (Arnett et al., 2011; Christley et al., 2012). Eleven out of the 12 participants were of Caucasian ethnic background.

Results of the Study

In this study, I aimed to explore in detail how participants conceptualized their personal experiences of living with CFS while pursuing an entrepreneurship/self-employment path. A semistructured interview of both preplanned and clarifying questions was conducted among 12 participants. The same general lines of enquiry were used across participants, while still allowing some flexibility for the interview to be conversational. The design of this inquiry was motivated by a desire to understand the intersection between self-employment and wellbeing/QOL among this population.

Factors explored included experiences with medical professionals, coping strategies, scheduling, relationships, and burdens, with room for participants to introduce additional elements that organically arose during the interview process. The presentation of the interview data includes exact statements from the participants, organized via the aforementioned process of manual coding and identifying themes generated by participant statements. The exact responses were used to enhance and provide credibility to my interpretation of participants' experiences. The following three overarching discussion topics arose from the participant responses:

- Personal transformation in connection with CFS
- Experience of being self-employed and living with CFS
- Interpersonal and relational factors influenced work, life, and wellbeing

Discussion Topic 1: Transforming as a Result of CFS

Participants talked about being transformed by their experiences of having CFS-the initial confusion of wondering what was wrong, struggles with medical professionals, grieving the former life and accepting a "new normal," and hope for a new and different path. In connection with this transformation, many participants also mentioned that they had to take their health and wellbeing into their own hands in various ways in order to survive this intense process of death and rebirth.

The medical community views CFS as a highly complex condition, due to its effects across several major bodily systems (Anderson, Jason, & Hllavaty, 2016). It is not possible at this time to diagnose CFS using brain scans, blood work, or any sort of medical test, and no cause has been identified that accounts for all cases of CFS. CFS causes much ambiguity not only for patients, but for medical professionals as well. All 12 participants spent significant interview time discussing various aspects of this arc of transformation.

Subtheme 1: Symptoms and confusion. All 12 participants discussed the early period of their illness, and they brought up various struggles associated with this chapter of their lives. All of their experiences were marked by a sense of confusion feeling disillusioned by medical professionals and often trying to get well or return to the life and state of health they had previously known.

Most of the participants spoke about initially being in denial and trying to get healthy again in order to get back to work or school and to continue life as normal. One participant spoke of these early days, saying, “I was just like, ‘Why can’t I do this?’ You know, that type of thing. ‘What’s going on?’ You know, feeling confused and frustrated by just not being able to function like I normally did.” Similarly, another participant said, “At first my objective was to get well, and I thought that was my responsibility, and I had to do everything I could to try to fix this and try to get back to full health.”

Other participants talked more explicitly about denial: “My initial thought was, ‘No, that’s not me, I don’t have it, I’m going to figure it out on my own.’” Another participant said that in trying to live her life as normally as possible.

> I was in denial about it for a long time, then I was making myself worse. We thought it was sleep apnea. And I got a machine and I went back to the gym and that’s when I finally thought, this is not sleep apnea. I’m really sick.

Nearly all participants discussed trust issues with medical professionals, given that CFS is misdiagnosed, and according to some doctors is not considered a valid diagnosis. As one participant said,

> My primary doctor was not taking it seriously, so that started a whole chain of events that lead me to not really trusting doctors as much as I used to. I used to think you go to the doctor when you're sick, and they tell you what's wrong with you, and then you get well. That's the story that I had in my mind. And now I know that's not the story for everybody.

Similarly, another participant said, "It's very mind bending, to try to live in a world where doctors are possibly more scary than they are helpful. I know a lot of people who have been made a lot worse by pursuing treatment."

Several other participants reported the frustration and upset that they felt when doctors accused them of faking their symptoms: "I remember when doctors were saying this thing didn't exist… now they know it's there, but they just don't know what the heck to do, because they don't know anything about it." Another participant reported that a medical professional told her "I can't find out what wrong with you. It must be in your head." Another participant said, "Doctors became so hard to see, because the doctors didn't believe you."

Participants perceived that given that there was no cure or medication for CFS, doctors were unable to help them and thus wanted them to stop coming in: "Doctors just don't want you to come in the door because you've been sick for so long, that they just don't have an answer." Another participant stated,

> I went through a dozen doctors before I gave up in the first year, year and a half. And I truly had to give up because they told me to go away and not come back…when they tell you to go away, there's really nowhere else to go for modern medicine. That was really tough when they said, There is really nothing wrong with you, please stop coming back.

The words of one participant summed up the experiences of nearly all.

> Doctors are mostly useless. Some of them may be trying to be helpful, but they're either not up to speed about chronic fatigue syndrome, or they don't really believe in it…I've had to become my own doctor...I just try to avoid the doctors as much as I can and take care of it myself. It's just not worth it. It's too much energy trying to get them to take you seriously, and they never have anything to offer.

Some participants expressed that it was a relief to be diagnosed, after having suffered from a mystery illness for so many years:

> It was just conformed by a doctor, so it just gave me a name for my illness. It certainly wasn't positive, but it wasn't negative. It was ok, this is what I have. And it was odd to find out that they didn't have nay treatments for it.

Another participant stated,

> It was little bit depressing to be honest, to have that official diagnosis. I was hoping that it was going to be something else...I was very ill at the time, but I will say it was a relief though because I didn't feel as crazy, and I felt like I just had more insight.

These statements shed light on the central struggles participants faced in the earlier stages of their illness-feeling confused about symptoms, unable to find answers within the medical field, and once diagnosed, relieved in some cases and in denial in others.

Subtheme 2: Letting go of old life, acceptance of new normal. In this section, I explored the next phase in the arc of transformation that participants underwent as a result of having CFS. Participants talked about a chapter postdiagnosis of acceptance of having CFS and all that entails. They talked about letting go of ideas, dreams, and hopes they had for the future and grieving the loss of this imagined life. They also talked about their increased inability to participate in the regular workforce and coming to terms with this loss as well. Lastly, they discussed accepting a new normal understanding that CFS brings significant limitations and learning to live within those limitations.

Regarding letting go of her former life, one participant said,

> I know the first 3 years, everyone was desperate that they just had to get me better. And get me back to well again. And it took a long time for that attitude to shift into this more sustainable, I just have to figure out how to live this life. That took maybe the better part of a decade.

She went on to say “It’s just so frustrating to feel sort of constrained…you want to be out there doing something positive and contributing in some way.”

Another participant talked about having to let go of her career ambitions upon being diagnosed with CFS.

> I was studying public health at the time and wanted to work for the EPA and look at the impact of climate change on the spread of disease-kind of pie in the sky

> kinds of ideas, but I wasn't able to pursue that. And I realized that wasn't something that was going to pan out because of my limitations.

Another participant talked about loss of faculties as a result of CFS and having to let go of this aspect of her identity.

> I've always counted on my body. I was a strong soul, and running was my outlet. And now that was gone, and how do I do that, how do I cope with that. And the active soul - how do I let her go?

Several participants also talked about no longer being able to function in their regular employment jobs and eventually having to let work life go.

> I was trying to work, and I would get to work, and I would be able to work a short time then have to come home early. Or I'd get on the bus and not make it to work, because I was so dizzy and tired, and it was confusing and frightening.

Another participant said,

> I couldn't produce at work. I was constantly going back and forth trying to get doctors to figure out what was going on, and then trying to get the doctor to get my office a work excuse, and they didn't want to do that. It was just frustration - you feel crappy, and you're just trying to advocate for yourself, and you're still trying to fulfill your work obligations.

Similarly, a third participant said,

> It was overwhelming at first. I was in so much pain I had to leave my work- well cut back, and then ended up leaving my job because even that was too much.

Another participant said, "The symptoms basically destroyed the life that I had

> before. The kind of professional life I had, which was highly intellectual and highly people driven.

One participant spoke of the financial ramifications of no longer being able to work:

> When I eventually needed to let go of my job in 2010, my husband and I couldn't afford our mortgage anymore so we eventually lost our house and had to move in with my parents for a while. It definitely changed our whole lives.

Lastly, many participants discussed arriving at a place of peace and acceptance, eventually coming to embrace their new normal. Many participants talked about adjusting standards and accepting a new identity. One participant simply said, "It's been a huge life switch. And a huge identity switch." Another said, "My mental health model no longer hinges upon that I'm going to get better one day. But instead its' going from what I have now, and that I need to do the best with what I have now."

One participant expressed, "If I were healthy, I would have much higher standards for myself. But I'm not, so they are just the way they are, and I have to accept that." Another said,

> I just can't keep thinking I'm going to get back to that person anymore. She's gone and I need to live my life. So about two years ago, I really stopped seeing anybody for an active sense of getting better. And then got a support system for accepting my new normal.

Regarding adjusting her expectations for her professional life, one participant said,

> I wish there was a way to have the dream job, but after a while I kind of came to the terms with the fact that having ‘a job’ was enough of a success. That I had to grieve the letting go of all of my dreams.

Subtheme 3: Growing through challenges and finding meaning in life. Eleven out of 12 participants shared about the turning point at which they essentially rose up in spite of having CFS. They talked about a change of mindset to think more positively and practicing compassion and self-love. For many participants, creating an avenue for self-employment was the final outcome of this, as it gave them a newfound sense of meaning and purpose in life.

Several participates spoke about the turning point at which they developed a new outlook about CFS and decided to reengage with life.

> One of the last doctors I went to told me that I had done everything that I could, and that I was not going to make myself well, and that I should de-medicalize my life. And what he meant by that was to do what I could do instead of always trying to get back to how I was before. So literally he said to get a hobby, get a pet, something to make your life meaningful as it is. So I took that to heart, and I stopped trying to find a cure to focus on the things I could do.
>
> Another participant said,
>
> You have to sit back and think, well, what does this mean? How meaningful is my life - if any meaning? What can I rebuild here to recreate a meaningful life? A third participant chose to approach it as a puzzle to solve: My husband’s an engineer, and in his logical problem solving he would say, you just need to solve

> for X. Your X is just different from other people. So I really took it as, this is a problem that I was going to figure out the solution to. I stopped reviewing here.

Many participants also talked about changing their perspectives to arrive at a place of self-love and compassion, gaining confidence, and focusing on what they can do rather than what they can't do. One participant said, "Chronic fatigue syndrome taught me how to love myself more...I started to just accept myself and to love myself for who I was, because you're lying in bed for weeks and months out of time, and it's an opportunity to change your mindset."

Another participant stated,

> I've just had to finally - and it took many many years, decades, in fact - to finally come to the conclusion or to accept that this is who I am. This is how I am and I cant mold myself into someone else's ideal. I cant be a type A personality and run around - I just cant do that. And I don't think I want to anyway. I don't want to. I think a huge part of it is accepting one's self the way one is. I'm still struggling with that, but I've learned to accept myself a lot more while I'm working for myself, and doing my own thing.

Similarly, a third participant said, "I have regained my a lot of my confidence as a person. I tried not to think of myself as less than. And even when I was trying to work and get accommodations, I tried to think of myself as not less than, different, failure, you know all these labels we can put on ourselves." For many participants, changing their outlook to one of empowerment and positivity was a critical turning point in being able to step back into life, and ultimately become an entrepreneur.

All participants expressed that they wanted to work, in spite of many being offered the opportunity to go on disability and receive government financial support. For some, self-employment was sought out as an approach to meet their health needs while still being able to participate in the work. For a few participants, they happened to be already working in a self-employed capacity before they were diagnosed with CFS, so their work lent itself well to the diagnosis and necessary lifestyle modifications.

One participant explained, “I still wanted to be able to work, but it needed to be on my own terms.” Another said,

> Our society puts such a premium on what you do, that when you don’t have a professional identity, that is so profoundly painful, right? And it really starts to get to how you see yourself, and your self-worth, even though none of that is true. It’s really hard, so that is what this work has done, is really sort of gone along to addressing that pain.

Another participant said, “It really started as something to find meaning.” And another said, “There’s so many things you can’t do with chronic fatigue that being able to create something and see it through is really important. And entrepreneurship lets you do that.”

Many participants spoke about entrepreneurship helping them to develop confidence, strength, positivity, self-esteem, and purpose.

> It has affected my well-being in a positive way. I enjoy working and problem solving and need that avenue in my life. Because we are so highly affected with symptoms of chronic fatigue, it’s important to have something that you can focus

> your energy on and can help you see past some of the negative things correlated with it.

Another participant said, “I think I discovered how strong I was and how much perseverance I had in the course of working for myself. These are traits in my personality that I didn’t necessarily know that I had.” She later went on to say, “I really enjoy it, because it really is about your own confidence and power. And it really makes me feel a lot more self-empowered.”

Several participants spoke to a sense of fulfillment and purpose being connected with their entrepreneurial successes: “Now that I know that I have CFS, I want to keep my business because it gives me a purpose to keep fighting and grow stronger.” Another said, “I feel fulfilled doing my own thing. And that’s important for self esteem and that’s important for raising my energy level and on and on and on. And for enduring my pain.”

One participant explained,

> It’s built my confidence, and even though there can be a lot of stress when you work for yourself - I mean, I think there’s a lot of stress that comes with being an entrepreneur - but I’ve gotten better at handling challenges. And I try to look at them as opportunities, and I try to look at it as an opportunity to serve. If I look at it that way, then it kind of changes my biochemistry - does that make sense? I feel more of the u-stress versus the distress when I’m working, just because I feel connected to my purpose.

Lastly, some participants touched on the ways in which they have grown through the experience of having CFS and having adopted an alternative professional life.

> Any positive experience that I've had, or negative for that matter, it's all helped me to build that sense of confidence in terms of connecting with other people, and in terms of being a professional. I would never wish anyone to have health issues, but looking at the gift, the gift part of having a health challenge is that it helped me to develop my potential not only professionally but in terms of compassion.

Similarly, another participant said,

> I kind of found my purpose. I think that great challenges - you can wither under the weight of them, or it makes you rise to the occasion, and I think working for myself has - even though it hasn't been easy at all - it's been worth it. I was able to get to know myself better, and in that process, realize what my purpose was. I really do believe it lessens symptoms for sure when you have a positive outlook.

Another participant said, "Having to problem solve makes symptoms harder, but they also make you stronger. Like 'I'm going to figure it out, I'll get through this.'" Finally, one participant said, "It's finding a way to share some of your skills with the world. To channel your ideas or energy into something productive. And it feels so good. And I think you can appreciate it more in coming through the struggle."

Subtheme 4: Taking health and well-being into one's own hands. In talking about this transformational process of being diagnosed with CFS, having to let go of their old life, and creating a new life with meaning and purpose, nine out of 12 participants talked about needing to take their health into their own hands. They discussed stepping away from Western medicine and exploring alternative methods of healing and self-care, as well as taking up more of a preventive medicine approach in order to sustain their well-being.

One participant said, “My parents are both engineers, and holistic was not on the radar ten years ago for them...5 years later I finally found my way to a holistic MD, which has helped a lot.” Some participants discussed physical interventions that have helped them, “It’s important to take care of oneself, especially if someone has chronic fatigue all the time. I feel better after I exercise.” Another participant said,

> I found that icing my legs was very valuable to reduce that inflammation and throbbing that I was getting. So I got full leg ice packs that were Velcro that I put on my legs. And that way they are cooled down so when I go to sleep my legs aren’t just throbbing.

Some participants spoke about diet and nutrition, “I’m trying to eat better. I’m not always that good, but I’m trying to limit my sugar. I’ve gone a couple of years without not having a lot of sugar, and that helps a heck of a lot.” For another participant, her explorations in self-healing led her to self-employment, “And still I pursued trying self treatment - so I became a fitness nutrition specialist.”

A handful of participants spoke about going to therapy to help them cope with the losses and emotional aspects of CFS, “I’ve had therapy. And I’ve done a lot more meditation and things when I get home so that I can cope and to be able to calm myself down. And alright, it gets me through the waves.” She went on to say,

> We’re really trying to tap into the emotions and the body’s response to what has happened. Those losses. And then using mediation during the therapy. So the

> therapy is just not cerebral but with bodywork as well. And then I do my maintenance right now which is somatic therapy, meditation on my own and then I have medical chi gong done. And that has been very valuable.

Another participant said she has been helped by

> years and years of therapy, and psychiatric medicine - which doesn't really help the chronic fatigue, but maybe for other things. Years and years of trying alternative remedies like acupuncture, acupressure, homeopathic, exercise, meditation, yoga.

Many other participants also mentioned engaging in alternative and contemplative healing practices to defuse stress and boost physical, mental, emotional, and spiritual well-being.

> For me, I found yoga is huge because that really helps my nervous system. It doesn't really make my body go into fight or flight, it helps me stay in the parasympathetic state, but it kind of makes my nervous system stronger. And then of course eating well, like really emphasizing healthy food and sleep.

Similarly, another participant said, "Meditation is a big part of my life. I take my eating and sleeping and stress management pretty seriously." Another participant reported using the contemplative practice of chi gong to reenergize.

> I have found that when I get a little agitated or fearful because I'm running out of fuel, then I take a few moments and do some mental sit down. And I have some chi gong exercises to bring the energy back to the core and see if I can get myself through whatever I need to get through."

A third participant said, "I have a massage therapist that comes to my home every week now. And that just helps with the pain and the energy levels, but bringing in support like that helps me focus on the work."

For a second participant, her explorations in self-healing ultimately led to an avenue for self-employment in EFT, a method of activating acupressure points on the body.

> We were going through a very traumatic time in our family due to a problem with an extended family member, and so I just said, I have got to do something to help me feel better about this and get better. And so I was told about Faster EFT, which is what I became, a Faster EFT practitioner...I just saw the benefits of it for my own emotional health, my physical health.

Lastly, one participant spoke about using medical marijuana, and how this has substantially improved her overall health.

> I almost made myself start smoking pot at least once a day. I think it helps. I really do. I don't have body aches and pains that I can't live with. I don't know if I have a higher pain threshold or if that means that mine is not as bad as other peoples, but mine doesn't ache that I cant live with. My hypothesis is that I sleep better with it. I get better rest. It doesn't make the pain go away, but there's better sleep. I could be wrong about that. But I've been making myself smoke it and I think it reduces stress and I think it helps me sleep.

For many participants, taking their health into their own hands was key when it came to enhancing their well-being. As a result, they seemed to enjoy a better quality of life both personally and professionally.

Discussion Topic 2: The Experience of Being Self-Employed and Living With CFS

This section is an explanation of participant's statements focusing on their experiences of living with CFS, and working in a self-employed capacity. Participants talked about general business skills and advice, and shared about balancing their health with the needs of their business. They also spoke directly to the benefits of being self-employed as it relates to their health and well being, as well as touching upon the ways in which finding meaning and purpose through self-employment has enhanced their well-being.

Subtheme 1: Business skills, training, and advice. Five of the participants specifically talked about training or guidance they sought out as they were developing their business, and/or gave advice about how to approach self-employment, particularly for those who are living with CFS. The overarching message is summed up by this statement by one participant, "Do some homework, don't just go by your initial enthusiasm for it. Talk to other people that are in the field you want to go into, do some online research."

Several participants talked about coursework, training, and mentorship. "If you're in school still - take a business class. Or shadow an entrepreneur of the field you want to be in so that you have a general idea of what you're getting into." Another said, "I got career coaching...she was familiar with people who have physical limitations." Another participant explained that her mother was self employed, “I saw all the pros and cons to her doing it. It was nice to have a role model, so I kind of know what’s coming.”

Several participants also offered some words of caution based on lessons learned about finances. “My advice to anybody that wants to become an entrepreneur is, have money. You’re going to need - no business can make it past the first 18 months without a capital infusion.” Keeping in mind the stress and pressure that starting a business can bring, another participant said, “Find an income source that doesn’t feel stressful to you for maybe part-time, so that you’re not stressing about creating your own income in the beginning.” A third participant echoed, “Don’t do something that’s going to be a huge financial investment if you realistically can’t absorb that initial financial investment.” One participant spoke at length about the tactics she uses to prioritize, and organize her days.

> I always make sure I have a good idea of what are the most important tasks. What are my biggest goals, and most important for the day in moving my business forward? Trying to just do one thing each day that will move my business forward. Those are just tactics that I have learned along the way. It makes a huge difference in being able to be more productive and serve better because you have to use your intuition and analytics. Is what I’m putting out being received at all? You just want to build on what’s working.

Subtheme 2: Balancing business and health. Eleven out of 12 participants shared about the challenges of balancing their well-being with the needs of their business. They touched on topics such as coping with health flare-ups, and trying to build self-care into their lives as a preventive measure. Many participants also spoke at length about the sustainability of their business being dependent on their well-being, and how they try to keep these in balance.

For many participants, there were moments in which they pushed themselves too hard at work and experienced a CFS flare-up of symptoms, or as some put it, a collapse. One participant built this into her schedule, saying, “I can put in three work days - and I come home and collapse and don’t get up the next day.” Another spoke similarly about pushing through when her work demands it,

> Work comes before day to day health - not long term, but if I’m in a flare today, I’m still going to work all day today. If I’m doing poorly for weeks, I will start cutting everything else out of my life so that I can sleep as much as I can outside of work - things like that. But work still trumps the desire to rest.”

One participant has learned to mitigate this to some degree, “I still overdo it on a regular basis but I would say it’s within a narrower band, so the consequences or reaction to that isn’t as extreme.”

Another participant explained,

> I do know that if there’s going to be a really intense or stressful time, that it’s going to be followed at some point with a very severe flare up. And the flare-up will probably take much longer to get over then a normal five to seven day flare-up. So, you know, trying to learn some of the strategies to know how to down the stress becomes important. But a lot of times you just go, I know it’s going to

> cause me a really horrific flare-up, but it’s worth doing - whatever that particular thing is.

She later went on to explain that she sees this as a worthwhile sacrifice in order to be able to engage in work that is meaningful.

Participants also spoke at length about doing their best to maintain a balance between the needs of their business, and their own health needs. The underpinning philosophy seemed to be that their well-being is what makes their business possible, and thus they have to hold all of these factors in the balance and keep sustainability in mind. In terms of recognizing limitations, one participant said, “You are wearing so many hats. And that is - there’s structural tension there, I’ll say, against the energy limitations.” As another participant pointed out, “We’re a little bit different than the average entrepreneur who can maybe pull an all nighter when they need to.” Another participant talked about honoring her own rhythms. “ It’s just part of the rhythm of having this illness. I think ideally we try to minimize the ups and downs so that the crashes aren’t so bad, but sometimes if you go up a little bit, you’re going to go down a little bit. And eventually it evens out again.”

Regarding pacing, one participant said, “If you can have an idea, think about what part of it you can do right now, and what part of it you can do tomorrow, and what part the next day. And if you only make 5 minutes of progress today, that’s fine, that’s better than zero.” Another participant referred to monitoring periods of work and rest, “I set a timer. And I work for an hour, then I rest for an hour. Otherwise I’m just too much of an A type personality that I just keep going and I wear myself out.”

Other participants talked about the importance of simply knowing when to stop: "For me its been helpful to identify that I'm really fatigued and I just have to give it up. I can't try to push through it and I don't. I just don't anymore." Another participant said, "I don't need more money, I need more sleep. So there's that sense of, there's always more that I can do. And it really learning and trying to figure it out. And sometimes working is good for my health, and sometimes its really not." Essentially, the final conclusion for participants was captured by one who said, "You have to make certain sacrifices that aren't the best for your business or your career in order to keep the whole thing sustainable."

Participants also talked about engaging in self-care and preventive health measures, in order to maintain a solid foundation of overall well-being that would enable them to thrive at work. One participant recommending feeling strong in this even before entering into entrepreneurship,

> Do something to make yourself stronger emotionally first, and physically. Take care of yourself first. Get yourself into a good place…you're going to have some tired times and some times of feeling frustrated. So have something you can turn to…get a little support system going for yourself before you jump in.

Another participant said, "I'm a big believer on working hard but also resting hard, so you have to build in just as much downtime and uptime, if not more. At least that's what I need to stay in balance." She continued,

> There are ways to reboot during the day. It doesn't mean that your challenges necessarily go away, but I find ways to create energy throughout the day. But

> there are some days that are better than others…I'm always having to buffer with self-care. The more self-care I do, the more I'm able to stay in balance."

Lastly, two participants talked about getting to the place in their career at which they were able to afford help in various capacities. "The great thing about bringing in money is that you can start to outsource energy intensive jobs." Another participant explained, "I only work when there's an assistant and others to help out. There's too much to do, to do it alone. I can't cover everything on my own. That's the biggest challenge, is trying to do things on your own. We don't have the energy for it." It is evident that participants have come up with many creative strategies to keep their health and professional life in balance, and feel well-equipped to cope with challenges as they arise.

Subtheme 3: Benefits of self-employment specific to individuals with CFS. In this section, participants spoke about the benefits they experience from being self-employed, specifically in regards to their CFS symptoms. Eleven out of 12 participants expressed that they experienced benefits in connection with working as an entrepreneur that supported their health and well-being given their CFS diagnosis and symptoms. They talked about the perks of having a flexible schedule, being able to work from home, being able to build in breaks, and engage in self-care throughout the day as needed.

One participant talking about having control over all elements of her work life, in a broader sense,

> I think it gives you some benefit with giving you some control over your life better, which you have to do when you have this…you have to be able to have

> that back up plan or that outlet. So it gives you that flexibility to allow your body to - for you to not have to continually push through, because that just is a vicious cycle.

Several participants specifically cited having a flexible schedule as a key benefit, and in fact a necessity in many cases: “The flexibility that’s in my situation is the only reason all of this has worked.” Another explained, “The goal was to have flexibility over my schedule - that was built into it. So that’s the beautiful part about working for yourself, is that you can call the shots, at least for the most part.” A third participant said, “I can take off whenever I want to. I don’t have to answer to anybody...if I’m too sick to come to work, I’m too sick to come to work. I don’t have to worry about if I don’t have enough leave to take.”

Other participants expressed that it has been a huge help to be able to work from home, and not have to go into an office.

> It’s much better for my health I would say. Just not having to physically go anywhere in order to accomplish my goals for the day is really helpful. I can’t deny the fact that having the ability to roll out of bed and not necessarily get dressed sand start my day, is a lot better than having to commute somewhere, go into a building and sit in an uncomfortable chair, walk around, carry a backpack, on someone else’s schedule.”

Another said,

> I found the things I wanted to do in terms of writing and teaching online, and finding ways to make them work so I can still be wearing my pajamas. And so

> that I had a safety net. So that if I couldn't be going out and seeing clients because I feeling too poorly, I still had ongoing, incoming income.

In connection with this, some of the participants talked about the importance of being able to rest throughout the day. One spoke of "setting up a home office where I can lie down all day…I don't sit at my desk, I'm actually half sitting right now reclined on this couch-type thing." Others talked about the importance of being able to say no to work opportunities. "Because you can say no, it allows you to determine how much work you are going to do. And you can't always do that in a structured role." Lastly, some participants also touched on the sense of relief that they have control over making overall choices about their business and work life. "There's the independence and the sense of calling the shots yourself, which is very rewarding."

Subtheme 4: Fulfillment through work. In this last subtheme, 10 out of 12 participants said that their CFS symptoms and well-being have improved as a result of being able to participate in the work force in a way that suits their health needs. They spoke about finding fulfillment, meaning, and passion, as well as doing what you love, and helping others.

Participants spoke about the importance of being a productive member of society and feeling that they are participating in the world. "Even though I'm not as successful as I hoped to be at this time, even a little bit of success can bring back that normalcy that I'm used to. Because I used to feel like a productive, earning member of society for a number of years." Another said, "Even though I'm not as successful as I hoped to be at this time, even a little bit of success can bring back that normalcy that I'm used to.

Because I used to feel like a productive, earning member of society for a number of years." A third participant said, "The inherent sense of accomplishment does help. Some days it's enough to muscle through a little bit. But overall, it has been rewarding to be building things with you own hands. There's a sense of accomplishment…I did it my myself, so that's been rewarding."

Similarly, many participants talked about garnering a sense of existential fulfillment or satisfaction through their work. "I love working. I've always felt that I get meaning, purpose, and fulfillment out of my career." Another participant said, "I've done something with my life, and given back to some people, and helped animals and that's rewarding…its all about finding something that can give you that sense of meaning in your life." Speaking to her health, another said, "Honestly I think having a purpose can help you override some physical problems."

Other participants also stated that their health and well-being actually improved due to being able to work. "My mental health and emotional health are better because of it. It's just not good to be lying around doing nothing. Even if you need to rest a lot, it's good to have some activity that has some direction to it. And for me that's helped me to feel better." Others said, "I'm sure a lot happier now mood-wise than I was at my prior job," and, "Anytime I've been able to do my own business…that is completely healing in itself." Lastly, one participant reflected, "My physical self isn't very different. But my mental and emotional health, I feel like I have more value. I feel like I have ownership in something. It's also so pleasurable to do something you're passionate about."

Some participants found fulfillment in being able to help others. “I want to be able to help people. It’s important that when people are struggling with something - this goes for anything really - if you know something, why not help them.” Another explained that the focus of her business is helping others,

> My goal is to help people, not to get money out of people. That’s never been my goal. So it’s a huge difference. I realize that it is tied in with the bigger purpose for me, and in helping people improve their well-being and to be able to do that on my own terms.

Lastly, some participants talked about following their passion, and encouraged others to do the same when pursuing self-employment. “Spend a lot of time doing what you love. Because you don’t have a lot of time when you have CFS.” A second participant said, “Do what you love, no matter what, and eventually it will probably come together as far as making a living and so forth. But do what you want to do, not what everyone else wants you to do or expects you to do.”

This section offered an in-depth exploration into the work lives of individuals with CFS - how they understand and conceptualize their work; how they keep it balanced and sustainable; how they benefit from being self-employed; and how their well-being is, in many cases, enhanced by their work.

Discussion Topic 3: Interpersonal Factors

Although it was not an outright focus of the study, the participants spoke frequently about interpersonal factors that are intertwined with their professional life and well-being. This discussion topic arose organically from the narratives of the participants as a highly influential element in their lives. Specifically, they discussed the impact of both supportive and unsupportive relationships with friends and family and the impact of these relationships on their life and work. Some participants also expressed feeling misunderstood by the greater culture due to their illness, and sometimes isolated and lonely as a result of this, which was also intertwined with their lives and careers. Lastly, several participants touched on their decision to either be secretive about their illness in a professional setting, or to be “out” as someone living with CFS, and how this has affected their work life.

Subtheme 1: Supportive and unsupportive interpersonal relationships. All 12 participants brought up interpersonal relationships in their interviews. They discussed the impacts of both the supportive and unsupportive relationships in their lives, and how these relationships affect their business as well as their health and wellness. They touched upon the support they receive from partners, friends, family, professionals, and various wider communities such as religious organizations and online communities. They also spoke about challenges with partners and family members, setting healthy interpersonal boundaries, and in some cases, the need for more relational or community support.

Several participants said that the financial, logistical, and/or emotional support of their partner was immeasurably helpful. “My husband has been the key support for everything in my life…for communication and moral support.” Another participant said, “I’m also dating someone and that has been huge on the emotional support side. He’s also able bodied, so that’s really nice. I’ve recently had a bad spell where I couldn’t drive for 6 weeks and so he would just come and pick me up, no problem.”

Another participant explained that being in a partnership with her husband takes off a lot of the financial pressure, allowing her to feel less pressured in her work,

> The primary support I have is that I’m not dependent on it for an income. It’s just a hobby. My husband works full time and I’m on social security. So I had the freedom to try it, even if it wouldn’t work out because I wasn’t depending on it for a household budget.

Several participants spoke similarly about support from friends and family, saying that this support has been critical in enabling them to thrive in their business,

> My family has been very supportive of me since the early days...I know a lot of patients don’t have that and so I’m always extremely grateful for it because it has been a long 10 years. But they’re still there and helping with whatever I need.

Other participants expressed that they felt it was important to seek professional help such as therapists, so as not to overburden their friends and family, “Friends you can only lean on five or six times, and then you don’t want to overuse this. And professionals, that’s their job.” Another participant said, “I’m glad that I have people dedicated to my condition, so when I really need professional services, I’ll go to them - instead of expecting my family to be that lifeline, which just stresses me more because that’s not their job.” One participant also cited her pet as a critical source of support: “I have a dog which really helps. She keeps me company. I’m not very good with people because I’m not around people very often. So at least I have my dog.”

Participants also shared about support they receive from wider communities such as healing communities, religious organizations, and in-person support groups. “The faster EFT community is one support...To help each other, we’ll do sessions with each other, on Skype… that’s very very helpful. I would say that’s the greatest help.” Another participant said, “We joined the church about four to five years ago. And we hadn’t previously been going to church for long stretches of time before that. And that church community helps me…a religious community can be very helpful for a lot of people.”

Participants also discussed the relational challenges that have arisen in connection with their illness.

> My husband has gotten to where he kind of accepts it, which was not true in the beginning. In the beginning, it was a great burden on him...if I talk about my symptoms too much, I’m not thinking of it as a complaint, I’m thinking of it as just a commentary of where I am. And sometimes that wears thin on him.

Another participant explained that her routine and relationship dynamics changed when her partner retired.

> My husband retired, and my lifestyle changed…he’s a good talker, but not a good communicator and he’s not a good cooperator. So that has really impacted my life. We just don’t want the same things in the morning. We are not in sync in the morning.

Some participants dealt with challenging family dynamics. “Friends and family are kind of tricky with this. I find that it’s sort of ok when they are not under a lot of stress. But if they are under a lot of stress and are expecting you to do certain things, then you have problems.” Another participant said, “My family, as far as moral support, they don’t really give me that. They might toss some money my way, but I don’t even need that as much as I need the emotional and moral support because I don’t get that.” Another participant explained that she intentionally lived apart from her family, “No family up here. And there’s a reason for that - my family is extremely stressful. I’m much better being away from them.”

In connection with this, some participants touched upon the importance of being able to set healthy interpersonal boundaries in order to keep themselves in balance and maintain their wellness.

> I think if you have chronic fatigue, you have to learn your boundaries. And that can be really hard. If you’re not used to telling people no, you have to do it. Learning to find that voice to say no is hard because they try to guilt trip you into doing things.

Another participant said, “There’s so many things you cannot do. You have to tell your family ‘No, sorry, I can’t come to Thanksgiving this year.’”

Several participants expressed a need for more support, particularly wider community, or a support network or group specifically for people with CFS. Some participants expressed that they did not feel that the online CFS communities are helpful due to the negative rhetoric in these groups. “Do I need more support? Yes - I think we all do. I think we all need more than we think we do. But it’s getting better. I think general community would be more helpful.” Another participant said, “Everything that I’ve seen online gets out of hand on the negative side, and I’m not good with negativity, and I don’t want to be a part of it.” Another participant expressed, “I frankly could use more support...I would love for there to be a CFS support group that I could go to.”

This subtheme illuminated the influential role interpersonal relationships of all kinds have on the well-being of individuals with CFS who are self-employed. In order for participants to thrive health-wise and in their work, it seems critical to have emotional and logistical support - and financial support is extremely helpful as well. As participants described, the absence of this support makes their lives far more challenging.

Subtheme 2: Feeling lonely, isolated, or misunderstood by others as a result of having CFS. Six of the 12 participants offered that having chronic fatigue syndrome has led them to feel excluded from society to some degree, due to the debilitating symptoms of the illness itself, or due to CFS remaining largely misunderstood and even denied by some of the medical community as well as the wider culture. For example, one participant who was diagnosed several decades ago said, “I mean nowadays it’s a lot better than it was back in the eighties and nineties. Because back then when I said I had chronic fatigue, they would say, ‘Oh that doesn’t exist. Oh come on. That a yuppie disease?”

Several participants expressed feelings of isolation in connection with living with CFS, using words such as “invisible” and “lonely” to describe their experiences. One participant said, “You feel so isolated. You know there’s hardly anyone you can rely on, and so that kind of distorts your image of people.” For another, the drastic change in lifestyle was difficult to adjust to because she identified as an extravert, “And the loneliness that comes with being chronically ill. I’m a strong extravert but I feel like I don’t have any friends because they’re all active.” One participant tried to bring more interpersonal interaction into her work, to feel less isolated, “It’s helpful to have video chats with people, it’s helpful to meet people in person whenever you can...you don’t want to be sitting in your home or office all day working, its really unhealthy. For a while there, it was getting too isolated”.

Other participants expressed that many people often seem to misunderstand chronic fatigue syndrome, and as a result can be unsympathetic to those living with the illness. Participants reported that as a result of this, at times they don’t feel known or seen by others. “You basically don’t feel known by very many people. Because even the people like your family - all they want is for you to be better. They want you to be back to where you were…what they are looking for is progress, and you’re not feeling progress.” Another participant perceived, “They feel like I’m still just wanting attention and making a lot of stuff up just so that I can get out of working.”

Subtheme 3: Being open about living with CFS, or choosing to conceal the illness. Lastly, five out of 12 participants brought up whether they have chosen to be open in professional settings about the fact that they are diagnosed with CFS, or to attempt to conceal their illness. They discussed how this decision has affected their work life. Those who seemed to think it was more appropriate for them to conceal their illness spoke about feeling that they are leading a “double life,” but believe this is necessary in order to be successful in their work.

In terms of being open about her CFS, one client said, “I was just really clear that my limitations had to be front and center, at least in my mind. And I needed to find a way to communicate that professionally at the onset in order to manage expectations.” She went on to say, “What’s key about that is having the abilities, if you’re working with other people even in a small group, to at least talk about what's going on and say, 'Today's a really bad day.'"

Other clients expressed that it was important to conceal their chronic fatigue syndrome from their coworkers and/or clients. One client, speaking about coping with CFS symptoms at work, said,

> I would run out and tell the group I'd be right back, and have to go to the bathroom to throw up, and go back in and continue to teach. But I would tell them it was food poisoning. I certainly wouldn't tell them it was a strange unknown disease."

Another participant said, "It's best not to talk about it because it will kill my practice." One participant summed up her situation by saying, "I had to create an outer shell that looked normal, because people don't hire sick people. They want to hire people that are energetic and that are on their game."

Similarly, another participant explained that being able to work remotely was critical in being able to conceal her illness with little effort,

> On the bad days I could just sit there quietly and get my work done without having to put on a show, without expectation, and your face needing to look like you're not dying when you're around other people. And in my room I can look miserable and not be put together, and just focus on getting the work done.

Lastly, one participant articulated the struggles echoed by others, of struggling with the difficulties of hiding CFS, but feeling that it was worth it in order to be able to work, "I did not want to become an invalid…from my perspective, my life had already changed enough. I wasn't going to totally throw in the towel. So if that requires creating a secret life, and an external life, then well that's the way it goes. But it is hard."

This section illuminated the great degree to which interpersonal factors such as supportive and unsupportive relationships, feeling lonely or misunderstood, and the decision whether or not to conceal one's illness are intimately intertwined with the experience of living and working with CFS. It seemed that it was important for participants to share about this area, given that, to a large degree, these interpersonal factors strongly influenced the success of individuals' efforts to engage in self-employment.

Evidence of Trustworthiness

To ensure that the data collection process adhered to the ethical considerations set forth by Walden University, I collected the data according to the procedures outlined in my proposal that was approved by the IRB (Approval Number XX-XX-XX-XXXXXXX). Utilizing an interpretive descriptive research design approach to the research, as deemed appropriate for qualitative inquiry, I verified the trustworthiness of my study by taking steps to increase its credibility, transferability, dependability, and confirmability.

Credibility

The study was designed to ensure that the methods used for data collection and analysis were as solid as possible. Each participant was allotted the same amount of time in order to share their beliefs, perceptions, and experiences without interruption. Each interview was recorded and transcribed. I went through this process three times to confirm the accuracy of each transcript, and to validate the transcribed information. I implemented multiple sources of data analysis to provide triangulation of the analysis, which lead the findings to be more credible. Allowing for the second reader to assess the efficacy of the codes and themes accomplished this objective. This element of the analysis adds more validity to the coding approach.

Transferability

The study's transferability was established in different ways. I spent considerable time and effort in collecting each participant's experiences in regard to living with CFS and being self-employed. In-depth descriptions of the research design, data collection, and results were provided to serve to increase readers' understanding of the study for those interested in applying the research findings to other contexts, settings, or groups of their own volition.

Due to the fact that this study's topic has been so sparsely explored, the purpose of this research project was to serve as a pilot study that will deeply explore the experiences of individuals living with CFS and working as entrepreneurs. This research will hopefully provide a platform for additional research, either qualitative or quantitative, that will continue to seek to understand the lived experiences of individuals diagnosed with CFS, and what avenues might allow them to participate in the workforce, achieve financial stability, and experience enhanced QOL.

Dependability

I increased the dependability of this study by using audit trails. Interview questions were consistent. Audio records, transcriptions, and written notes were included.

The transcripts produced from the audio recordings showcased the participants' responses word for word. My written notes included coding of the participants' responses, and transcription into themes and trends for further synthesis and interpretation. The second reader served to determine that the analysis and interpretation, as well as the findings and results, were reported thoroughly and accurately. The dissertation committee members ensured that I made no errors in conceptualizing and designing the study. I attempted to be as transparent as possible in explaining how and why each element of the study was designed as it was.

Confirmability

Evidence of confirmability in this study was demonstrated by documentation of the entire research process. The audio and documents were stored in a secure, password protected folder on my desktop computer should they be needed in the future. Moreover, I upheld neutrality when analyzing and interpreting the raw data collected. I interpreted the qualitative research findings based on the theoretical framework of this research study. The study was designed to ensure that I and would first become clear about assumptions and biases before conducting the data collection - this step lends considerable confirmability to the research.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this chapter is to interpret the findings presented in Chapter 4 about the lived experiences of individuals with CFS who are working or have attempted to work as entrepreneurs. The qualitative approach was used to explore the challenges and setbacks faced by participants, as well as factors that have brought about success and improved QOL. This chapter contains discussion of findings, conclusions, and recommendations for future research based on the data that emerged from this study. It is divided into five major sections: interpretation of the findings, limitations of the study, recommendations, implications for social change, and conclusion.

Although the literature on QOL among entrepreneurs living with chronic illness was extensive (Kawabe et al., 2015; Reilly et al., 2012; Sirgy et al., 2012; Yamamoto et al., 2011), there was limited research on QOL dimensions among entrepreneurs living with CFS. CFS is a unique illness that affects several different systems of the body, and it differs from other chronic illnesses. This study and findings were designed to address this gap in research and to shed light on the experience of living with CFS and working as an entrepreneur. Additionally, this study built upon prior research on the relationship between QOL and CFS by exploring this phenomenon in the self-employment sector. I also established a foundation for future research.

Using an interpretive, descriptive, phenomenological method, the essential experience of living and working as an entrepreneur with CFS is presented within an existential psychology perspective. A meaning-centered approach includes the recognition of the correlation of meaning with job satisfaction and productivity (Pryce-Jones, 2010; Wong, 2011). Connecting oneself to a greater purpose decreases negative thoughts, symptoms, and stressors associated with CFS, overall enhancing QOL within this population.

Interpretations of the Findings

Interviews conducted with 12 self-employed women provided an understanding of how CFS symptoms impacted their lives; the factors that led them to pursue entrepreneurship; and the challenges, coping practices, support systems, and rewards they experienced along the way. Although there were differences in their individual experiences and backgrounds, three major themes emerged from the analysis of the data. The themes identified were (a) personal transformation as a result of having CFS, (b) the lived experience of being self-employed with CFS, and (c) interpersonal factors that organically arose in participants' stories. Eleven subthemes emerged, dispersed across the three overarching themes.

Research Question 1

The first research question of the study was the following: How do participants with CFS describe their QOL/overall well-being when working in an entrepreneurial or self-employed capacity? This research question was addressed by participants in several of the subthemes. Essentially, participants reported that being self-employed affected their QOL and overall wellbeing both positively and negatively in different ways.

In Subtheme 2.2, I summarized the ways in which participants described having to balance the needs of their business with their personal wellbeing and heath needs. In this regard, being self-employed brought about some challenges that participants spoke about having to deal with. Starting and running any sort of entrepreneurial pursuit involves responsibility, and it is often accompanied by many stressors. Participants expressed that initially it was difficult to balance the demands of their work and their health, and in some cases, still remained difficult.

In this subtheme, some participants discussed having CFS flare-ups or health crises associated with overworking. The symptoms of CFS are exacerbated by stress. CFS is, in part, an illness of the nervous system; stress is the ultimate kryptonite, so to speak, for individuals living with this illness. Fatigue is caused not only by physically taxing activities, but mentally demanding tasks as well. One participant spoke about how frustrating it is that even if she is working on her laptop in a reclined position, her work still contributes to her fatigue due to the mental exertion, and it chips away at her energy level during the day.

Several participants spoke about occasions in which they pushed themselves too hard at work, and the result was a CFS flare-up that required recovery time. Some participants talked about getting to know their limits better and realizing when to stop; whereas, others said that they sometimes made the decision to push through their limits and accept that their health would suffer; but, dealing with a flare-up was worth it for the business benefit of having pushed through.

Participants talked about needing to build self-care into their business model. For many, this meant working from home and being able to take breaks as necessary. Several participants explained that it helped to not to have to be “on” - meaning they did not need to get dressed up for work and pretend to be energetic in the company of coworkers. Working from home allows for physical accommodations, such as wearing comfortable clothes and working in a relaxed position.

Participants were aware that the long-term sustainability of their business was dependent on their health. The participants kept this in mind when making business decisions, and they had to weigh the costs and benefits of taking on more at work both daily as well as on a long-term basis. Many of the participants had grown versed in weighing self-care and preventive health actions with pushing themselves or making personal health sacrifices in the name of growing their business.

In Subtheme 2.4, I touched on the other side of being self-employed while living with CFS. Being self-employed and being able to participate in the workforce as a contributing member to society brings fulfillment. For participants in this study, the plusses of being self-employed with CFS outweighed the minuses, because they were choosing to continue to work when they had the option of being on disability. In this subtheme, participants explained that despite the challenges of being self-employed with CFS, the experience of being able to work improves their QOL enough to make the pursuit worthwhile.

Ten out of 12 participants reported that generally speaking, their CFS symptoms and overall wellbeing and QOL improved as a result of being self-employed. The statements that participants made in this section had existential undertones. They talked about the importance of having some semblance of normalcy and routine in life, saying it did not feel good to be lying around doing nothing. Some participants found that they were happier when they were engaged in work, and their mental and emotional health improved as compared with when they had paused work due to CFS.

Participants reflected about the importance of being a productive member of society and participating in the world. They said this gave them a sense of accomplishment. Using terms frequently heard in the areas of existential philosophy and psychology, the participants talked about garnering a sense of fulfillment, meaning, purpose, value, and satisfaction from being able to continue participating in the workforce on their own terms. Some participants were engaged in work that involved doing what they loved, and/or helping others, and spoke about how rewarding this has felt.

Lastly, in Subtheme 3.1, I illuminated the influence of interpersonal support on the wellbeing and QOL among individuals living with CFS and working as entrepreneurs. Greater levels of support enhanced QOL for participants, while lack of support made it all the more difficult to run a business while living with CFS. Whether or not participants felt supported by partner, family, friends, and/or community was an additional factor in the balance when it came to assessing how being self-employed affected the wellbeing and QOL of participants.

All 12 participants talked about interpersonal relationships, whether these relationships were supportive or unsupportive. Living with CFS is difficult and hindering, and it is made easier with some degree of outside help whether it is emotional, financial, or logistical. Out of all participants, only one participant was essentially “doing it on her own” without a partner or family nearby. The participants stated that the help and support they received from others benefited their QOL and wellbeing, as well as their ability to run their business smoothly.

Participants noted various kinds of interpersonal support: emotional support, financial support from their families or partners, and logistical support such as picking up groceries. Some participants also talked about paying professionals such as therapists or healers for support. Support in any of these areas helped to ease the burden of living with CFS, simply by taking some things off participants' plates, or giving them an outlet to vent about the struggles they were dealing with. Some participants expressed that they felt it was important to work with professionals, so as not to overburden partners, family, or friends.

Several participants expressed that it was the financial support of their partner that made it possible for them to be self-employed in a manner that was well-balanced with maintaining their health and quality of life. Without the stability of their partner's income, they would be under a lot more pressure to work harder to make more profit, or perhaps would have less flexibility when it comes to doing what they love.

Many participants expressed that they would benefit from participating in some sort of CFS support group, but a local group did not exist. Several participants reported that they had participated in some CFS forums or support groups online, but found that the discourse was negative, and this was unhelpful in terms of feeling better and uplifted by the group. Some participants had local communities such as church groups that offered them support.

For individuals without many supportive relationships, this lack contributed a certain pressure to their work and QOL, due to essentially having to keep themselves afloat and not having a security net. It seemed that in many senses, these participants had to be even more vigilant about their self-care practices, and keeping their health and work in balance. They seemed to acutely feel the absence of interpersonal support. One participant explained, they can only count on friends to show up and help so many times. Another participant talked about her family's hope and expectation that she would improve or get better, and it was difficult for her to have to keep affirming to them that this was essentially her ongoing state of functioning due to having a chronic illness.

Some participants had challenging relationships with their partner or family, and the stress of this simply made life more difficult, and factored into the balance of work and self-care/well-being. Participants spoke about the importance of having good boundaries particularly when it comes to challenging relationships - being able to say no to family when necessary, and insisting that health must come before family obligations even when faced with pressure.

This section explored the way in which participants' QOL was impacted by living with CFS and working as an entrepreneur. Overall, being self-employed has enhanced the quality of life of participants in this study. They choose to continue working in spite of the challenges that come with self-employment because they experience a sense of purpose and fulfillment from participating in the world and being engaged in the workforce. These factors contribute greatly to quietly of life. Lastly, participants reported that interpersonal relationships, depending on whether they are supportive or unsupportive, strongly influence the ease with which they can engage in work as well as maintain their health and quality of life.

Research Question 2

The second research question of this study was: What challenges do participants with Chronic Fatigue Syndrome experience when working in an entrepreneurial or self-employed capacity? Some of the challenges were touched upon in the prior section, specifically lack of interpersonal support in the cases of some participants, and the challenges of balancing the demands of work with one's health. Another challenge that arose from participant responses was the decision whether to be professionally open about having CFS, or feeling that hiding the illness was important for professional success. Some participants expressed that they wish they could have had more business skills training or mentorship, and that lacking in these skills posed some challenges.

In regard to professional decorum, some participants expressed that they felt it was important that they conceal their illness from their clients and/or coworkers. They held the belief that being open about their illness would negatively impact their business, and thus made various types of efforts to conceal their CFS, which posed some challenges and brought about some limitations.

These participants expressed that they sometimes felt they were leading a double life, and this was challenging in many ways, but necessary for their success. For those who had to interact with clients or coworkers, they explained that they essentially had to create an "outer shell" to appear to be a healthy and fully functional person. They inferred that this took a certain amount of energy to uphold, which contributed to their fatigue. Some participants expressed that their colleagues and/or clients expected them to be energetic and on their “A game,” which they had to work hard to muster up particularly during difficult days or flare-ups.

Some participants expressed that they anticipated the challenge of having to “put on a show,” and built their business around maintaining the ability to work remotely. Among participants for which this was not possible, they expressed that being able to continue working was well worth the effort and energy expenditure of having to conceal their illness.

Another challenge expressed by many participants was the lack of business skills training they had prior to becoming self-employed. Nearly every participant expressed that they hadn’t planned or expected to be an entrepreneur. Being self-employed was the product of having sought a work solution that would accommodate CFS. Several participants explained that their lack of business training or experience posed many challenges as they were growing their business. They said that they wished they had taken some business classes, or had some training or mentorship prior to having started their business. Without this experience, they essentially had to cope with the challenge of figuring things out as they went along during the process of developing their business. One participant reported that she had hired a career coach to help her navigate these challenges, and several participants gave the advice to others to take business and finance classes and/or seek mentorship if possible. It is widely accepted that starting a business is very challenging, and participants expressed that it’s helpful to mitigate this particular challenge as much as possible so as not to exacerbate the symptoms of CFS.

The section addressing Research Question 1 above discusses how participants’ quality of life was affected by the degree and quality of interpersonal support they had. For those who lacked support or who had difficult relationships with others in their lives such as family members, this posed a challenge that significantly impacted their ability to be successful in their work, and in balancing the demands of their work with their health.

Some participants expressed that there were challenges or pressures in their relationships with their significant other and/or family, such as people wanting them to participate in family events more than they were able to given their limited energy. They explained that keeping a business afloat while tending to their health already felt like a lot on their plate, without the added pressures of family demands.

Several clients expressed that they feel a need for more emotional and moral support, and more community. Some said that they had connected with other individuals with CFS via online communities, but found that these spaces tend to focus on the negative, which did not feel helpful. Some reported that they had sought professional help and/or community by working with therapists or other kinds of healers, and/or being involved in a religious community.

A few participants who did not have a significant other reported that it was challenging to be without the support of a partner, and also to feel the burden of being completely responsible for one's own financial security and not having someone to lean on in this manner. This seemed to add to the pressure of needing to be successful at work.

In contrast, participants who did have an abundance of financial, logistical, and/or emotional support reported that this alleviated many of the challenges of being self-employed and living with CFS, as it gave them a sense of stability and security and also allowed them to take some things off their plate and be more able to focus solely on their health and work.

The prior section on Research Question 1 also explored the way in which participants' ability to balance health and work affected their quality of life. Similarly, there were aspects of maintaining this balance that were challenging for participants. They discussed moments at which they were forced to make a decision between health and work, in which they had to push ahead at work and suffer the health consequences, or prioritize health and make some sacrifices in terms of growing their business or keeping clients happy.

Participants expressed that holding the balance between maintaining their health and being successful in their work is an ongoing challenge that they must constantly reevaluate on a daily or sometimes even hourly basis. They are aware that the long-term sustainability of their business is dependent on their health, and are constantly weighing the costs and benefits of prioritizing work over health or vice versa.

Some participants talked about moments during which they pushed themselves too hard at work, either intentionally or unconsciously, and it resulted in a CFS flare-up which required a recovery period. Others were more cognizant about pulling back at work and focusing on their well-being when their symptoms seemed to be escalating. Nearly all clients talked about the importance of building in self-care practices, but explained that this can be a challenge to balance as well.

This section illuminated and unpacked the challenges reported by participants when it comes to living with CFS and working as an entrepreneur. Some participants felt the need to hide their illness and appear to be fully healthy and functional, which posed a challenge due to being draining at times. Participants also brought up the challenges of jumping into self-employment without business training or prior experience, which added a certain degree of pressure on top of trying to start a business and manage CFS symptoms. For participants who lacked interpersonal support and/or had challenging interpersonal relationships, the added stress of this challenged their ability to be successful in balancing self-employment and CFS care. Having to make ongoing decisions about whether to prioritize work or health moment by moment was a challenge expressed by nearly all participants.

Research Question 3

The final research question posed by the study was: How do individuals with Chronic Fatigue Syndrome who are working or have attempted to work in an entrepreneurial or self-employed capacity describe, comprehend, and interpret changes in their quality of life? This question was addressed in several of the subthemes in Chapter 4. Firstly, many participants reported that due to having CFS, they often felt misunderstood, lonely, and isolated. They expressed that being limited in mobility and stamina, and living with a chronic illness that is poorly understood led them to feel this way. To them, it was a notable change in their QOL.

Another major change in QOL experienced by participants was captured in the first theme, which explored an essential death and rebirth that participants experienced. This was a process of accepting the fact that their lives would no longer be the same, and in many cases would not be the lives they had dreamed of for themselves. Upon accepting their limitations, they were able to envision a new life, in which self-employment was a foundational element. This process of deep transformation greatly impacted their quality of life, as many of them seemed to travel across a trajectory from feeling hopelessness and despair to feeling empowered and re-inspired.

Six out of 12 participants brought up feeling lonely, isolated, and misunderstood as a result of having CFS. Participants talked about the skepticism they are faced with from members of general public and even the medical community at times, who can be doubting and callous in spite of CFS being a valid and painful chronic illness. Some participants said they had been accused of making up their symptoms for the sake of getting attention, or in order to get out of work. Some said that while others believed them and had a more accurate understanding of the illness, family and friends still pressured them to get better, and expected to see symptoms improving. Participants explained that it feels isolating when others are looking for progress, because it illuminates the degree to which loved ones misunderstand the illness and the individual. Some said that these interactions have caused them to feel that people are generally unsympathetic.

Several participants also said that they felt excluded from society due to their symptoms and inability to participate in life as they had previously known it. One participant who identified as an extreme extravert explained that it was very difficult to adjust to a lifestyle of being homebound and having a very minimal social life. Other participants echoed this, saying that they were isolated as a result of the debilitating symptoms, and felt lonely and even invisible. It was clear by participant reports that the feeling of being isolated and misunderstood was a significant change that negatively impacted their QOL.

The entire arc of the first theme sheds further light on the ways in which participants interpret changes in their quality of life as a result of having CFS. In this theme participants talk about the experience of getting CFS and coming to accept the diagnosis, letting go of the prior plans they had for their life, and ultimately finding ways to bring meaning and purpose into their lives, in many cases specifically via self-employment. Lastly, they talked about taking their health into their own hands when Western medicine was not able to meet their needs. Then narratives folded into each subtheme convey the viewpoints from which participants describe and interpret changes in their quality of life as a result of living with CFS and being self-employed.

In the first subtheme, participants discuss the early period of coming down with the symptoms of CFS, and feeling confused about what was going on. Many of them spoke about having negative experiences with medical professionals who misdiagnosed them or even denied their illness altogether, which was upsetting and frustrating. Participants talked about being in denial of the fact that they could have a debilitating chronic illness, and trying to get well. It is clear that during this period, participants felt that their QOL was severely diminished as they struggled to find answers about their health crisis.

The next subtheme explored the following phase, in which participants were forced to begin to let go of their old life, including professional life, as well as let go of many of the dreams and hopes they had for their futures. Participants reflected that this was a drastic turning point in which they had to let go of many aspects of their identity. During this time it was important to fully grieve these losses, in order to be able to accept the “new normal.” Fully feeling this grief and coming to a place of acceptance seemed to be critical in transforming their perspective to interpret their quality of life differently. Rather than focusing on what was lost, they were able to open to the idea of, as one participant said, “doing the best with what I have now.”

In the third subtheme, participants talked about growing through the challenges of CFS and taking the initiative to bring newfound meaning and purpose into their lives in a way that would honor their limitations. It is at this point in the arc of transformation that it seems participants stepped into a more active stance, and their own interpretation of their quality of life was transformed from one of loss and lack to one of re-empowerment. They talked about changing their thinking to be more positive, focusing on the things they can do rather than the things they cant, and rising up to the challenge of living well with CFS. For many participants, creating a business was their answer to the need to recreate meaning in their lives in a manner that would be compatible with their CFS. They expressed that this pivotal moment helped them to experience more self-love and compassion, as well as to feel more strong, confident, purposeful, and fulfilled.

In the last subtheme, participants spoke about the ways in which they improved their quality of life by taking their healing into their own hands. Where Western medicine was unable to provide them with answers and cures, they turned to alternative healing methods and preventive or symptom reduction measures. Some participants benefitted from holistic medicine, or changes in dietary, nutrition, and exercise habits. Other clients mentioned going to therapy for support with processing grief and fully experiencing emotions. Some participants engaged in contemplative practices such as meditation, yoga, and qi gong, all of which seemed to have beneficial effects on the neurological symptoms of CFS. Participants reported feeling more empowered by being able to improve their health via these avenues, and improvement in quality of life went hand in hand.

This section on the final research question explored the ways in which participants described and interpreted changes in their QOL as a result of having CFS and working in an entrepreneurial capacity. Participants described feeling isolated and misunderstood by others as a result of having the illness, as well as struggling with accepting the diagnosis in the early phases. They also discussed having to let go of many aspects of their identities including professional identity. These experience negatively impacted QOL. On the other hand, changing their perspective to imbue their life with meaning even while living with CFS, as well as taking their well-being into their own hands empowered them and improved QOL.

Limitations of the Study

There were several limitations in this study: (a) lack of generalizability and transferability due to the small sample size of the participants, (b) the information was self-reported, (c) the high proportion of Caucasian women in the study, (d) the interviews were held via phone, and (e) the potential that bias may have been introduced as the researcher has a diagnoses of with CFS.

This study was qualitative in nature, therefore the small sample size limits generalizability (Creswell, 2009). Due to the fact that the information provided by the participants was self-reported, some of the information (diagnoses of CFS and self-employment) could not be verified.

The study consisted of participants who were recruited from online CFS organizations. It is important to note that of the 12 participants that contacted the researcher to participate, 11 were Caucasian and all 12 were female. There are predominantly more females affected by CFS as a whole (Arnett et al., 2011; Christley et al., 2012). Other participants meeting the study's criteria may have had different experiences that are not captured in the study.

The interviews were conducted remotely via phone, therefore body language was not detected. However, I attempted to gather as much insight during the interview as possible, and asked for clarification when necessary. There was no need to conduct follow up interviews, as the information provided was sufficient. All the interviews were audio recorded so that the researcher could return to the audio when necessary.

Bracketing one's bias is important in social science research, especially when the researcher is the primary instrument. Although I attempted to reduce the likelihood that my own bias would affect the results of this study, it is possible that my own experiences with CFS have influenced the results, as I had disclosed my diagnosis along with experiences to build rapport with the participants throughout the interview. It is widely accepted that bias is inevitable in social science research, and acknowledging possible areas of bias helps to mitigate its effects (Podsakoff et al., 2012).

Recommendations for Future Research

As this is one of the few studies of its kind to have been conducted, additional research is needed to gain a deeper understanding of the role that entrepreneurship plays in the CFS community. After conducting research and reviewing the data, I would suggest future research that would increase the sample size to gain further data across various demographics including age, gender, and ethnicity. Moreover, such demographic information as socioeconomic status and number of people in the household would be helpful to share, as this would add to the participants' context with regard to work and the potential financial pressures.

Because there are numerous factors that affect both the entrepreneurial capacity and individuals with CFS, there is an opportunity for further research to examine the relationship between these factors and the individuals' behavior, attitude, health, and lifestyle. Such factors to consider may include personal characteristics, severity of CFS symptoms, education and work experience, type and success of the business, support networks, and environment. Future research in the aforementioned areas could add to the limited literature that exists, and further CFS patients' understanding of the effective strategies ultimately used to increase their QOL.

Implications for Positive Social Change

The interviews provided rich data on how participants viewed self-employment in relation to their experiences, symptoms, and limitations associated with CFS. The CFS community can gain insight into the benefits, challenges, and other factors related to self-employment from those who have ventured into this line of work. Individuals with CFS can use the findings of this study to develop the strategies necessary for increasing their ability to achieve success in the workforce, ultimately benefiting their employees, families, and communities.

CFS has forced many individuals from their previous jobs and careers. The topic of work can play a critical role in well-being and the meaning of life (Pryce-Jones, 2010; Wong, 2011). This research presents an opportunity to observe the participants' entrepreneurial experiences while managing CFS. Although severity of symptoms may greatly vary with CFS patients, the participants in this study overall found meaningful work experiences correlated to their jobs. This in turn, had an impact on their purpose, sense of accomplishment, and well-being.

From a societal perspective, the research can be used to further educate businesses, companies, and organizations on employment challenges that individuals with a chronic illness bear. With acknowledgement and education of this illness, organizations can implement supportive practices to help their employees increase their productivity and achieve success in the workplace. There is an opportunity for the development of entrepreneurship programs to work alongside the CFS community, and who can help facilitate financial, educational, and emotional support needed to start a business. The findings provide the potential for improving the overall percentage of success and independence within this population, with the hopes of reducing the amount of individuals who are constrained from the workforce.

Conclusion

Currently, between 836,000 and 2.5 million Americans are diagnosed with CFS.

Of that number, 25% of these individuals are bed-bound during the course of their illness (Institute of Medicine, 2015), with physical, mental, and emotional symptoms making it a challenge to maintain full-time employment. Research conducted by the Institute of Medicine (2015) estimated 17 to 24 billion dollars as the annual economic cost of CFS/ME. Parker et al. (2014) indicated that entrepreneurship can act as a vehicle for empowerment for one to become financially self-sufficient while overcoming the physical, emotional, and mental barriers presented with various types of disabilities or chronic illness.

The current study offers important perspectives from self-employed individuals, who are living with CFS. The findings suggested that self-employment is an opportunity to achieve a path to the workforce; one that would align with the needs of CFS patients. It was evident in the study that these individuals found great difficulty in being employed in a typical work environment, but still wanted to work. With that said, self-employment offers independence, control, flexibility in scheduling, and sense of purpose that is critical in managing health needs associated with CFS. The results of this research may bring forth concepts for educational purposes to help improve the state of health and well-being among this population.

References

Ahuvia, A. C. (2002). Individualism/collectivism and cultures of happiness: A theoretical conjecture on the relationship between consumption, culture and subjective wellbeing at the national level. *Journal of Happiness Studies 3*, 23-36.

Ahuvia, A. C., & Friedman, D. (1998). Income, consumption, and subjective well-being: Toward a composite macromarketing model. *Journal of Macromarketing, 18*, 153-168.

Ahmadi, S. A. A., Alamzadeh, Y., Daraei, M., & Akbari, J. (2012). Relationship between organizational culture and strategy implementation: Typologies and dimensions. *Global Business & Management Research: An International Journal*, *4*(3/4), 286–299.

Aldrich, H. E., & Yang, T. (2014). How do entrepreneurs know what to do? Learning and organizing in new ventures. *Journal of Evolutionary Economics*, *24*(1), 59–82. doi:10.1007/s00191-013-0320-x

Ali, A., & Topping, K. J. (2011). Entrepreneurial attitudes among potential entrepreneurs variables. *Pak. J. Commer. Soc. Sci.*, *5*(1), 12–46.

Amorós, J. E., Bosma, N., & Global Entrepreneurship Research Association. (2014). *Global Entrepreneurship Monitor 2013 global report: Fifteen years of assessing entrepreneurship across the globe*, Babson College, Babson Park, United States.

Anderson, B. L., Kiecolt-Glaser, J. K., & Glaser, R. (1994). A biobehavioral model of cancer stress and disease course. *American Psychologist, 49*, 389-404.

Anderson, V. R., Jason, L. A, Hlavaty, L., & Porter, N. (2013). A review and meta-synthesis of qualitative studies on myalgic encephalomyelities/chronic fatigue syndrome. *Patient Educ Couns. 86*(2), 147-155. doi:10.1016/j.pec.2011.04.016

Anderson, V. R., Jason, L. A., & Hlavaty, L. E. (2016). A qualitative natural history study of ME / CFS in the Community. *Health Care Women Int. 35*(1), 1–21. doi:10.1080/07399332.2012.684816.A

Andrews, F. M., & Withey, S. B. (1976). *Social indicators of well-being*. New York, NY: Plenum Press.

Arnett, S. V., Alleva, L. M., Korossy-Horwood, R., & Clark, I. A. (2011). Chronic fatigue syndrome-A neuroimmunological model. *Medical Hypotheses*, *77*(1), 77–83. doi:10.1016/j.mehy.2011.03.030

Arnold, N., & T. Seekins. (2002). Self-employment: A process for use by vocational rehabilitation agencies. *Journal of Vocational Rehabilitation, 17*, 107–13.

Argyle, M. (1999). Causes and correlates of happiness. In D. Kahneman, E. Diener, & N. Schwarz (Eds.), *Well-being: The foundations of hedonic psychology* (pp 353-373). New York, NY: Sage.

Argyle, M. (2001). *The psychology of happiness* (2nd ed.). London, England: Routledge.

Arroll, M. A., & Senior, V. (2008). Individuals' experience of chronic fatigue syndrome/myalgic encephalomyelitis: An interpretative phenomenological analysis. *Psychology & Health*, *23*(4), 443–58. doi:10.1080/14768320701246469

Asbring, P. (2001). Chronic illness–a disruption in life: identity□transformation among women with chronic fatigue syndrome and fibromyalgia. *Journal of Advanced Nursing, 34*(3), 312-319.

Atkinson, R., & Flint, J. (2001). *Accessing hidden and hard-to-reach populations—Snowball research strategies*: University of Surrey Social Research Update, v. 33. Accessed from http://sru.soc.surrey.ac.uk/SRU33.html. I stopped reviewing here. Please go through the rest of your references and look for the patterns I pointed out to you.

Auwalu Ibrahim, N., & Mas, A. (2016). Moderating role of entrepreneurial orientation on the relationship between entrepreneurial skills, environmental factors and entrepreneurial intention: A PLS approach. *Management Science Letters*, *6*, 225–236. doi:10.5267/j.msl.2016.1.005

Ayyash-Abdo, H., & Alamuddin, R. (2007). Predictors of subjective well-being among college youth in Lebanon. *Journal of Social Psychology, 147* (3), 265-284.

Backstrom, G. (2002*). I'd rather be working: A step-by-step guide to financial self-support for people with chronic illness.* AMACOM Div American Mgmt Assn.

Barker, L. M., & Nussbaum, M. A. (2011). Fatigue, performance and the work environment: A survey of registered nurses. *Journal of Advanced Nursing*, *67*(6), 1370–1382. doi:10.1111/j.1365-2648.2010.05597.x

Baron, R. A, Franklin, R. J., & Hmieleski, K. M. (2013). Why entrepreneurs often experience low, not high, levels of stress: The joint effects of selection and psychological capital. *Journal of Management*, *20*(10), 1–27. doi:10.1177/0149206313495411

Barrows, D. M. (1995). Functional capacity evaluations of persons with chronic fatigue immune dysfunction syndrome. *American Journal of Occupational Therapy, 49,* 327–337

Beatty, J. E. (2012). Career barriers experienced by people with chronic illness: A U.S. study. *Employee Responsibilities and Rights Journal*, *24*(2), 91–110. doi:10.1007/s10672-011-9177-z

Beatty, J. E., & Joffe, R. (2006). An overlooked dimension of diversity: The career effects of chronic illness. *Organizational Dynamics*, *35*(2), 182–195. doi:10.1016/j.orgdyn.2006.03.006

Beck, A., Lauren Crain, A., Solberg, L. I., Unützer, J., Glasgow, R. E., Maciosek, M. V., & Whitebird, R. (2011). Severity of depression and magnitude of productivity loss. *Annals of Family Medicine*, *9*(4), 305–311. doi:10.1370/afm.1260

Bell, T. J., & Tracey, J. G. (2006). The relation of cultural mistrust and psychological health. *Journal of Multicultural Counseling and Development, 34* (1), 2-14.

Benz, M., & Frey, B. S. (2008). Being independent is a great thing: Subjective evaluations of self-employment and hierarchy. *Economica*, *75*(298), 362–383. doi:10.1111/j.1468-0335.2007.00594.x

Binder, M., & Coad, A. (2013). Life satisfaction and self-employment: A matching approach. *Small Business Economics*, *40*(4), 1009–1033. doi:10.1007/s11187-011-9413-9

Blascovich, J., Mendes, W. B., Hunter, S. B., & Salomon, K. (1999). Social 'facilitation' as challenge and threat. *Journal of Personality & Social Psychology, 77* (1), 68-77.

Bolger, N., & Schilling, E. (1991). Personality and the problems of everyday life: The role of neuroticism in exposure and reactivity to daily stressors. *Journal of Personality, 59,* 355-386.

Bombardier, C. H., & Buchwald, D. (1995). Outcome and prognosis of patients with chronic fatigue vs. chronic fatigue syndrome. *Archives of Internal Medicine, 155*, 2105–2110.

Bombardier, C. H., & Buchwald, D. (1996). Chronic fatigue, chronic fatigue syndrome, and fibromyalgia: Disability and health-care use. *Medical Care, 34,* 924–930.

Bordas, J. (2007). How salsa, soul and spirit strengthen leadership. *Leader to Leader Journal, 46,* 35-41.

Bostic, T. J., & Ptacek, J. T. (2001). Personality factors and the short-term variability in subjective well-being. *Journal of Happiness Studies 2,* 355-373.

Boylan, A., & T. Burchardt. (2002). *Barriers to self-employment for disabled people, Report for the small business services.* London: Department of Trade and Industry. Retrieved from http://www.berr.gov.uk/files/file38357.pdf

Braithwaite, V. A., & Scott, W. A. (1991). Values. In J. P. Robinson, P. R. Shaver, & L. S. Wrightsman (Eds.), *Measures of personality and social psychological attitudes* (pp. 661-753). San Diego, CA: Academic Press.

Braun, V., & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative*

Research in Psychology, 3(2), 77-101. Retrieved from http://eprints.uwe.ac.uk/11735

Brown, M., Kaplan, C., & Jason, L. (2013). Factor analysis of the Beck depression inventory-II with patients with chronic fatigue syndrome. *Journal of Health Psychology, 17*(6), 799–808. doi:10.1177/1359105311424470.

Brurberg, K. G., Fønhus, M. S., Larun, L., Flottorp, S., & Malterud, K. (2014). Case definitions or chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME): a systematic review. *BMJ Open*, *4*(2), e003973. doi:10.1136/bmjopen-2013-003973

Burger, D. H., Crous, F., & Roodt, G. (2013). Exploring a model for finding meaning in the changing world of work (Part 3 : Meaning as framing context). *SA Journal of Industrial Psychology/SA Tydskrif Vir Bedryfsielkunde*, *39*(2), 1–10. doi:10.4102/sajip.v39i2.1022

Cacioppo, J. T., Hawkley, L. C., Kalil, A., Hughes, M. E., Waite, L., & Thisted, R. A. (2008). Happiness and the invisible threads of social connection: The Chicago health, aging, and social relations study. In M. Eid & R. J. Larsen (Eds.), *The science of subjective well-being* (pp. 195-219). New York: The Guilford Press.

Cairns R, Hotopf M. (2005). A systematic review describing the prognosis of chronic fatigue syndrome. *Occup. Med* (55), 20–31.

Campbell, A. (1981). *The sense of well-being in America*. New York: McGraw-Hill.

Campbell, A., Converse, P. E., & Rogers, W. L. (1976). *The quality of American life.* New York: Russell Sage.

Cantor, N., & Blanton, H. (1996). Effortful pursuit of personal goals in daily life. In P. M. Gollwitzer, & J. H. Bargh (Eds.), *The psychology of action: Linking cognition and motivation to behavior* (pp. 338-359). New York: Guilford.

Cantor, N., & Sanderson, C. A. (1999). Life task participation and well-being: The importance of taking part in daily life. In D. Kahneman, E. Diener, & N. Schwarz (Eds.), *Well-being: The foundations of hedonic psychology* (pp. 231-243). New York: Russell Sage Foundation.

Carey, L., Shaw, D. D., & Shiu, E. (2008). The impact of ethical concerns on family consumer decision-making. *International Journal of Consumer Studies*, *32*(5), 553–560.

Carlsson, B., Braunerhjelm, P., McKelvey, M., Olofsson, C., Persson, L., & Ylinenpää, H. (2013). The evolving domain of entrepreneurship research. *Small Business Economics*, *41*(4), 913–930. doi:10.1007/s11187-013-9503-y

Carruthers, B. M., van de Sande, M. I., De Meirleir, K. L., Klimas, N. G., Broderick, G., Mitchell, T., ... & Bateman, L. (2011). Myalgic encephalomyelitis: international consensus criteria. *Journal of Internal Medicine*, *270*(4), 327-338.

Carver, C. S., & Baird, E. (1998). The American dream revisited: Is it what you want or why you want it that matters? *Psychological Science, 9* (4), 289-292.

Caseras, X., Mataix-Cols, D., Giampietro, V., Rimes, K.A., Brammer, M., & Zelaya, F. (2006). Probing the working memory system in chronic fatigue syndrome: a functional magnetic resonance imaging study using the n-back task. *Psychosom Med.* (68)*,* 947–55.

Cella, M., White, P. D., Sharpe, M., & Chalder, T. (2013). Cognitions, behaviours and co-morbid psychiatric diagnoses in patients with chronic fatigue syndrome. *Psychological Medicine*, *43*(2), 375–80. doi:10.1017/S0033291712000979

Centers for Disease Control and Prevention. (2012). *Chronic Fatigue Syndrome.* Retrieved from http://www.cdc.gov/cfs/

Chou, K. L. (1999). Social support and subjective well-being among Hong Kong Chinese young adults. *Journal of Genetic Psychology, 160*(3), 319-331.

Christley, Y., Duffy, T., Everall, I. P., & Martin, C. R. (2013). The neuropsychiatric and neuropsychological features of chronic fatigue syndrome: revisiting the enigma. *Current Psychiatry Reports*, *15*(4), 353. doi:10.1007/s11920-013-0353-8

Christley, Y., Duffy, T., & Martin, C. R. (2012). A review of the definitional criteria for chronic fatigue syndrome. *Journal of Evaluation in Clinical Practice*, *18*(1), 25–31. doi:10.1111/j.1365-2753.2010.01512.x

Cimarolli, V. R., & Boerner, K. (2005). Social support and well-being in adults who are visually impaired. *Journal of Visual Impairment and Blindness*, 521-535.

Clark, A. E., & Oswald, A. J. (1994). Unhappiness and unemployment. *Economic Journal, 104,* 648-659.

Costa, P. T., & McCrae, R. R. (1980). Influences of extraversion and neuroticism on subjective well-being: Happy and unhappy people. *Journal of Personality and Social Psychology, 38,* 668-678.

Creswell, J. W. (2013). *Qualitative inquiry and research design: Choosing among five approaches (3rd ed.).* Thousand Oaks, CA: Sage Publishers.

Croson, D. C., & Minniti, M. (2012). Slipping the surly bonds: The value of autonomy in self-employment. *Journal of Economic Psychology*, *33*(2), 355–365. doi:10.1016/j.joep.2011.05.001

Csikszentmihalyi, M. (1997). *Finding flow: The psychology of engagement with everyday life.* New York: Basic Books.

Csikszentmihalyi, M. (1999). If we are so rich, why aren‟t we happy? *American Psychologist 54*(10), 821-827.

Csikszentmihalyi, M., & LeFevre, J. (1989). Optimal experience in work and leisure. *Journal of Personality and Social Psychology, 56*(5), 815-822.

Cummins, R. A. (2000). Personal income and subjective well-being: A Review. *Journal of Happiness Studies, 1,* 133-158.

Dahalan, N., Jaafar, M., & Mohd Rosdi, S.A. (2013). Local community readiness in entrepreneurship: Does gender differ in searching business opportunity, *Procedia-Social and Behavioural Sciences, 91,* 403-410,.Retreived from http://ac.els-cdn.com/S1877042813025688/1-s2.0-S1877042813025688-main.pdf?_tid=a1cbb10e-b6d6-11e4-8576-00000aacb35d&acdnat=1424199548_bd3d0182e7091a14e95d20b5e225ff21.

de Lourdes Drachler, M., de Carvalho Leite, J. C., Hooper, L., Hong, C. S., Pheby, D., Nacul, L., ... & Poland, F. (2009). The expressed needs of people with chronic fatigue syndrome/myalgic encephalomyelitis: a systematic review. *BMC Public Health*, *9*(1), 1.

DeNeve, K. M. (1999). Happy as an extraverted clam? The role of personality for subjective well-being. *Current Directions in Psychological Science, 8*(5), 141-144.

DeNeve, K. M., & Cooper, H. (1998). The happy personality: A meta-analysis of 137 personality traits and subjective well-being. *Psychological Bulletin, 124*(2), 197-229.

Dickson, A., Knussen, C., & Flowers, P. (2008). "That was my old life; it's almost like a past-life now': identity crisis, loss and adjustment amongst people living with Chronic Fatigue Syndrome. *Psychology & Health*, *23*(4), 459–76. doi:10.1080/08870440701757393

Diener, E. & Lucas, R. E. (1999). Personality and subjective well-being. In Kahneman, D. Diener, E., & Schwarz, N. (Eds.), *Well-being: The foundations of hedonic psychology (pp. 213-229)*. New York: Russell Sage Foundation.

Diener, E., & Oishi, S. (2000). Money and happiness: Income and subjective well-being across nations. In E. Diener, & E. M. Suh (Eds.), *Subjective well-being across culture*. Cambridge, MA: MIT Press.

Diener, E., Oishi, S., & Lucas, R. (2003). Personality, culture, and subjective well-being: Emotional and cognitive evaluation of life. *Annual Review of Psychology, 54*, 403-425.

Diener, E., & Seligman, M. E. (2002). Very happy people. *Psychological Science, 13*(1), 81-84.

Diener, M. L., & McGavran, M. B. (2008). What makes people happy? A developmental approach to the literature on family relationships and well-being. In M. Eid & R. J. Larsen (Eds.), *The science of subjective well-being* (pp. 17-43). New York: The Guilford Press.

Dik, B. J., Byrne, Zinta S., & Steger, M. (2013). *Purpose and meaning in the workplace.* Washington, DC, US: American Psychological Association. doi:10.1037/14183-000

Emmons, R. A. (1996). Striving and feeling: Personal goals and subjective well-being. In P. M. Golwitzer, P., & Bargh, J. (Eds.), *The psychology of action: Linking cognition and motivation to behavior* (pp. 313-337). New York: Guilford.

Eren, I., Erdi, O., & Sahin, M. (2008). The effects of depression on quality of life of patients with type II diabetes mellitus. *Depression and Anxiety,* 98-106. doi:10.1002/da.20288

Fairlie, R. W., & Holleran, W. (2011) Entrepreneurship training risk aversion and other personality traits: Evidence from a ransom experiment. *Journal of Economic Psychology*. doi:10.1016/j.joe.2011.02.001

Falch, R., & Hernæs, U.J.V. (2012). Disability, social identity, and entrepreneurship: Evidence from a laboratory experiment in rural Uganda.

Farrar, D. J., Locke, S. E., & Kantrowitz, F. G. (1995). Chronic Fatigue Syndrome 1: Etiology and pathogenesis. *Behavioral Medicine*, *21*(1), 5–16. JOUR. doi:10.1080/08964289.1995.9933737

Feiring, C., & Lewis, M. (1991). The transition from middle childhood to early adolescence: ex difference in the social network and perceived self-competence. *Sex Roles, 24*(7/8), 489-509.

Feldman, D. C., & Bolino, M. C. (2000). Career patterns of the self-employed: Career motivations and career outcomes. *Journal of Small Business Management*, *38*(3), 53–67. Retrieved from http://www.scopus.com/inward/record.url?eid=2-s2.0-0034215171&partnerID=40&md5=ecbd2a7d4aef1ee9fd98e64073daebc3

Fernández, A., Martín, Á., Martínez, M., Bustillo, M., Hernández, F. J., Labrado, J., … Ramón Giménez, J. R. (2009). Chronic fatigue syndrome: aetiology, diagnosis and treatment. *BMC Psychiatry*, *9*(1), S1. doi:10.1186/1471-244X-9-S1-S1

Fernet, C., Torrès, O., Austin, S., & St-Pierre, J. (2016). The psychological costs of owning and managing an SME: Linking job stressors, occupational loneliness, entrepreneurial orientation, and burnout. *Burnout Research*, *3*(2), 45–53. doi:10.1016/j.burn.2016.03.002

Frisch, M. B., Clark, M. P., Rouse, S. V., Rudd, M., Paweleck, J., Greenstone, A., & Kopplin, D. A. (2005). Predictive and treatment validity of life satisfaction and the quality of life inventory. *Assessment, 12*(1), 66-78.

Fukuda, K., Straus, S. E., Hickie, I., Sharpe, M. C., Dobbins, J. G., & Komaroff, A. (1994). The chronic fatigue syndrome: A comprehensive approach to its definition and study. *Annals of Internal Medicine, 121*(12), 953–959. Retrieved from Academic Search Premier database.

Fuller-Thomson E., & Nimigon J. (2008). Factors associated with depression among individuals with chronic fatigue syndrome: findings from a nationally representative survey. *Fam Pract,* (25) 414–22.

Funk & Wagnalls New World Encyclopedia. (2016). *Chronic Fatigue Syndrome.* Retrieved from http://onlinelibrary.utah.gov/research/databases/index.html

Geldhof, G. J., Porter, T., Weiner, M. B., Malin, H., Bronk, K. C., Agans, Mueller, M., Damon, W., & Lerner, R. M. (2014). Fostering youth entrepreneurship: Preliminary findings from the young entrepreneurs study. *Journal of Research on Adolescence*, *24*(3), 431–446. doi:10.1111/jora.12086

Gee, G. C., Chen, J., Spencer, M. S., See, S., Kuester, O., & Tran, D. (2006). Social support as a buffer for perceived unfair treatment among Filipino Americans: Differences between San Francisco and Honolulu. *American Journal of Public Health, 96* (4), 677-666.

Gilbert, P. (2000). The relationship of shame, social anxiety and depression: the role of the evaluation of social rank. *Clinical Psychology and Psychotherapy 7,* 174–189.

Giorgi, A. (2006). Difficulties encountered in the application of the phenomenological method in the social sciences. *Analise Psicologica, 3*(XXIV), 353- 361.

Glaser, R., & Kiecolt-Glaser, J. K. (1998). Stress-associated immune modulation: relevance to viral infections and chronic fatigue syndrome. *American Journal of Medicine*, *105*(3A), 35S–42S. doi:10.1016/S0002-9343(98)00160-0

Glenn, N. D., & Weaver, C. N. (1981). Education's effects on psychological well-being. *Public Opinion Quarterly, 45*, 22-37.

Gonzales, L. R., Lewinsohn, P. M., & Clarke, G. N. (1985). Longitudinal follow-up of unipolar depressives: An investigation of predictors of relapse. *Journal of Consulting and Clinical Psychology, 53* (4), 461-469.

Hagner, D., & Davies, T. (2002). "Doing my own thing": Supported self-employment for individuals with cognitive disabilities. *Journal of Vocational Rehabilitation*, *17*(2), 65–74. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=2002-15919-001&site=ehost-live

Haney, E., Beth Smith, M. E., McDonagh, M., Pappas, M., Daeges, M., Wasson, N., & Nelson, H. D. (2015). Diagnostic methods for myalgic encephalomyelitis/chronic fatigue syndrome: A systematic review for a national institutes of health pathways to prevention workshop. *Annals of Internal Medicine*, *162*(12), 834–840. doi:10.7326/M15-0443

Hardt, J., Buchwald, D., Wilks, D., Sharpe, M., Nix, W., & Egle, U. (2001). Health-related quality of life in patients with chronic fatigue syndrome. *Journal of Psychosomatic Research, 51* (2), 431-434.

Harter, J. K., Schmidt, F. L., & Hayes, T. L. (2002). Business-unit-level relationship between employee satisfaction, employee engagement, and business outcomes: A meta-analysis. *Journal of Applied Psychology, 87*, 268-279.

Hawkins, D. N., & Booth, A. (2005). Unhappily ever after: Effects of long-term, low quality marriages on well-being. *Social Forces, 84* (1), 451-471.

Heady, B., & Wearing, A. (1991). Subjective well-being: A stocks and flows framework. In F. Strack, M. Argyle, & N. Schwarz (Eds.), *Subjective well-being* (pp. 49-76). Oxford: Pergamon Press.

Hill, N. R., Leinbaugh, T., Bradley, C., & Hazler, R. (2005). Female counselor educators: Encouraging and discouraging factors in academia. *Journal of Counseling and Development, 83* (3), 374-380.

Hopstaken, J. F., van der Linden, D., Bakker, A. B., & Kompier, M. A. J. (2015). A multifaceted investigation of the link between mental fatigue and task disengagement. *Psychophysiology*, *52*(3), 305–315. doi:10.1111/psyp.12339

Holgate, S. T., Komaroff, A. L., Mangan, D., & Wessely, S. (2011). Understanding a complex illness. *Prevention*. doi:10.1038/nrn3087

Hottard, S. R., McFatter, R. M., McWirter, R. M., & Stegall, M. E. (1989). Interactive effects on extraversion, neuroticism, and relationships on subjective well-being. *Journal of Personality and Social Psychology 57*, 321-331.

Hundley, G. (2001). Why and when are the self-employed more satisfied with their work? *Industrial Relations, 40*(2), 293-316.

Hunt, M. R. (2009). Strengths and challenges in the use of interpretive description: reflections arising from a study of the moral experience of health professionals in humanitarian work. *Qualitative Health Research*, *19*(9), 1284–1292. doi:0.1177/1049732309344612

Hvidberg, M.F., Brinth, L.S., Olesen, A.V., Petersen, K.D., & Ehlers, L. (2015). The health-related quality of life for patients with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). *PLoS ONE, 10* (7), 1-17.

Institute of Medicine. (2015). *Beyond myalgic encephalomyelitis/chronic fatigue syndrome. Refining an Illness.* Retrieved from: www.iom.edu/

International Labour Organization. (2013). *Global employment Trends*. Retrieved from: http://www.ilo.org/wcmsp5/groups/public/---dgreports/---dcom/publ/documents/publication/wcms_202326.pdf

Isen, A. M., & Labroo, A. A. (2003). Some ways in which positive affect facilitates decision making and judgment. In S. L. Schneider & J. Shanteau (Eds.), *Emerging perspectives on judgment and decision research* (pp. 365-393). Cambridge: Cambridge University Press.

Jacob, S. A., & Furgerson, S. P. (2012). Writing interview protocols and conducting interviews: Tips for students new to the field of qualitative research. *Qualitative Report, 17*(T&L Art, 6), 1-10.

Jason, A., L., Corradi, K., Gress, S., Williams, S. & Torres-Harding, S. (2006). Causes of death among patients with chronic fatigue syndrome. *Health Care for Women International 27:615-626.* doi:10.1080/073993306008-3766.

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

Jones, T. G., Rapport, L. J., Hanks, R. A., Lichtenberg, P., & Telmet, K. (2003). Cognitive and psychological predictors of subjective well-being in urban older adults. *Clinical Neuropsychologist 17* (1), 3-18.

Joyce E., Blumenthal S., & Wessely S. (1996). Memory, attention, and executive function in chronic fatigue syndrome. *Journal of Neurosurgical Psychiatry*, 60, 495–503.

Judge, T. A., & Klinger, R. (2008). Job satisfaction: Subjective well-being at work. In Eid, M. & Larsen, R. (Eds.), *The science of subjective well-being* (pp. 393-413).New York: The Guilford Press.

Juster, R.P., Marin, M.F., Sindi, S., Nair, N.P., Ng, Y.K., Pruessner, J.C., & Lupien, S.J. (2011). Allostatic load associations to acute, 3-year and 6-year prospective depressive symptoms in healthy older adults. *Physiological Behaior, 104,* 360—364.

Karlsen, E., Dybdahl, R., & Vitterso, J. (2006). The possible benefits of difficulty: How stress can increase and decrease subjective well-being. *Scandinavian Journal of Psychology, 47,* 411-417.

Kasser, T. (2002). *The high price of materialism*. Cambridge, MA: MIT Press.

Kasser, T., & Ryan, R. M. (2001). Be careful what you wish for: Optimal functioning and the relative attainment of intrinsic and extrinsic goals. In Schmuck, P., & Sheldon, K. (Eds.), *Life goals and well-being: Towards a positive psychology ofhuman striving* (pp. 116-131). Ashland, OH: Hogrefe & Huber Publishers.

Kawambe, Y., Nakamura, Y., Kikuchi, S., Suzukamo, Y., Murakami, Y. Tanaka, T.,…Ueshima, H. (2015). Relationship of type of work with health-related quality of life. *Quality of Life Research*, *24*(12), 2927-2932.

Keech, A., Sandler, C. X., Vollmer-Conna, U., Cvejic, E., Lloyd, A. R., & Barry, B. K. (2015). Capturing the post-exertional exacerbation of fatigue following physical and cognitive challenge in patients with chronic fatigue syndrome. *Journal of Psychosomatic Research*, *79*(6), 537–549. doi:10.1016/j.jpsychores.2015.08.008

Kempke, S., & Claes, S. (2016). Perfectionism and stress reactivity in patients with chronic fatigue syndrome. *Psychoneuroendocrinology*, *61*, 59. doi:10.1016/j.psyneuen.2015.07.551

Kennedy, G., Spence, V. A., McLaren, M., Hill, A., Underwood, C., & Belch, J. J. F. (2005). Oxidative stress levels are raised in chronic fatigue syndrome and are associated with clinical symptoms. *Free Radical Biology and Medicine*, *39*(5), 584–589. doi:10.1016/j.freeradbiomed.2005.04.020

Kerr, J. R., Christian, P., Hodgetts, A., Langford, P. R., Devanur, L. D., Petty, R., … Collaborative Clinical Study, G. (2007). Current research priorities in chronic fatigue syndrome/myalgic encephalomyelitis: disease mechanisms, a diagnostic test and specific treatments. *Journal of Clinical Pathology,60*(2), 113–116. doi:10.1136/jcp.2006.042374

Kim, H. K., & McKenry, P. C. (1998). Social networks and support: A comparison of African Americans, Asian Americans, Caucasians, and Hispanics. *Journal of Comparative Family Studies, 29*(2), 313-334.

Kingdon, G. G., & Knight, J. (2006). Subjective well-being poverty vs. income poverty and capabilities poverty? *Journal of Developmental Studies, 42*(7), 1199-1244.

Klonowicz, T. (2001). Discontented people: Reactivity and locus of control as determinants of subjective well-being. *European Journal of Personality, 15*, 29-47.

Koivumaa-Honkanen, H., Honkanen, R., Viinamaki, H., Kaprio, J., & Koskenvuo, M. (2001). Life satisfaction and suicide: A 20-year follow-up study. *American Journal of Psychiatry, 158*(3), 433-439.

Komaroff A. (1993). *Clinical presentation of chronic fatigue syndrome, in Chronic Fatigue Syndrome*, ed Bock G. W. J., editor. (Hoboken, NJ: Ciba Foundation Symposium), 43–61.

Komaroff, L., A. & Cho, A. T. (2011). *Role of infection and neurologic dysfunction in chronic fatiguesSyndrome*. Retrieved from https://www.thieme-connect.com/products/ejournals/html/10.1055/s-0031-1287654

Lam, C. L., & Lauder, I. J. (2000). The impact of chronic diseases on the health-related quality of life (HRQOL) of Chinese patients in primary care. *Family Practice*, *17*(2), 159–166. hdoi:10.1093/FAMPRA/17.2.159

Larsen, R. J. & Eid, M. (2008). Ed Diener and the science of subjective well-being. In M.Eid & R. J. Larsen (Eds.), *The science of subjective well-being* (pp. 1-13). New York: The Guilford Press.

Lattie, E. G., Antoni, M. H., Fletcher, M., Czaja, S., Perdomo, D., Sala, A., Nair, S., Fu, S. H., Penedo, F. J., & Klimas, N. (2013). Beyond myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) symptom severity: Stress management skills are related to lower illness murden. *Fatigue, 1*(4). doi:10.1080/21641846.2013.843255.

Lawrence, C., Roy, A., Harikrishnan, V., Yu, S., & Dabbous, O. (2013). Association between severity of depression and self-perceived cognitive difficulties among full-time employees. *Primary Care Companion for CNS Disorders*, *15*(3), 1–10. doi:10.4088/PCC.12m01469

Le, A. (1999). Empirical studies of self-employment. *Journal of Economic Surveys, 13,* 381–416.

Lee, C. (1999). Specifying intrusive demands and their outcomes in congregational ministry: A report on the Ministry demands inventory. *Journal for the Scientific Study of Religion, 38* (4), 477-489.

Lim, K. (2015). *New evidence on self-employment and workplace flexibility for US mothers.* Retrieved from http://sites.lsa.umich.edu/katherinelim/wp-content/uploads/sites/287/2015/10/Lim_2015.pdf

Lin, J.-M. S., Resch, S. C., Brimmer, D. J., Johnson, A., Kennedy, S., Burstein, N., & Simon, C. J. (2011). The economic impact of chronic fatigue syndrome in Georgia: Direct and indirect costs. *Cost Effectiveness and Resource Allocation 9*(1), 1. doi:10.1186/1478-7547-9-1

Linley, P. A., & Joseph, S. (Eds.), (2004). *Positive psychology in practice*. Hoboken, NJ: Wiley.

Lloyd AR, Pender H. The economic impact of chronic fatigue syndrome. *Med J Aust, 157*(9) 599-601.

Löfgren, M., Schult, M.-L., Öhman, A., Julin, P., & Ekholm, J. (2016). Fibromyalgia syndrome or chronic fatigue syndrome/myalgic encephalomyelitis and factors influencing work disability in Women. In Z. I. Schultz & J. R. Gatchel (Eds.), *Handbook of Return to Work: From Research to Practice* (pp. 459–480). Boston, MA: Springer US. doi:10.1007/978-1-4899-7627-7_26

Lu, L. (1999). Personal or environmental causes of happiness: A longitudinal analysis. *Journal of Social Psychology, 139* (1), 79-90.

Lu, L., Gilmour, R., & Kao, S. -F. (2001). Cultural values and happiness: An east-west dialogue. *Journal of Social Psychology, 141* (4), 477-493.

Luyten, P., Kempke, S., Van Wambeke, P., Claes, S., Blatt, S. J., & Van Houdenhove, B. (2011). Self-critical perfectionism, stress generation, and stress sensitivity in patients with chronic fatigue syndrome: relationship with severity of depression. *Psychiatry*, *74*(1), 21–30. doi:10.1521/psyc.2011.74.1.21

Maes, M., Twisk, F. N. M., & Ringel, K. (2012). Inflammatory and cell-mediated immune biomarkers in myalgic encephalomyelitis/chronic fatigue syndrome and depression: Inflammatory markers are higher in myalgic encephalomyelitis/chronic fatigue syndrome than in depression. *Psychotherapy and Psychosomatics*, *81*(5), 286–295. doi:10.1159/000336803

Majer, M.,Welberg, L.A., Capuron, L., Miller, A.H., Pagnoni, G., & Reeves, W.C. (2008). Neuropsychological performance in persons with chronic fatigue syndrome: results from a population-based study. *Psychosom Med, 70,* 829–36

Martin, F., Student, G., & Alonzo, A. (2013). Processes of self-management in chronic illness. *NIH Public Access, 44*(2), 136–144. doi:10.1111/j.1547-5069.2012.01444.x.

Marumoagae, M. C. (2012). Disability discrimination and the right of disabled persons to access the labour market. *Potchefstroom Electronic Law Journal*, *15*(1), 244–365. doi:10.4314/pelj.v15i1.10

Masaaki, T., Akira, I., & Yasuyoshi, W. (2013). Neural dysfunction in chronic fatigue syndrome. *Journal of Advances in Neuroimmune Biology, 4*(4), 291-300. doi:10.3233/NIB-130065

Maslow, A. H. (1970). *Motivation & personality* (2nd Edition ed.). New York: Harper & Row.

Mawle, A., C, Reyes M., Schmid D.S., (1994). Is chronic fatigue syndrome an infectious disease? *Infectious Agents and Disease*, *2*, 333–341.

Maziriri, E. T., & Madinga, N. W. (2016). A qualitative study on the challenges faced by entrepreneurs living with physical disabilities within the Sebokeng Township of South Africa. *Research in Business Studies and Management, 3*(5), 1–13.

Mccrone, P., Darbishire, L., Ridsdale, L. & Seed, P. (2003). The economic cost of chronic fatigue and chronic fatigue syndrome in UK primary care. *Psychological Medicine*, *33*(2), pp. 253–261. doi:10.1017/S0033291702006980.

Mehl-Madrona, L. (2005). *Coyote wisdom: The power of story in healing.* Rochester, VT: Bear & Company.

Mizuno, K., Tanaka, M., Yamaguti, K., Kajimoto, O., Kuratsune, H., & Watanabe, Y. (2011). Mental fatigue caused by prolonged cognitive load associated with sympathetic hyperactivity. *Behavioral and Brain Functions, 7*(1), 17. doi:10.1186/1744-9081-7-17

Moroz, P. W., & Hindle, K. (2012). Entrepreneurship as a process: Toward harmonizing multiple perspectives. *Entrepreneurship: Theory and Practice*, *36*(4), 781–818. doi:10.1111/j.1540-6520.2011.00452.x

Morris, G., Berk, M., Galecki, P., & Maes, M. (2014). The emerging role of autoimmunity in myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). *Molecular Neurobiology*, *49*(2), 741–756. doi: 10.1007/s12035-013-8553-0

Morse, J.M., & Chung, S.E. (2003). Toward holism: The significance of methodological pluralism. *International Journal of Qualitative Methods, 2*(3). Retrieved from http://www.ualberta.ca/~iiqm/backissues/2_3final/html/morsechung.html

Mounstephen, A., & Sharpe, M. (1997). Chronic fatigue syndrome and occupational health. *Occupational Medicine,* 47, 217 – 227.

Mpofu, J., & Shumba, A. (2013). Disabilities and entrepreneurship in Makonde rural community in Zimbabwe. *Stud Tribes Tribal, 11*(2), 135-144.

Myers, D. G., & Jeeves, M. A. (1987). *Psychology through the eyes of faith*. San Francisco: HarperCollins.

Nater, U. M., Maloney, E., Heim, C., & Reeves, W. C. (2011). Cumulative life stress in chronic fatigue syndrome. *Psychiatry Research*, *189*(2), 318–320. doi:10.1016/j.psychres.2011.07.015

Naudé, W. (2012). Entrepreneurship and economic development: Theory, evidence and policy. *UNU-Merit Working Paper Series*, (31).

Newman, M. A., Guy, M. E., & Mastracci, S. H. (2009). Beyond cognition: Affective leadership and emotional labor. *Public Administration Review, 69*(1), 6-20.

Ng, A. K., Ho, D. Y., Wong, S. S., & Smith, I. (2003). In search of the good life: A cultural odyssey in the East and West. *Genetic, Social, and General Psychology Monographs, 129(4)*, 317-364.

Nieman, L. & Cheng, L. (2011). Chronic illness needs educated doctors: An innovative primary care training program for chronic illness education. *Medical Teacher, 33*(6), e340-e348, doi:10.3109/0142159X.2011.558532

Nijs, J., Aelbrecht, S., Meeus, M., Van Oosterwijck, J., Zinzen, E., & Clarys, P. (2011). Tired of being inactive: a systematic literature review of physical activity, physiological exercise capacity and muscle strength in patients with chronic fatigue syndrome. *Disability and Rehabilitation*, *33*(17-18), 1493–500. doi:10.3109/09638288.2010.541543

Nolen-Hoeksema, S. & Rusting, C. L. (1999). Gender differences in well-being. In D.Kahneman, E. Diener, & N. Schwarz (Eds.) *Well-being: The foundations of hedonic psychology* (pp. 330-352). New York: Sage.

Núñez, M., Fernández-Solà, J., Nuñez, E., Fernández-Huerta, J.-M., Godás-Sieso, T., & Gomez-Gil, E. (2011). Health-related quality of life in patients with chronic fatigue syndrome: group cognitive behavioural therapy and graded exercise versus usual treatment. A randomised controlled trial with 1 year of follow-up. *Clinical Rheumatology*, *30*(3), 381–9. doi:10.1007/s10067-010-1677-y

National Content Standards for Entrepreneurship Education. (2004). *Preparing youth and adults to succeed in an entrepreneurial economy.* Retrieved from http://www.entreed.org/Standards_Toolkit/Helpful%20Downloads/NCSEE%20Website.pdf

Ocon, A. J. (2013). Caught in the thickness of brain fog: Exploring the cognitive symptoms of Chronic Fatigue Syndrome. *Frontiers in Physiology*, *4,* 1–8. doi:10.3389/fphys.2013.00063

Office of Disability Employment Policy. (2001). *Small business and self employment for people with disabilities: A world in which people with disabilities have unlimited employment ppportunities.* Washington, DC: US Department of Labor.

Okwiet, B. (2013). Entrepreneurship in small and medium enterprises sector–development barriers and opportunities. *Journal of Management Studies. 7*, 37–47.

Oishi, S., Schmmack, U., & Diener, E. (2001). Pleasures and subjective well-being. *European Journal of Personality, 15,* 153-167.

Olesen, S. C., Butterworth, P., Leach, L. S., Kelaher, M., & Pirkis, J. (2013). Mental health affects future employment as job loss affects mental health: findings from a longitudinal population study. *BMC Psychiatry*, *13*, 144. doi:10.1186/1471-244X-13-144

Pagán, R. (2009). Self employment among people with disabilities: evidence for Europe. *Disability & Society*, *24*(2), 217–229. doi:10.1080/09687590802652504

Patton, M. (2002). *Qualitative research & evaluative methods*. Thousand Oaks, CA: Sage.

Parker Harris, S., Caldwell, K., & Renko, M. (2014). Entrepreneurship by any other name: self-sufficiency versus innovation. *Journal of Social Work In Disability & Rehabilitation*, *13*(4), 317–349. doi:10.1080/1536710X.2014.961115

Patzelt, H., & Shepherd, D. A. (2011). Negative emotions of an entrepreneurial career: Self-employment and regulatory coping behaviors. *Journal of Business Venturing*, *26*(2), 226–238. doi:10.1016/j.jbusvent.2009.08.002

Pena, P. A. I., Jamilena, F. D. M., & Molina, R. M. A. (2011). Impact of market orientation and ICT on the performance of rural smaller service enterprises. *Journal of Small Business Management,* 49, 331-360. doi:10.1111/j.1540-627X.2011.00332.x

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

Pinquart, M., & Sorensen, S. (2000). Influences of socioeconomic status, social network, and competence on subjective well-being in later life: A meta-analysis. *Psychology and Aging*, 15, 187-224.

Podsakoff, P. M., MacKenzie, S. B., & Podsakoff, N. P. (2012). Sources of method bias in social science research and recommendations on how to control it. *Annual Review of Psychology, 63,* 539–569. doi:10.1146/annurev-psych-120710-100452

Poudyal, N. C., Siry, J. P., & Bowker, J. M. (2012). Stakeholders' engagement in promoting sustainable development: Businesses and urban forest carbon. *Business Strategy and the Environment,* 21, 157-169. doi:10.1002/bse.724

Pryce-Jones, J. (2010). *Happiness at work: maximizing your psychological capital for success.* Chicester, UK: John Wiley & Sons Ltd

Rahim, H.L., Abidin, Z.Z., Ping, S.D.S., Alias, M.K., & Muhamad, A.I. (2014). Globalization and its effect on world poverty and inequality. *Global Journal of Management and Business, 1*(2), 09-13.

Rakib, A., White, P.D., Pinching, A.J., Hedge, B., Newbery, N., Fakhoury, W.K., & Priebe, S. (2005). Subjective quality of life in patients with chronic fatigue syndrome. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation, 14*(1), 11-19.

Register, C. (1987). *Living with chronic illness: Days of patience and passion*. New York: Free Reilly, N. P., Sirgy, J., & Gorman, C. A. (2012). *Work and quality of life: Ethical practices in organizations*. Springer Netherlands. Retrieved from https://books.google.com/books?id=DKEn2r9e8qAC

Reitinger, C. (2015). Viktor Frankl’s logotherapy from a philosophical point of view. *Existential Analysis: Journal of the Society for Existential Analysis*, *26*(2), 344–357. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&AuthType=ip,cookie,url,uid&db=aph&AN=109576316&lang=es&site=ehost-live&scope=site

Reynolds, F., Vivat, B., & Prior, S. (2008). Women's experiences of increasing subjective well-being in CFS/ME through leisure-based arts and crafts activities: a qualitative study. *Disability and Rehabilitation*, *30*(17), 1279–1288. doi:10.1080/09638280701654518

Rietveld, C. A., van Kippersluis, H., & Thurik, A. R. (2014). Self-employment and health: Barriers or benefits? *Health Economics*, 10.1002/hec.3087. doi:10.1002/hec.3087

Ross, S. D., Estok, R. P., Frame, D., Stone, L. R., Ludensky, V., & Levine, C. B. (2004). Disability and chronic fatigue syndrome: A focus on function. *Archives of Internal Medicine,* 164, 1098– 1107.

Rowe, P. C., Calkins, H., Debusk, K., Mckenzie, R., Hohman, P., Snader, S., … Wolff, M. (2001). Fludrocortisone Acetate to Treat. *The Journal of the American Medical Association*, *285*(1), 52–59.

Rusu, C., Gee, M. E., Lagac, C., & Parlor, M. (2015). Chronic fatigue syndrome and fibromyalgia in Canada: Prevalence and associations with six health status indicators. *Chronic Diseases and Injuries in Canada*, *35*(1), 3–11.

Saarni, S.I., Saarni, E.S., & Saarni H. (2008). Quality of life, work ability, and self employment: A population survey of entrepreneurs, farmers, and salary earners. *Occupational and Environmental Medicine, 65* (2), 98-103.

Sagiv, L., & Schwartz, S. H. (2000). Value priorities and subjective well-being: Direct relations and congruity effects. *European Journal of Social Psychology, 30,* 177-198.

Schmit-Rodermund, E. (2004). Pathways to successful entrepreneurship: parenting, personality, early entrepreneurial competence, and interests. *Journal of Vocational Behavior, 65*(*3*), 498-518. doi:10.1016/j.jvb.2003.10.007

Schonfeld, I. S., & Mazzola, J. J. (2015). A qualitative study of stress in individuals self-employed in solo businesses. *Journal of Occupational Health Psychology*, *20*(4), 501–513. doi:10.1037/a0038804

Schwartz, S. (1996). Value priorities and behavior: Applying a theory of integrated value systems. In C. Seligman, J. M. Olson, & M. P. Zanna (Eds.), *The psychology of values: The Ontario symposium* (pp. 1-24). Hillsdale, NJ: Lawrence Erlbaum Associates.

Schweitzer, R., Kelly, B., Foran, A., Terry, D., & Whiting, J. (1995). Quality of life in chronic fatigue syndrome. *Soc. Sci. Med, 41* (10), 124-7.

Schyns, P. (2001). Wealth of nations, individual income and life satisfaction in 42 countries: A multilevel approach. In B. Zumbo (Ed.), *Advances in quality of life research* (Vol. 2, pp. 1319-1331). Dordrecht/Boston/London: Kluwer Academic Publishers.

Schweitzer, R., Kelly, B., Foran, A., Terry, D., & Whiting, J. (1995). Quality of life in chronic fatigue syndrome. *Social Science and Medicine*, 41, 1367– 1372.

Sharpe, M. C., Archard, L. C., Banatvala, J. E., Borysiewicz, L. K., Clare, a W., David, A., … Lane, R. J. (1991). A report-chronic fatigue syndrome: guidelines for research. *Journal of the Royal Society of Medicine*, *84*(2), 118–121.

Shaw, E., & Carter, S. (2007). Social entrepreneurship: Theoretical antecedents and empirical analysis of entrepreneurial processes and outcomes. *Journal of Small Business and Enterprise Development, 14,* 418–434.

Sirgy, M. J., Reilly, N. P., Wu, J., & Efraty, D. (2012). Review of research related to quality of work life (QWL) programs. In *Handbook of social indicators and quality of life research* (pp. 297-311). Springer Netherlands.

Spiegel, D. (2003). What causes chronic fatigue syndrome?. *Emerg Med J*,*20*, 447-8.

Spira, M., & Kenemore, E. (2002). Cancer as a life transition: A relational approach to cancer wellness in women. *Clinical Social Work Journal, 30*(2), 173-186.

Strine, T. W., Mokdad, A. H., Balluz, L. S., Gonzalez, O., Crider, R., & Berry, J. T. (2008). Depression and anxiety in the United States: Findings from the 2006 Behavioral Risk Factor Surveillance System. *Psychiatr. Serv., 59,* 1383-1390.

Stringer, E. A., Baker, K. S., Carroll, I. R., Montoya, J. G., Chu, L., Maecker, H. T., & Younger, J. W. (2013). Daily cytokine fluctuations, driven by leptin, are associated with fatigue severity in chronic fatigue syndrome: evidence of inflammatory pathology. *Journal of Translational Medicine*, *11*, 93. doi:10.1186/1479-5876-11-93

Tait, M., Padgett, M. Y., & Baldwin, T. T. (1989). Job satisfaction and life satisfaction: A reexamination of the strength of the relationship and gender effects as a function of the date of the study. *Journal of Applied Psychology, 74,* 502-507.

Tanaka, M., Sadato, N., Okada, T., Mizuno, K., Sasabe, T., Tanabe, H. C., … Watanabe, Y. (2006). Reduced responsiveness is an essential feature of chronic fatigue syndrome: a fMRI study. *BMC Neurology*, *6*, 9. doi:10.1186/1471-2377-6-9

Taylor, R. R. (2004). Quality of life and symptom severity for individuals with chronic fatigue syndrome: Findings from a randomized clinical trial. *American Journal of Occupational Therapy,* 58, 35 – 43.

Taylor, R. R., & Kielhofner, G. W. (2005). Work-related impairment and employment-focused rehabilitation options for individuals with chronic fatigue syndrome: A review. *Journal of Mental Health*, *14*(3), 253–267. doi:10.1080/09638230500136571

Tedeschi, R. G., Park, C. L., & Calhoun, L. G. (1998). Posttraumatic growth: Conceptual issues. In R. G. Tedeschi, C. L. Park, & L. G. Calhoun (Eds.), *Posttraumatic growth: Theory and research on change in the aftermath of crisis* (pp. 1-22). Mahwah, NJ: Lawrence Erlbaum.

Theofilou, P. (2013). Quality of life: definition and measurement. *Europe's Journal of Psychology, 9* (1), 150-162.

Thorne, S. (2000). Data analysis in qualitative research. *Evidence Based Nursing, 3,* 68-70.

Tiersky, L.A., Matheis, R.J., Deluca, J., Lange, G., & Natelson, B.H. (2003). Functional status, neuropsychological functioning, and mood in chronic fatigue syndrome (CFS): relationship to psychiatric disorder. *J Nerv Ment Dis.*19, 324–31.

Tufford, L., & Newman, P. (2012). Bracketing in qualitative research. *Qualitative Social Work*, *11*(1), 80–96. doi:10.1177/1473325010368316

The World Health Organization. (2016). *Disabilities*. Retrieved from http://www.who.int/topics/disabilities/en/

Uslan, D. (2003). *Rehabilitation counseling*. In L. A. Jason, P. A. Fennell, & R. R. Taylor, Handbook of chronic fatigue syndrome (pp. 654 – 690). New York: Wiley & Sons.

Van Houdenhove, B., Kempke, S., & Luyten, P. (2010). Psychiatric aspects of chronic fatigue syndrome and fibromyalgia. *Curr Psychiatr Rep*, *12,* 208–14.

Van Vugt, M. (2006). Evolutionary origins of leadership and followership. *Personality and Social Psychology Review, 10,* 354-372.

Vercoulen, J. H., Swanink, C. M., Fennis, J. F., Galama, J. M., Van der Meer, J. W., & Bleijenberg, G. (1994). Dimensional assessment of chronic fatigue syndrome. *Journal of Psychosomatic Research, 38,* 383–392.

Veenhoven, R. (1999). Quality-of-life in individualistic society: A comparison of 43 nations since the early 1990s. *Social Indicators Research, 48*, 157-186.

Veenhoven, R. (2004). Happiness as a public policy aim: The greatest happiness principle. In. P. A. Linley & S. Joseph (Eds.), *Positive psychology in practice* (pp.658-678). New York: Wiley.

Ventegodt, S., Merrick, J., & Andersen, N.J. (2003). Quality of life theory I. The IQOL theory: an integrative theory of the global quality of life concept. *Scientific World Journal, 3*.

Vercoulen JH, Swanink C, Fennis J, Galama JM, van der Meer JW, Bleijenberg , & G. (1994). Dimensional assessment of chronic fatigue syndrome. *J Psychosom Res, 38,* 383-392

Viner, R., & Hotopf, M. (2004). Childhood predictors of self reported chronic fatigue syndrome/myalgic encephalomyelitis in adults: national birth cohort study. *bmj, 329*(7472), 941.

Vitaliano, P. P., Dougherty, C. M., & Siegler, I. C. (1994). Biopsychosocial risks for cardiovascular disease in spouse caregivers of persons with Alzheimer's disease. In R. P. Abeles, H. C. Gift, & M. G. Ory (Eds.), *Aging and quality of life* (pp. 145-159). New York: Springer.

Ware, N. (1998). Sociosomatics and illness course in chronic fatigue syndrome. *Psychosomatic Medicine,* 60, 394–401

Warr, P. (1999). Well-being and the work place. In D. Kahneman, E. Diener, & N.Schwarz (Eds.), *Well-being: The foundations of hedonic psychology* (pp. 392-412). New York: Sage.

Webb, J. W., Bruton, G. D., Tihanyi, L., & Ireland, R. D. (2013). Research on entrepreneurship in the informal economy: Framing a research agenda. *Journal of Business Venturing*, *28*(5), 598–614. doi:10.1016/j.jbusvent.2012.05.003

Whitehead L. (2006). Quest, chaos and restitution: Living with chronic fatigue syndrome/myalgic encephalomyelitis. *Soc Sci Med, 62,* 2236–2245.

Whittemore, R., Chase, S. K., & Mandle, C. L. (2001). Validity in qualitative research. *Qualitative Health Research*, 11,117-132.

Wiese, B.S. (2007). Successful pursuit of personal goals and subjective well-being. In B.R. Little, K. Salmela-Aro, & S.D. Phillips (Eds.), *Personal project pursuit: Goals, action and human flourishing* (pp. 301-328). Hillsdale, NJ: Lawrence Erlbaum.

Willis, J. (2007). *Foundations of qualitative research: Interpretive and critical approaches.* Thousand Oaks, CA: Sage.

Wilson, A., Hickie, I., Hadzi-Pavlovic, D., Wakefield, D., Parker, G., Straus, S. E., et al. (2001). What is chronic fatigue syndrome? Heterogeneity within an international multicentre study. *Australian & New Zealand Journal of Psychiatry,* 35, 520–527.

Winger, A., Ekstedt, M., Wyller, V. B., & Helseth, S. (2014). “Sometimes it feels as if the world goes on without me”: Adolescents’ experiences of living with chronic fatigue syndrome. *Journal of Clinical Nursing*, *23*(17-18), 2649–2657. doi:10.1111/jocn.12522

Wojcik, W., Armstrong, D., & Kanaan, R. (2011). Chronic fatigue syndrome: Labels, meanings and consequences. *Journal of Psychosomatic Research*, *70*(6), 500–504. doi:10.1016/j.jpsychores.2011.02.002

Wong, P.T.P. (2011). Reclaiming positive psychology: a meaning-centered approach to sustainable growth and radical empiricism. *Journal of Humanistic Psychology*, *51*(4).

Wong, P., & Wong, L. (2013). 2012 Meaning Conference. *International Journal of Existential Psychology and Psychotherapy*. doi:10.1056/NEJM197302222880814

Wright, T. A., & Cropanzano, R. (2000). Psychological well-being and job satisfaction as predictors of job performance. *Journal of Occupational Health Psychology, 5,* 84-94.

Wright, T. A. & Staw, B. M. (1999, Jan). Affect and favorable work outcomes: Two longitudinal tests of the happy-productive worker thesis. *Journal of Organizational Behavior, 20*(1), 1-23.

Yamamoto, S., Unruh, D., & Bullis, M. (2011). The viability of self-employment for individuals with disabilities in the United States: A synthesis of the empirical-research literature. *Journal of Vocational Rehabilitation, 35*(2), 117–127. doi:10.3233=jvr-2011-0559

Yancey, J. R., & Thomas, S. M. (2012). Chronic fatigue syndrome: diagnosis and treatment. *American Family Physician*, *86*(8), 741-746.

Young, J.E., Weinberger, A.D., & Beck, A,T. (2001). *Cognitive therapy for depression.* In *Clinical Handbook of Psychological Disorders: A Step-by-Step Treatment Manual* (ed. D. D. Barlow), pp. 264–308. Guilford: New York.

Zahra, S. A., Gedajlovic, E., Neubaum, D. O., & Shulman, J. M. (2009). A typology of social entrepreneurs: Motives, search processes and ethical challenges. *Journal of Business Venturing*, 24, 519–532.

Appendix A: CFS Interview Questions

Demographic Questions
Age:
Ethnicity:
Gender:
When were you diagnosed with Chronic Fatigue Syndrome:

Interview Questions
1) When you were first diagnosed with Chronic Fatigue Syndrome, how did the symptoms and the diagnosis itself impact your life?
2) What were the factors that led you to pursue entrepreneurship or self-employment?
3) Did you face any challenges along the way?
4) How did you cope with these challenges?
5) Have your symptoms been exacerbated by your work at any point, and how did you manage this?
6) Have you noticed any changes in your health since starting this entrepreneurial/ self-employed endeavor?
7) Did you have any supports in place? What additional supports might have been helpful?
8) What are the rewards of having pursued a path of entrepreneurship?
9) Has working as an entrepreneur given you a sense of meaning, purpose, or fulfillment?
10) Over the course of being self-employed and/or working as an entrepreneur, how has your work or life changed?
11) Has being self-employed or working as an entrepreneur affected your well-being and overall health? If so, how?
12) Based on your experiences, what advice would you give to an individual with Chronic Fatigue Syndrome who would like to be self-employed or become an entrepreneur?