EVALUATING THE WORLD HEALTH ORGANIZATION INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH FRAMEWORK AS AN EMPLOYMENT MODEL FOR PEOPLE WITH EPILEPSY

by

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DEDICATION

I dedicate this dissertation to my family, especially to
my lovely Mom, Lei Ying Cheung, and Dad, Wan Chu Sung.

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ABSTRACT

Work is fundamental to the well-being and quality of life of people with epilepsy. However, the employment rate of people with epilepsy is notoriously low and has not changed materially during the last three decades. A thorough understanding of complex person-environment factors and their interaction effects on employment will help researchers and clinicians better understand the dynamics of disability and work so that they can develop effective interventions to improve employment outcomes of people with epilepsy. The purpose of this study was to evaluate the World Health Organization's International Classification of Functioning, Disability, and Health (ICF) framework as a comprehensive employment model for people with epilepsy. The contribution of each individual ICF construct on work participation and the interaction effects among ICF constructs were analyzed using hierarchical regression analysis. This study also examined the extent to which the relationship between contextual factors and work participation for this population might be mediated by work-related skills. Results from the hierarchical regression analysis suggest that demographic variables (i.e., disincentives), disability-related variables (i.e., number of antiepileptic drugs), work-related variables (i.e., general employability, work tolerance, and work communication skills), and environmental variables (i.e., perceived stigma and social support) account for over 55% of the variance in work participation in this study. Follow-up mediator analyses provide support for the partial mediating effect of work-related skills on the relationships between self-esteem and work participation as well as perceived stigma and work participation. However, support for the moderating effect of work-related skills on the relationship between perceived stigma and work participation was not found. This study contributes new knowledge about the effect of work functioning, personal factors, and environmental factors on work participation of people with epilepsy, providing theoretical guidance and research evidence for developing and validating efficacious, effective, and efficient employment interventions. Clinical interventions focused on enhancing seizure control, improving work-related skills, and increasing social support are likely to increase work participation for, and subsequent employment outcome for, people with epilepsy.

CHAPTER ONE

Introduction

This chapter provides an overview of the World Health Organization (WHO) International Classification of Functioning, Disability, and Health (ICF) and current challenges related to employment of people with epilepsy. A description of the problem and a theoretical framework are provided and the purpose of this study and its significance are explained.

Statement of the Problem

Employment is fundamental to the physical health, psychological well-being, and quality of life of people with and without disabilities, including people with epilepsy (De Boer, 2005; Dutta, Gervey, Chan, Chou, & Ditchman, 2008). Research suggests that employment is a critically important factor in providing avenues for economic security and access to health insurance and in facilitating social participation as well as improving health and quality of life (Bishop & Chiu, 2011).

Epilepsy is the fourth most common neurological disorder in the United States. It is a chronic condition that is often viewed as a “hidden” disorder in an apparently “normal” individual (Tedman, Thornton, & Baker, 1995). It affects more than 2.2 million people (i.e., 1 in 26 people will develop epilepsy at some point in their lifetime) in the United States and more than 65 million people worldwide (Institute of Medicine [IOM], 2012). Most people with epilepsy want to and are able to work. Neither the epilepsy condition itself nor related treatments affect the ability to work. Despite this, literature shows that unemployment and underemployment continue to be a profound problem for people with epilepsy (Smeets, van Lierop, Vanhoutvin, Aldenkamp, & Nijhuis, 2007). For instance, the 1978 report by the U.S.-based Commission for the Control of Epilepsy and its Consequences acknowledges that although understanding and treatment of epilepsy have progressed and laws have been enacted to protect people with disabilities, "the number of unemployed people with epilepsy remains disproportionately high--over twice the national average" (p. 85).

Importantly, despite numerous employment-related services offered by various organizations, research has indicated that this situation has not changed substantially during the last three decades, and the employment rate of people with epilepsy continues to be notoriously low (Bishop & Chiu, 2011; Smeets et al., 2007). A recent U.S. Bureau of Labor Statistics (BLS; 2009) Employment Situation report estimated the employment rate for individuals with disabilities to be 18% compared to 64% for people without disabilities. The Epilepsy Foundation (2010) further reported that people with epilepsy have an unemployment rate of 25% compared to the 9.5% rate for workers without disabilities. Known consequences of unemployment and underemployment include depression and anxiety, alcohol and other drug abuse, low self-esteem, and poor quality of life (Dutta et al., 2008).

Unemployment and underemployment. Employment serves a number of important functions such as providing a sense of self-worth, identity, and personal status. It is a very important factor in providing economic security and access to health insurance as well as facilitating psychosocial adjustment, social participation, and community integration of people with epilepsy (Baker, 2005; Fisher, Vickrey, & Gibson et al., 2000). Although most people living with epilepsy are capable of full participation in the labor market, they consistently have higher levels of unemployment compared to the general population (Bishop, 2002, 2004; Fisher, 2000; Kobau et al.,2008; Smeets et al., 2007). For some people with epilepsy, transportation to and from work poses major challenges in obtaining and maintaining regular employment (Bishop, 2002, 2004). Research figures indicate that the unemployment rate of people with epilepsy is at least two times greater than that of the general population and higher than is seen in people with other disabilities (Clarke, Upton, & Castellanos, 2006; Fisher, 2000). The recent recession has had a disproportionate impact on workers with disabilities, with the number of employed workers with disabilities declining at a rate that is more than three times higher than that of workers without disabilities. Further, people with disabilities who are employed are more likely to be employed in unskilled and manual labor jobs or to be underemployed (employed in a position that requires less skill, education, or training than they possess, resulting in lower earnings) (Bishop & Chiu, 2011; Fisher et al., 2000; Smeets et al., 2007).

A recent large community-based survey of more than 1000 people with epilepsy suggested that 25% of the sample was unemployed. Among those whose seizures are poorly controlled, the unemployment rate approaches 50%. Of these, 64% attributed their unemployment to their epilepsy (Fisher et al.). This study was conducted at a time when the average unemployment rate in the United States was slightly over 5%. Although disability legislation (e.g., Americans with Disabilities Act [ADA] of 1990) has been enacted to protect the rights of people with epilepsy in the workplace, inequity and unfair treatment still persist. One of the enormous challenges is acceptance by employers (Sample, Ferguson, Wagner, Elisabeth-Pickelsimer, & Selassie, 2006), and it was noted that a critical factor for maintaining a job was finding an employer who was supportive and knowledgeable concerning epilepsy (Bishop, 2002).

Estimated financial losses. People with disabilities make up 20% of the U.S. population but account for 47% of health care expenditures. As mentioned, epilepsy and seizures affect approximately 2.2 million Americans of all ages at an estimated annual cost of $15.5 billion in the United States through direct and indirect costs. Data from a 2005 Behavioral Risk Factor

Surveillance Study (BRFSS) from the Centers for Disease Control and Prevention (CDC) (Kobau et al., 2008) summarized population-based data derived from 19 U.S. states showing that individuals with a history of active epilepsy are more likely than people with no history of epilepsy to report fair or poor health, to be unemployed or unable to work, to live in households with the lowest annual incomes, and to have a history of co-occurring medical and psychiatric disorders (Bishop & Chiu, 2011). A survey in South Carolina further shows that of those who are unemployed, 73% attribute unemployment to their epilepsy. However, 68% of them had gone to college, technical school, or graduate school, which indicates that they have been very well prepared to participate in the workforce and society is not benefiting from their talent. Thus, it is essential to improve secondary physical and mental health conditions, employment status, and quality of life of people with epilepsy (Ravesloot, Seekins, & White, 2005).

Impact on quality of life. A productive and satisfying work life is an important ingredient to overall quality of life for people with epilepsy (Collings, 1990a, 1990b; De Boer, 2005). Working and earning a living are external signs of integration into society and acceptance by others (Baker, 2005). It is suggested that employment is a significant predictor of the well-being of people with epilepsy (Collings, 1990a) and is also a very important factor in psychosocial adjustment (Dodrill, Batzel, Queisser, & Temkin, 1980). Employment, apart from its economic value, has a strong positive effect on self-esteem, self-fulfillment, self-image, self-worth, and identity of people with epilepsy (Bishop, Berven, Hermann, & Chan, 2002; Collings, 1990b; Schachter, Shafer, & Murphy, 1993). For all people, being unemployed contributes to emotional and behavioral problems. For people with epilepsy, unemployment and underemployment serve as a major source of stress and distress, which in turn increases the risk for psychiatric comorbidities such as anxiety and depression. Aside from personal satisfaction, health care benefits available from employers are a factor in improved life quality. Full time employment may greatly reduce the financial burdens and comorbidities associated with epilepsy (Bishop & Chiu, 2011).

Factors affecting employment for people with epilepsy. Research exploring the array of clinical and psychosocial variables contributing to the employment problems and barriers faced by people with epilepsy suggests that employment disparity is not due to any single factor (e.g., seizure severity) (Clarke et al., 2006; Smeets et al., 2007), but is the result of a set of adverse factors interacting with each other in a complex manner (Thorbecke & Fraser, 1997). Along with the physical and cognitive implications associated with seizures, epilepsy has been associated with psychological and emotional problems, with social isolation, and also with problems in education, family life, leisure activities, and employment (Thompson & Oxley, 1993). The stigma and social misunderstanding associated with the epilepsy label frequently result in isolation, social restriction, and barriers to work and psychosocial functioning.

The literature indicates that the unemployment and underemployment problem of people with epilepsy continues to be profound but it is still underexplored. Efforts at understanding the employment challenges faced by people with epilepsy have revealed a complex interaction of internal (personal) and external (environmental) factors. A number of epilepsy-related variables and potential barriers to employment have been examined for their impact on employment status. Among the most frequently evaluated variables that have been investigated for relationship to employment are seizure type, severity, and frequency (e.g., Bishop, 2004; Chaplin, Wester, & Tomson, 1998; Heaney, 1999; Jacoby, 1995). Rates of unemployment have consistently been found to be higher among individuals with more frequent seizures (Chaplin et al., 1998; Yagi, 1998), and among persons with active epilepsy compared with people whose epilepsy is in remission or is well controlled (Elwes, Marshall, Beatty, & Newman, 1991; Jacoby, 1992). Cognitive and neuropsychological functions have also been examined for their relationship to employment status, and neuropsychological indicators have also consistently been demonstrated to predict employment (Clemmons & Dodrill, 1983, 1984; Fraser, Clemmons, Dodrill, Trejo, & Freelove, 1986). Additionally, various psychosocial factors have been implicated in the high unemployment rate among people with epilepsy. These factors include lack of education, social isolation, lack of information, social skill deficits, and lack of family support (Devinsky, 1994; Thorbecke & Fraser, 1997). Finally, fear of employer discrimination or stigmatization at work appears to significantly influence the employment situation for people with epilepsy.

Recognizing the importance of employment, vocational rehabilitation (VR) professionals have consistently advocated for employment as being a fundamental human right of people with disabilities (Chan, Shaw, McMahon, Koch, & Strauser, 1997). Clearly, the consistent employment challenges facing people with epilepsy cannot be attributed to seizure severity alone, and a new approach to conceptualize employment issues and interventions is very much warranted. Since the late 1980s, the conceptualization of *disability* has shifted from a medical model to a socio-ecological model, emphasizing the contribution of the environment to the definition of disability and the importance of inclusion of people with disabilities into society (Chan, Sasson, Ditchman, Kim, & Chiu, 2009).

The effort that has been made since that time in promoting equality, health, and accurate information and knowledge for people with epilepsy is unrivaled in human history and heralds a more promising employment future. However, much work remains to be done in advocating for equal access and legal protection, changing public and employer attitudes, and developing effective and innovative methods of preparing people with epilepsy to succeed in employment.

Therefore, a thorough understanding of these complex interactions between adverse internal (personal) and external (environmental) factors is particularly important (Smeets et al., 2007), not only to understand the dynamics of epilepsy and employment but also to develop and validate efficacious, effective, and efficient employment interventions.

Assumptions and Theoretical Framework

Recently, the WHO International Classification of Functioning, Disability, and Health (ICF) model has gained wide acceptance among international rehabilitation health researchers and professionals as a framework that can be used to support a systematic approach for understanding the effects of chronic illness and disability on inclusion and community participation across cultures, thus increasing the empirical basis for rehabilitation counseling practice (Chan, Keegan, et al., 2009; Chan, Sasson, et al., 2009; Peterson & Rosenthal, 2005). Within the ICF framework, functioning and disability have a complex interaction with the health condition of the individual and with the contextual factors of the environment (e.g., negative societal attitudes) as well as with personal factors (e.g., coping styles).

Specifically, the ICF paradigm as originally put forth by the WHO is structured around five components: (a) *body functions and structures*, (b) *activities* (related to tasks and actions by an individual), (c) *participation* (involvement in a life situation), (d) *personal factors,* and (e) *environmental factors*. Chan et al. (2011) revised the ICF model slightly to show the complex relationships among all the components and added a sixth component, *quality of life*. Figure 1 depicts the ICF model as proposed by Chan et al., showing the relationships among all the components. The emphasis of the ICF is on function (capabilities) rather than condition or disease (incapabilities) and is designed to be relevant across multiple cultures as well as age, gender, and disability, making it highly appropriate for heterogeneous populations. As illustrated in Figure 1, the ICF is a biopsychosocial model that provides a coherent view of the various dimensions of health at the biological, individual, and social levels.

The ICF model was used as a framework because it integrates aspects of the need to treat and prevent disease (the traditional medical model) with the goal of increasing participation in daily life activities (the social model) (Crimmins & Seeman, 2004). Literature suggests that the unpredictable nature of seizures can have a great impact on employment and quality of life. This study covers each of the five components from an employment focus. *Body functions and structures* refer to the impact of epilepsy. *Activities* refer to the work abilities and skills of people with epilepsy. *Participation* refers to the employment situation for people with epilepsy. *Personal factors* correspond to the internal and psychosocial factors of people with epilepsy (in this study, personal factor construct was specifically conceptualized as *positive personal traits*). *Environmental factors* refer to stigma at the workplace and in society toward people with epilepsy.

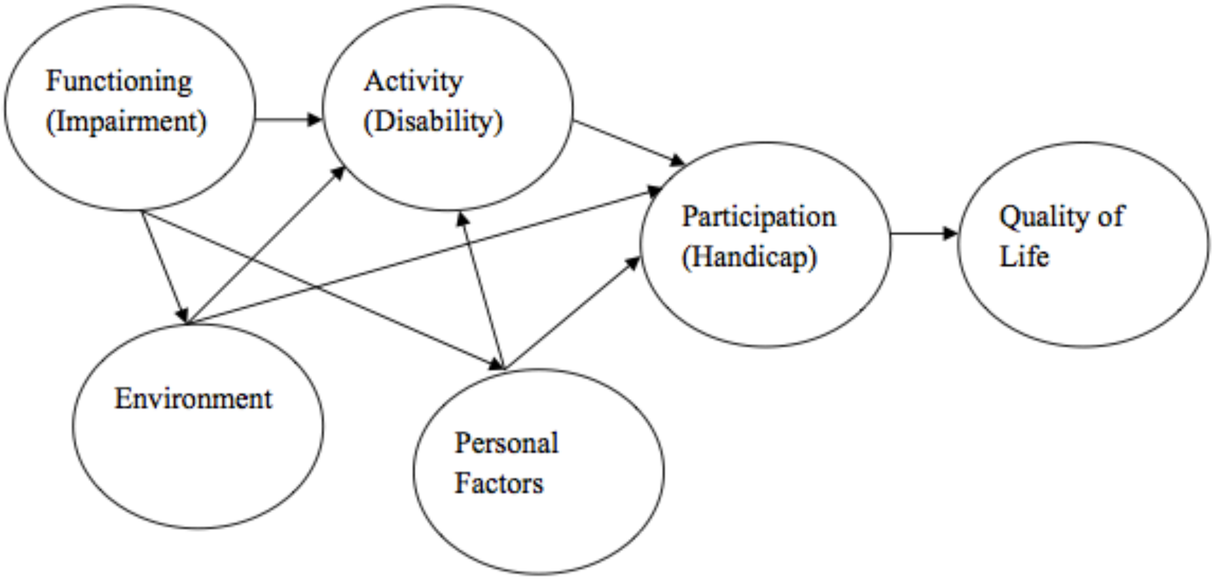

Figure 1. *The Framework of the World Health Organization ICF Model adapted from Chan et al. (2011).*

Literature indicates that persistent unemployment and underemployment problems of people with epilepsy cannot be reduced to a single factor (e.g., seizure severity) but the result of a set of adverse internal (personal) and external (environmental) factors interacting with each other in a complex manner. The ICF, because of its emphasis on the effects of contextual factors, is therefore ideally suited for use by rehabilitation counselors as a vocational rehabilitation framework to conceptualize medical, psychosocial, and vocational rehabilitation assessment and service needs and to provide holistic evidence-based interventions for people with significant disabilities, including people with epilepsy. The ICF can also be used to develop a systematic research agenda to develop and validate evidence-based practices for vocational rehabilitation (Chan, Tarvydas, Blalock, Strauser, & Atkins, 2009). A thorough understanding of these complex factors and their interaction effects on employment helps researchers and clinicians better understand the dynamics of disability and work so that effective interventions can be developed to improve employment outcomes of individuals with many types of disabilities.

In particular, the ICF can serve as a useful conceptual framework for studying complex internal and external factors associated with employment outcomes of people with epilepsy. As a first step, epilepsy researchers must scientifically examine the relationships among the constructs in the ICF and determine how these constructs interact to affect employment and quality of life of people with epilepsy (Chan, Keegan, et al., 2009). Subsequently, evidence-based employment interventions can be developed to improve functioning, increase activity levels, maximize individual strengths, modify the environment (e.g., employer attitudes), encourage full participation in the community, promote health and mental health well-being, and increase employment opportunities for people with epilepsy. The time is now ripe to apply the ICF framework to the development of such an evidence-based employment model.

Statement of Purpose

The primary purpose of this study was to formulate and evaluate an ICF-based model of employment for individuals with epilepsy. This study was based on the fundamental assumption that employment is a personally meaningful life event that involves dynamic and idiosyncratic processes encompassing multiple variables associated with work functioning, personal factors, and the environment.

The ICF conceptual framework has not been used to evaluate employment outcomes for people with disabilities, but it has been used to evaluate health conditions, quality of life, and other outcome measures in studies about people with a variety of chronic illnesses and disabilities. The ICF has also been used with extant data such as surveys and established scales of measurement (e.g., Brockow et al., 2004). In this study, the ICF model was used as a research framework to evaluate, through hierarchical regression analysis, a comprehensive employment model for people with epilepsy. This study examined how functioning/severity, activities, personal factors, and environmental factors are associated with work participation for people with epilepsy. This study was intended to generate new knowledge about the contribution of personal and environmental factors to employment outcomes of people with epilepsy, and to provide a new research direction for developing and validating innovative, efficacious, effective, and efficient employment interventions. The specific research questions were as follows:

Research Question 1: Do the ICF constructs (i.e., *functioning/severity, activities, personal factors,* and *environment factors*) predict *work participation* of people with epilepsy? For this research question, it was hypothesized that all four contributing *ICF constructs* account for a significant amount of variance in *work participation*.

Research Question 2: Do *work-related abilities/skills* mediate the relationship between selected personal factor (i.e., *self-esteem*) and *work participation*, it was hypothesized that *work-related abilities/skills* partially mediate the relationship between *self-esteem* and *work participation*.

Research Question 3: Do *work-related abilities/skills* mediate the relationship between selected environmental factor (i.e., *perceived stigma*) and *work participation*? For this research question, it was hypothesized that *work-related abilities/skills* partially mediate the relationship between *perceived stigma* and *work participation*.

Research Question 4: Do *work-related abilities/skills* moderate the relationship between selected environmental factor (i.e., *perceived stigma*) and *work participation*? For this research question, it was hypothesized that *work-related abilities/skills* moderate the relationship between *perceived stigma* and *work participation*.

Significance of This Study

Unemployment and underemployment of people with epilepsy continue to be serious problems. The literature indicates that people with epilepsy may face a number of complex and interacting problems in finding and maintaining employment (Smeets et al., 2007). Researchers agree that, among people with epilepsy, the opportunities to find and maintain regular employment are often limited. To increase the employment prospects of people with epilepsy, much work has to be done. This study provides a pioneer conceptual overview of the employment outcomes experienced by people with epilepsy and the main factors that contribute to those outcomes. Personal/internal factors always play a significant role in employment and quality of life of people with epilepsy. However, psychosocial problems are highly diverse and often difficult to define, so specifying the precise interactions between psychosocial variables and the employment position of people with epilepsy is challenging. Furthermore, the complexity of behavioral factors, internal/personal factors, and external/environmental factors makes it even more difficult to determine the exact impact of psychosocial problems on work participation. To classify the affecting (internal and external) factors, the ICF framework becomes a useful and effective tool.

This study is significant and unique in a number of respects. First, in this study, a comprehensive evaluation of various demographic, disease-related, and work-related variables associated with employment among individuals with epilepsy is conducted using the ICF framework. The variables that distinguish people with epilepsy who work are determined, and those variables that are independently associated with employment are identified. The literature indicates that employment problems for people with epilepsy are still underexplored, especially in light of the previously mentioned multifactorial approach. Given the enormous indirect costs of epilepsy (Begley et al., 2000) and the increasing number of disability beneficiaries (Social Security Administration [SSA], 2006), it is particularly important to understand these unemployment problems and it is helpful to give this information to numerous agencies (Epilepsy Foundation, 2010; Morrell, 2002) whose goal is to increase the productivity of people with epilepsy. While current studies advance researchers' knowledge of intervention factors affecting employment among people with epilepsy, a significant deficit remains in terms of thorough understanding of these complex factors and their interaction effects on employment.

Second, this study provides an increased understanding of the personal and environmental factors related to employment in people with epilepsy that can assist in addressing significant concerns about issues of comorbidities. Unemployment and underemployment are major sources of stress and distress, which in turn increase the risk for psychiatric comorbidities such as anxiety and depression. Studies indicate that depression occurs in approximately 20% of people with epilepsy. Also, suicide rates among people with epilepsy are five times higher than the rate for the general population, so people with epilepsy must be aware of depression and its warning signs. Factors independently associated with higher mortality include poor personal-social abilities (Sachs & Barrett, 1995). Moreover, physical and psychological morbidity in people with epilepsy is significant. Activity limitations are common and the most problematic limitations are related to work ability.

Third, this study represents a fundamental step in future research direction. Understanding the patterns and predictors of employment in people with chronic epilepsy represents an introductory step in characterizing the vocational rehabilitation needs of this population. Although a number of personal and environmental factors influence employment outcomes, vocational rehabilitation systems vary widely within districts and states. Thus, it may be inherently more useful in terms of potential interventions to understand the individual predictors of employment outcomes as they relate to people with epilepsy. If researchers are able to consistently demonstrate patterns and predictors of employment, then efficacious, effective, and efficient employment interventions can be developed and implemented to identify and assist at-risk people with epilepsy in obtaining employment.

CHAPTER TWO

Literature Review

This chapter provides a review of the current literature pertaining to the topics associated with the variables of interest in this study to inform the research design and the subsequent discussions regarding research findings. A review of the International Classification of Functioning, Disability, and Health (ICF) framework was conducted in order to describe its historical development, components, and research needs. In addition, the literature associated with employment specific to people with epilepsy is summarized. The primary focus is on the studies pertaining to employment outcomes and work participation, although studies pertaining to functioning/severity and activities in people with epilepsy is also reviewed. Finally, an introduction to personal factors and environmental factors and how they impact employment for people with epilepsy is provided.

Epilepsy and Employment Research

Epilepsy is one of the most common neurological disorders worldwide, affecting 65 million people (World Health Organization [WHO], 2010), including an estimated 2.2 million people in the United States alone (Epilepsy Foundation, 2010; Hirtz, Thurman, Gwinn-Hardy, Mohammed, Chaudhuri, & Zalutsky, 2007). Epilepsy is a chronic, episodic neurological disorder characterized by recurrent, transient disturbances in the electrical functions of the brain that result in seizures. Signs and symptoms of seizures include sudden and transitory phenomena, such as alterations of consciousness, or involuntary motor, sensory, autonomic, or psychic effects (Hauser, Annegers, & Kurland, 1993). Many people with epilepsy also experience certain signs and symptoms immediately after seizures, such as memory impairment, fatigue, depressive symptoms, or anxiety (i.e., the postictal state) (Fisher & Schachter, 2000). Seizures are broadly classified into generalized, partial, and unclassifiable types, with additional subcategories; persons can experience more than one seizure type (Hauser et al., 1993).

The unpredictable nature of seizures, as well as the adverse effects of treatment, can make epilepsy particularly disruptive of daily life in all domains. Because of the stigma and lack of understanding associated with epilepsy, however, a diagnosis of epilepsy can lead to issues completely unrelated to seizures or their treatment. Indeed, the fear and stigma associated with the diagnosis of epilepsy can be much more restrictive and disabling than the seizures that led to the diagnosis. In addition to the physical and cognitive implications of seizures, epilepsy has been associated with psychological and emotional problems, with social isolation, and with problems in education, family life, leisure activities, and employment (Thompson & Oxley, 1993).

Being employed or participating in work is an important ingredient to quality of life for people with epilepsy. The World Health Organization (WHO) also recognizes employment as an important part of social health. Even though the majority of professionals working in epilepsy care now believe that most people with epilepsy should and can perform as well in the labor market as other people do, research tells a different story. Unemployment and underemployment have been recognized as significant problems for people with epilepsy over the last three decades (Dreifuss, 1995; Fraser, 1980). Available evidence underscores consistent and persistent employment problems for people with epilepsy. Responses to a community-based survey of adults with epilepsy indicated that 25% of eligible workers reported being unemployed at a time when the average unemployment rate in the United States was slightly greater than 5% (Fisher et al., 2000). Data from the 2005 Behavioral Risk Factor Surveillance Study (BRFSS), which included population data from 19 states, suggested that the unemployment rate was 9.8% for people with active epilepsy, 8.3% among those with inactive epilepsy, and 5.4% for those with no epilepsy history (Kobau et al., 2008). Nine-state data from the 2006 BRFSS indicated that people with a lifetime prevalence of epilepsy were more than three times as likely to be unemployed or unable to work as people who did not have epilepsy (34% versus 9%), and in a similar comparison, people with active epilepsy were more than four times as likely to be unemployed or unable to work (42% versus 9%) (Konda et al., 2009).

Although estimates of the extent of employment disparities vary based on methodology and sample characteristics, relatively lower levels of employment have been consistently found for people with epilepsy for more than three decades (Bishop, 2002). Employment disparities have continued despite improvements in clinical treatment and laws protecting the employment rights of people with disabilities (Jacoby, Gorry, & Baker, 2005). The potential loss of manpower from nonuse of the full economic potential of individuals with epilepsy is substantial. The indirect cost of epilepsy (lost income due to unemployment or underemployment) is estimated to be 86% of the total cost of the disease, or more than $10 billion per year (Begley et al., 2000). The consistent nature of unemployment and underemployment among people with epilepsy is likely associated with the fact that problems in attaining and maintaining employment are complex and multifaceted (Baker, Nashef, &VanHout, 1997; Birbeck, Hays, Cui, & Vickrey, 2002; Sperling, 2004). Thus, it is important to understand not only the possible problems but also the underlying factors contributing to the problems.

There remains broad agreement in the literature that the employment problems of people with epilepsy cannot be reduced to only one factor (e.g., seizure severity) but rather that they are the result of a bundle of adverse internal (personal) and external (environmental) factors interacting with each other in a complex fashion (Clarke et al., 2006; Thorbecke & Fraser, 1997).

In addition to the effects of functional limitations directly associated with seizures or the side effects of seizure medications, employer and coworker discrimination and stigma remain implicated in the low employment rate among people with epilepsy (Bishop, 2002).

In the last two decades, researchers have made numerous efforts to understand determinants of employment among people with epilepsy. However, most studies that have looked at the employment situation of people with epilepsy in the United States have focused on the subset of factors that are attributed to unemployment and underemployment. Dimken and Morgan (1980) and Fraser et al. (1986) looked at different neuropsychological parameters associated with employability, whereas Scambler and Hopkins (1980, 1986) focused on social class and seizure frequency as predictors of employability. Other major studies have undertaken a comprehensive evaluation of the employment characteristics of people with epilepsy. Collings and Chappell (1994) and Elwes et al. (1991) studied individuals with epilepsy from the United Kingdom, whereas Chaplin et al. (1998) looked at people with epilepsy in Sweden, and Yagi (1998) focused on Japan. These studies concluded that employment among people with epilepsy is due to a combination of favorable clinical variables (e.g., good seizure control) and psychosocial variables (e.g., higher education and decreased fears of stigma). However, there is limited underlying theoretical framework behind those studies due to lack of clearly defined and comprehensive model for the conceptualization of the employment issues among people with epilepsy, and there are cultural and other limitations that may affect the generalizability of these studies to the situation in the United States.

Various theoretical models have been reviewed to conceptualize the employment situation of people with epilepsy. The ICF has been adopted as a framework to classify the affecting (internal and external) factors and understand how they affect the employability and regular employment positions of people with epilepsy. This state-of-the-art model developed by the WHO reflects the interactive relationship between health conditions and contextual factors (Rosenbaum & Stewart, 2004). The ICF is an international standard focusing on the capabilities of people rather than their incapabilities. It is intended to be a universal classification system, meaning that it covers not just people with disabilities but all people.

Historical Context of the ICF Model

The international classification of population health began with a focus on the prevalence of medical diagnoses and causes of death. For many years, the medical model drove assessment practices in health care service provision, focusing on the diagnosis of a disease, disorder, or injury (Wright, 1980). Within the medical model, less attention was given to contextual factors (e.g., social and environmental factors) and to the subjective experiences of individuals with disabilities. A disability tended to be conceptualized as a personal problem that required treatment by medical professionals (WHO, 2001).

One example of the medical model's influence on the diagnostic classification of illness or injury is the International Statistical Classification of Diseases and Related Health Problems (ICD), which evolved from the Bertillon Classification or the International List of Causes of Death, which was formalized in 1893. The ICD provides an etiological classification of health conditions (e.g., diseases, disorders, and injuries) related to mortality (death) and morbidity (illness). Although the ICD continues to be influential, its limitations, combined with civil rights and disability activism, contributed to the development of the social model of disability. Contemporary scholarship suggests that behavioral and social factors affect the course of chronic disease and disability over a life span; the medical model and related diagnostic information have a limited capacity for assessment and improvement in these areas (Peterson & Elliott, 2008).

In the social model of disability, disability is no longer seen as a simple personal attribute but rather as a complex social construct reflecting the interaction between an individual and his or her environment (WHO, 2001). The social model of disability highlights the importance of a person's subjective experience as it relates to facilitators and barriers that the environment may present, their impact on health and functioning (such as daily activities, life skills, social relations, life satisfaction, and participation in society), and ultimately an individual's quality of life (Elliott, Kurylo, & Rivera, 2002; Ueda & Okawa, 2003). However, historically, the social model has neither clearly distinguished who qualifies as a person with a disability nor how disability is measured or determined.

The predecessor to the ICF was the International Classification of Impairments, Disabilities and Handicaps (ICIDH), put forth by the WHO (1980), which became the ICIDH-2 (WHO, 1999) and finally the ICF. Hurst (2003) challenged the ICIDH development efforts, claiming that it perpetuated the medical model, countered the social model of disability, and presented barriers to the understanding of issues related to social justice and disability among health care providers. In response to this criticism, the WHO made a concerted effort to involve people with disabilities and disability rights advocates in the ICIDH revision process that produced the ICF.

The evolution of the ICIDH to the current iteration of the ICF reflects the international zeitgeist to embrace a biopsychosocial model of disability rather than a medical or social model exclusively. The ICF was developed through years of international participation and systematic revision, including longitudinal consensus building efforts and extensive field-testing, and it is a significant development in psychology and general health care. On May 22, 2001, the ICF was endorsed by the 54th World Health Assembly for international use and was subsequently accepted by 191 countries as the international standard for classification of health and health-related states.

The ICF integrates the medical and social models of disability, addressing biological, individual, and societal perspectives on health in a biopsychosocial approach (Peterson, 2005). The origins of the biopsychosocial framework can be traced to an article from the 1970s arguing for a new medical model for biomedicine (Engel, 1977). Ultimately, the biopsychosocial model integrates all that is useful from both the medical and social models of disability.

Disability Policy and the ICF Model

A review of disability policy from the 1940s through the 1960s shows how the new thinking affected policy shifts away from the traditional medical model and the disparity between physical and mental health, toward a more inclusive approach to resourcing both physical and mental health initiatives and addressing the contextual issues in the environment that present barriers to full participation in society for people with physical disabilities. One example of such a policy shift is the Vocational Rehabilitation Act amendments of 1954, 1965, and 1967, which provided an income allowance (Supplemental Security Income, [SSI]) to individuals with disabilities, behavior disorders, or substance use problems and people from socially disadvantaged backgrounds. These amendments also included major funding for research and development grants. The increase in resources for disability-related research undoubtedly had an impact on scholars’ ability to invest time, think creatively, and consider the benefits of movement away from the medical model toward the social model and, ultimately, the biopsychosocial model of disability conceptualization that currently informs the ICF (Peterson, 2011).

A review of the 1970s disability policy developments reveals emphases on consumerism, informed choice, and full participation of clients in their physical rehabilitation, vocational rehabilitation, and health-related services. One such policy was in the Rehabilitation Act of 1973, which emphasized increased services to persons with the most severe disabilities and greater consumer involvement in the rehabilitation planning process (Rubin & Roessler, 2008). There was also a greater recognition of the detrimental effects of societal and individual discrimination on persons with disabilities. It was during the early 1970s when these policies were implemented that work began on the ICIDH (Peterson, 2011).

Later, in 1992 additional amendments to the Rehabilitation Act ensured increased emphasis on independent living services and highlighted the importance of employment outcomes for persons with disabilities. The 1992 amendments included provisions that empowered people with disabilities by requiring increased participation of people with disabilities in the planning and implementation of rehabilitation services. These amendments influenced subsequent developments in addressing context within the ICF.

Theoretical Framework of the ICF Model

The ICF is a biopsychosocial model that provides a coherent view of the various dimensions of health at the biological, individual, and social levels. In the biopsychosocial model, the ultimate goal of rehabilitation is participation, that is, returning people with disabilities to active, productive lives in the community. The ICF enables rehabilitation health professionals to conceptualize the problem that an individual is presenting and to provide treatment solutions from a holistic perspective. The ICF draws on the voluminous research generated by ICF researchers from different health care and rehabilitation disciplines to enhance clinical decision-making. The ICF also provides a framework with unified and standard language that enables sharing of information across different systems internationally (WHO, 2001).

The ICF consists of two main parts: (1) *functioning and disability*, and (2) *contextual factors.* These are further subdivided into two subcomponents each. The first subcomponent of *functioning and disability* is *body functions and structures*, which are interpreted through changes in physiological systems or anatomical structures. The second subcomponent is *activities and participation,* which are interpreted through capacity and performance (Peterson & Rosenthal, 2005). The first subcomponent of *contextual factors* is *environmental factors,* or factors in the physical, social, or attitudinal world, ranging from the immediate to more general environment. Environmental factors either facilitate or hinder functioning. The second subcomponent is *personal factors*, which are not currently classified in the ICF due to the complex nature of social and cultural variations across the world, but this factor exists in the conceptual framework to call attention to the need to consider unique factors like gender, race, age, fitness, religion, lifestyle, habits, upbringing, coping styles, social background, education, profession, past and current experience, overall behavior pattern and character, individual psychological assets, and other health conditions.

Definition of ICF Components

Functioning, impairment, and disability. *Functioning* within the ICF includes all body functions, structures, activities, and participation in society. It denotes the positive aspects of health and functioning. *Impairments* are defined as the manifestations of dysfunction in the body structures or functions rather than as the underlying pathology itself. Etiology of dysfunction is not the focus of the ICF but rather is the focus of its sister classification, the ICD-10 (WHO, 1992).

Impairments do not necessarily imply the presence of a disorder or disease but "represent a deviation from certain generally accepted population standards" of functioning (WHO, 2001, p. 12). Determination of impairment is made by "those qualified to judge physical and mental functioning according to these standards" (p. 12).

Disability refers to any impairments, activity limitations, or participation restrictions, or "the outcome or result of a complex relationship between an individual's health condition and personal factors, and of the external factors that represent the circumstances in which the individual lives" (WHO, 2001, p. 17). In contrast with functioning, disability relates the negative aspects of the interaction between the individual with a health condition and his or her context (i.e., environment and personal factors).

Body functions and structure. The first component of *functioning and disability*, *body function and structures*, comprises two classifications: (1) *Body functions,* that is, physiological and psychological functions of body systems (e.g., mental/sensory/speech/language functions, and functions of digestive/metabolic/endocrine systems) and (2) *body structures,* that is, anatomical parts of the body (e.g., organs, limbs, and their components, including the brain and nervous system) (WHO, 2001). The ICF uses *body functions* and *body structures* to identify problems in related functioning for a given health condition, which may then inform treatment needs, intervention targeting, or even prevention efforts. Body functions and body structures are qualified according to the level of impairment (i.e., severity). The criteria for impairment are the same for body functions and structures and are classified according to (a) loss or lack, (b) reduction, (c) addition or excess, and (d) deviation. The *body functions and structures* component is intended to be complemented by the *activities and participation* component.

Activities and participation. The second component of functioning and disability, *activities and participation*, covers a wide range of different aspects of functioning from both individual and societal perspectives. *Activity* is defined as the execution of a task or action by an individual (e.g., sitting, running, eating, or driving). It represents the individual perspective of functioning. *Activity limitations* are difficulties that an individual may have in executing activities, from slight to severe deviation in comparison with someone without a given health condition. *Participation* is involvement in a life situation or the societal perspective of functioning. The domains in this component can be used to describe either or both concepts. *Participation restrictions* are problems that an individual may experience in involvement in life situations, determined by comparing an individual's participation to the participation of an individual without disability in that culture or society.

The ICF proposes four possible conceptualizations of the relationship between *activities* and *participation*. The user can code each category as either an activity or participation issue, resulting in two mutually exclusive lists. Australia has adopted this method in their clinical implementation manual. Alternatively, one can use the domains for both *activities* and *participation* simultaneously or as an overlapping list, which is how the U.S. version of a clinical implementation manual in progress is proceeding (Reed et al., 2005; Threats & Worrall, 2004).

Personal factors. *Personal factors* are defined as individual, personal, and inner features that can impact an individual's performance in body functions, activities, and participation (WHO, 2001). Personal factors may include gender, race, age, fitness, religion, lifestyle, habits, upbringing, coping styles, social background, education, profession, past and current experience, overall behavior pattern and character, individual psychological assets, and other conditions, all of which can affect health and functioning. Although *personal factors* are a consideration within the *contextual factors*, they are not described or coded specifically in the ICF because they are not considered to be part of a health condition or health state. However, personal factors are considered within the overall model because they may play a role in the manifestation of functioning, disability, or health at any level and also may affect the outcome of a given intervention.

Environmental factors. *Environmental factors* are defined as the physical, social, and attitudinal environmental (external) features that facilitate or hinder all components of an individual's functioning and disability at the *body functions and structures* levels as well as the *activities and participation* levels (WHO, 2001). *Environmental factors* are organized to focus on two different levels, the individual and societal levels. The individual level has the most immediate environmental influence, for instance, one's home, workplace, or school. Within these contexts, one is influenced by family, peers, acquaintances, and strangers. The physical and material features of the immediate environment are also considered here. The societal level addresses both formal and informal social structures, services, and overarching approaches or systems in the community or society. Related organization services may include work environment, community activities, government agencies, communication and transportation services, informal social networks, laws, regulations, formal and informal rules, attitudes, and ideologies (WHO, 2001, p. 17). Evaluation of these factors provides opportunity for exploration into determinants and risk factors of health conditions as they exist in the environment.

Implementation of the ICF Framework as an Employment Model

Studying the employment outcomes of people with epilepsy is an essential and important activity for rehabilitation researchers and practitioners alike (Worrell & Vandergoot, 1980), and the identification and understanding of variables and strategies related to the successful employment of people with epilepsy is imperative. In addition, given the fact that an individual with a disability is still more likely to be unemployed and living at or below poverty level, as compared to a person who does not have a disability (Szymanski & Parker, 1996), the identification and understanding of personal factors, environmental factors, strategies, and methods effective in improving the quantity and quality of employment outcomes for people with epilepsy remains of utmost importance. The apparently difficult employment situation for people with epilepsy is not reducible to a single factor, such as the experience of seizures, but rather represents a complex interaction of variables (Thorbecke & Fraser, 2008).

A variety of seizure-related factors (e.g., seizure frequency, type, perceived impact, and felt stigma) have been shown to predict employment outcome, as have the age of epilepsy onset, comorbid mental health and cognitive conditions, the adverse effects of seizure medications, and various psychological factors, such as depression and anxiety (Bishop, 2004; Chaplin et al., 1998; Jacoby et al., 1996, 2005; Rätsepp et al., 2000; Yagi, 1998). Psychosocial factors relevant to unemployment rates among people with epilepsy include social isolation, social skill deficits, low self-esteem, lack of social support, and fears about negative attitudes on the part of employers (e.g., Smeets et al., 2007; Thorbecke & Fraser, 2008). External factors, such as enacted stigma and discrimination, also contribute to employment problems for people with epilepsy, and the effects of these may be more significant in times of high unemployment, when competition for jobs is heightened (Jacoby et al., 2005).

There are a multitude of studies examining a variety of variables and their relationships to the employment outcomes of people with epilepsy. Frequently, the results of these studies are not completely consistent. Therefore, employing a theoretical model or framework to determine an overall picture of what seems to be most and least influential in assisting people with epilepsy in becoming successfully employed is crucial to an understanding of the employment outcome research for people with epilepsy conducted to date (Saunders, Leahy, McGlynn, & Estrada-Hernandez, 2006).

The ICF is consistent with the holistic philosophy of vocational rehabilitation, and it holds significant promise as a rehabilitation model that can be used to conceptualize vocational rehabilitation assessment, planning, and intervention for improving employment outcomes and quality of life of people with disabilities (Chan, Tarvydas, et al., 2009). A comprehensive taxonomy of outcome measures can be organized around the major constructs of the ICF to assess the effectiveness of different service providers in the rehabilitation process. This study, therefore, focused on the relationships among constructs in the ICF and how these constructs interact with each other to affect employment outcomes of people with epilepsy (Chan, Keegan, et al., 2009).

In this study, *body functions and structure* referred to epilepsy-related severity and functioning of people with epilepsy. *Activities* referred to the work-related skills and abilities of people with epilepsy. *Participation* referred to the employment situation for people with epilepsy. *Personal factors* referred to the internal and psychosocial factors of people with epilepsy. *Environmental factors* referred to the societal stigma and social support perceived by the people with epilepsy. These components were hypothesized to interact with each other to affect full inclusion, employment, health status, and quality of life of people with epilepsy (WHO, 2001).

The ICF, applied to epilepsy, could facilitate the understanding of needs and successful vocational rehabilitation outcomes. In addition, the model is useful for the identification and remediation of factors contributing to successful employment for people with epilepsy. Based primarily on the ICF framework (WHO, 2001), this study posited that work-related skills/abilities mediate or moderate employment outcomes. Using this framework as a guide and the theoretical and empirical evidence that supports the role of functioning/severity, activities, personal factors, and environment in the employment outcomes, this study investigated the relationship of these internal and external factors to both the positive and negative impact on employment outcomes.

Type of Employment Outcomes

Given the importance of understanding what can influence successful employment outcomes for people with epilepsy, rehabilitation researchers have explored employment outcomes using various definitions, including State/Federal Vocational Rehabilitation closure status (e.g., Andrews, Barker, Pittman, Mars, Struening, & LaRocca, 1992; Wheaton, Wilson, & Brown, 1996), and using competitive employment as a definition for a successful employment outcome (e.g., Moore, 2002; Poole, 1987). Wages are another measure of employment outcome for persons with disabilities (e.g., Fitzgerald, McGowan, & Kutner, 1982; La Forge & Harrison, 1987). Other researchers have explored disability or demographic variables in relation to employment outcomes (e.g., Beck, 1989; Belgrave & Walker, 1991; Bose, Geist, Lam, Slaby, & Arens, 1998; Capclla, 2003a, 2003b; Gouvier, Sytsma-Jordan, & Mayville, 2003; Kaplan, 1988; Saxon, Spitznagel & Shelhourn-Schutt, 1983; Szymanski & Danek, 1992; Vander Kolk & Vander Kolk, 1990). The important employment outcome that was used for this study, however, was stages of change for work participation driven by an empirically derived model proposed by Prochaska and DiClemente (1983). Work participation was adopted as a measured outcome for employment instead of other conventional employment outcomes, such as wage and employment status. Given work participation was highly correlated with employment outcome and considering the nature of the variables (dichotomous vs. continuous), work participation was used to provide additional information.

The Transtheoretical Model (Stages-of-Change Model) proposed by Prochaska and DiClemente (1983) was derived mainly from the work of smoking cessation and substance abuse and addiction. Prochaska and his associates (DiClemente & Hughes, 1990; DiClemente & Prochaska, 1982; Prochaska, DiClemente, & Norcross, 1992) suggested in their Stages-of-Change Model that people modify problem behaviors along a five-stage continuum: *Precontemplation*, *Contemplation*, *Preparation*, *Action*, and *Maintenance*. According to Prochaska, DiClemente and Norcross (1992), people approach any decision to change with a wide variety of internal sets regarding their readiness and willingness to change, and furthermore, behavior change goes through a pattern of stages of readiness. These stages tend to be recursive rather than linear.

Recognizing that welfare recipients faced similar reluctance and ambivalence in returning to work, Lam, Wiley, Siu, and Emmett (2010) proposed an intervention model based on Prochaska's Stages-of-Change Model (Prochaska et al., 1992). The return-to-work model consists of three stages parallel to Prochaska's five stages. The *Precontemplation* stage occurs when someone may not recognize that he or she needs to change, the *Contemplation* stage is when someone is thinking about change but has not made a decision, and the *Action* stage is when the individual is ready to pursue change. Since the Stages-of-Change Model is generic for understanding stages of behavior changes, the adoption of this model to define work participation is appropriate not only for people with epilepsy but can also be generalize to people with other disability as a whole. In the following sections, how the three relevant stages were applied to this study to understand stages of change in work participation was described.

Precontemplation. People in the *Precontemplation* stage are unaware or underaware of their problems regarding work. They usually have no intention of working in the foreseeable future. They often feel “forced or coerced” into attending work programs, or they express a desire to change the environment or the system but not themselves. To move ahead in the stages of change, precontemplators need to acknowledge or take ownership of the problem and to increase their awareness of the negative aspects of the problem.

Contemplation/preparation. In the *Contemplation* stage, people are aware of the problem and are considering the prospects of change but have not yet made a commitment to change. Indecision and lack of commitment are the most distinctive characteristics of this group. People usually are seesawing and weighing the pros and cons of leaving welfare and finding a job. When the balance starts to consistently tip in favor of positive aspects of work, individuals are ready to move toward change. People in the *Preparation* stage are aware of the need to obtain a job and make tentative steps to achieve behavior change (e.g., going for job interview, attending vocational training).

Action/maintenance. Individuals in the *Action* stage are involved in the overt modification of the problem behavior. They have actually engaged in a job hunt, removed many of the barriers related to returning to work, and taken the steps to become employed. People in this stage are looking for assistance in coming up with strategies to help expedite the change process. This stage typically encompasses the time of greatest risk of relapse for many problem behaviors (e.g., quitting the job). In the *Maintenance* stage, people are usually preoccupied with preventing relapse (e.g., motivated to work hard and keep the job). Maintenance is thus a continuation of the change process and is not static. In this stage there is still a risk of relapse, and for some individuals this struggle may be life-long.

Role of Demographics on Employment

Demographics have been implicated in the unemployment rate among people with epilepsy (Clarke et al., 2006). Factors that may be significant in predicting employment status include age, race/ethnicity, and education level.

Age. Research on the relationship between age and obtaining or retaining employment is mixed; some studies have indicated that younger individuals have better employment outcomes, whereas other studies are less clear or reveal no relationship between age and obtaining or regaining employment (Saunders et al., 2006). Bishop and Chiu (2011) also note that the relationship between age and employment status has been infrequently examined with conflicting results. According to Hauser and Hesdorffer (1990), age per se is not a predictor of employment status, but age at onset of epilepsy may be. That is, the earlier the onset, the more likely epilepsy is to negatively affect employment status.

Race/ethnicity. Race is significantly related to employment outcome of people with epilepsy (Dunham, Schrader, & Dunham, 2000; Moore, 2002). Specifically, ethnic minorities (e.g., Latinos and African Americans) have been found less likely to achieve a successful employment outcome.

Education. The effects of level and type of education on employment have again been mixed. Some studies indicate that individuals who had a college education had less success at obtaining employment than persons without college training, whereas other studies found just the opposite, that individuals with a college degree had more success at obtaining employment than those without a college degree (Saunders et al., 2006). Poole (1987) found that utilizing education in a path model, in conjunction with beneficiary status and transportation, explained 37% of the total variation in competitive employment of individuals with severe disabilities.

Bishop and Chiu (2011) found that education level has frequently been associated with employment status of people with epilepsy (e.g., Rätsepp et al., 2000; Reuvekamp et al, 1999; Scambler & Hopkins, 1980, 1986).

Previous work experience. Literature reveals that work-related interpersonal skills (Blackwell et al., 2004), work-related knowledge (Gallenbeck, 1988), and work experience (Gouvier et al., 2003) have all been positively correlated with employment outcomes.

Other factors. Saunders et al. (2006) found conflicting evidence on the relationship between gender and employment outcomes. Also, the effects of marital status on employment outcome have been mixed.

Role of Functioning/Severity on Employment

Unpredictability of seizures can significantly impair quality of life (Fisher, 2000; Schachter, 2005; Bishop, Berven, Hermann, & Chan, 2002) and can have serious effects on the work prospects of people with epilepsy (Baker, 2005; Bishop, 2002, 2004; Jacoby, 1995). The findings concerning the effects of seizure type, frequency, and severity on employment status have generally supported a direct and significant effect. However, some researchers have suggested that the evidence to date does not conclusively support a direct relationship between seizure variables and employment (Hauser & Hesdorffer, 1990; Thorbecke & Fraser, 1997).

Seizure frequency and type. Several cross-sectional studies indicate higher rates of unemployment among individuals with more frequent and more functionally involved seizures (Bishop, 2004; Chaplin et al., 1998). In a community-based sample of 153 adults with epilepsy in the United States, seizure frequency was shown to be significantly related to employment status, with the likelihood of employment decreasing as seizure frequency increased (Bishop, 2004). There is broad agreement in the literature that people with more frequent seizures experience the greatest burden. Jacoby et al. (1996) reported that seizure type is associated with employment status: Individuals who had a type of severe seizure called “tonic-clonic” seizures were less likely to be employed. Unemployment rates are reported to be higher among people who seek care in tertiary care centers, which are often those individuals with more severe types of seizures (Hauser & Hesdorffer, 1990; Thorbecke & Fraser, 2008), specifically, those who have one or more generalized tonic-clonic seizures or complex partial seizures a year (Thorbecke & Fraser, 1997).

Seizure severity and controllability. Previous studies have revealed a significant relationship between severity of disability and employment outcome, indicating that the more severe the disability, the less likely a successful employment outcome will occur (Saunder et al., 2006). Collings and Chappell (1994) state that employability is related to perceptions as to the absence of effects of epilepsy on job prospects, good experiences with colleagues and management, low seizure severity, and good seizure control. There is evidence that people whose seizures are well controlled and uncomplicated by other handicaps do not generally experience problems with employment (Jacoby, 1995). In other words, people with uncontrolled seizures experience more job problems than do people with seizures in remission (Chaplin et al., 1998; Heaney, 1999). Bishop (2004) reports that the level of interference by seizures in daily life and the number of antiepilepsy drugs used are also significantly related to employment status. Also, a study conducted by Roessler, Rumrill, and Fitzgerald (2004) indicates that persistence of symptoms is related to employment outcomes of persons with chronic illness; that is, the more persistent the symptoms are, the greater the likelihood is of an unsuccessful employment outcome.

Side effects of antiepileptic medication. Treatment with antiepileptic drugs (AEDs) quickly renders most people seizure free, and seizure freedom is strongly associated with employability. Drug treatment is therefore an important, if indirect, employment determinant. However, the positive effects of AEDs for seizure control are counterbalanced by their potential adverse side effects. People with epilepsy commonly report more than one AED-related side effect (Perucca, Gilliam, & Schmidt, 2009). Only limited research, however, has investigated the relative contribution of specific adverse effects to employment (Perucca et al., 2009). Adverse side effects may be one of the most clinically relevant determinants, aside from seizure frequency, of employment in people who have resistant epilepsy. A large survey of more than 5,000 people with epilepsy from 15 different European countries found that approximately 50% reported fatigue and 40% had concentration problems associated with each of the investigated AEDs (Baker et al., 1997).

Comorbidity. The two most common psychiatric comorbidities among people affected by epilepsy are anxiety and depression. The prevalence is high. It is estimated that between 10% and 25% of people who have epilepsy experience anxiety (Gaitatzis, Trimble, & Sanderand, 2004) and 10% to 60% of people with epilepsy experience depression (Gilliam & Kanner, 2002); further, 30% of people with epilepsy have been found to attempt suicide (Mendez, Cummings, & Benson, 1986). In a large sample of adults who completed the U.S. 2004 Health Styles Survey, those self-reporting epilepsy were twice as likely to self-report anxiety or depression in the previous year as those not affected by epilepsy; and those who had active epilepsy (defined as seizures in the last 3 months or on AED medication) were three times more likely (Kobau, Gilliam, & Thurman, 2006). Depression can result from the side effects of certain medications or may result from psychological reactions such as fear (of having a seizure). A recent study of people with epilepsy indicated that many harbored fears of death and brain damage as a result of their seizures. It is thought that these fears may be a leading cause of psychosocial impairment in people with epilepsy, which can interfere with a person's ability to work and interact with people, including family (Saunders et al., 2006). Bolton (1983) found better self-appraised physical and mental health to be positively correlated with employment outcome in the state-federal vocational rehabilitation agency, and Belgrave and Walker (1991) found health locus of control to be a significant predictor of employment outcome.

Implications. Frequency of seizures may be one of the important factors influencing the employment of people with epilepsy (Thorbecke & Fraser, 1997). Adverse side effects of drugs, environmental factors such as social and workplace stigma, and psychosocial variables such as low self-esteem, passive coping style, and low self-efficacy have also been implicated as factors that play an important role in predicting employment (Clarke et al., 2006).

Role of Personal Factors on Employment

Various psychosocial and personal factors have been implicated in the high unemployment rate among people with epilepsy (Bautista & Wludyka, 2007; Clarke et al., 2006; Levin, Banks, & Berg, 1988). Factors that may be significant in predicting employment status include intelligence, personality, coping styles, social skills, psychosocial functioning, and neuropsychological functioning (Batzel, Dodrill, & Fraser, 1980; Fraser, Clemmons, Trejo, & Temkin, 1983). While many people with epilepsy may have few, if any, disruptions of social interaction or psychosocial functioning, others have severe problems due to the uncertain and unpredictable nature of epilepsy, which make it more difficult for them to engage in fully productive lives and employment (Austin & deBoer, 1997). In general, people with epilepsy have been found to have a higher prevalence of not only psychosocial problems (Jacoby, Baker, Steen, Potts, & Chadwick, 1996; Upton & Thompson, 1992), including social isolation and problems with psychosocial adaptation (Stong, 2008), but also low self-esteem, low self-efficacy, and primary use of a passive coping style (Clarke et al., 2006). They may also have a higher risk of developing psychiatric comorbidity (e.g., anxiety and depression) compared to people in the general population (Austin & deBoer, 1997). These psychosocial problems may have a greater impact on employment outcomes for people with epilepsy than do the recurring seizures (Livingston, 1981). People with epilepsy who are employed have been found to have fewer psychosocial problems than unemployed people with epilepsy (Jacoby, 1995).

Research has generally shown that the self-efficacy of people with epilepsy tends to be low. Additionally, people with epilepsy often use passive coping strategies to manage their disabilities. These two factors can generate a vicious circle, especially with respect to employment. Coping, self-efficacy, and social support play important roles in the management of psychosocial consequences or effects of having epilepsy. High self-efficacy and an active coping strategy often result in successful psychosocial adaptation to the disorder. Therefore, self-efficacy beliefs and active coping strategies can play a key role in helping people with epilepsy enhance their employment opportunities.

Coping. Coping refers to the behaviors, cognitions, and perceptions that people engage in when faced with life stressors. It is a complex, dynamic, and multidimensional process that is sensitive not only to the interactive relationships between person and environment but also to the personality dispositions that impact appraisal of stress and use of resources (Folkman & Moskowitz, 2004). Coping strategies are purposeful thoughts and behaviors that people utilize to manage situations that are appraised as stressful so as to increase a sense of well-being and avoid being harmed by stressful demands (Lazarus & Folkman, 1984, 1987; Folkman & Lazarus, 1988).

Coping has been conceptualized according to its functional properties, an approach that has been theoretically and empirically supported. Specifically, coping encompasses two broad domains: problem-focused coping, which deals with the problem that is causing the distress, and emotion-focused coping, which regulates the emotions associated with the situation (Billings & Moos, 1981, 1984; Lazarus & Folkman, 1984, 1987). Although most stressors elicit both types of coping, research suggests that problem-focused coping tends to predominate when something constructive can be done, whereas emotion-focused coping tends to predominate when the stressor must be endured (Folkman & Lazarus, 1980, 1985, 1988). Although these coping distinctions have a stronghold in the literature, researchers caution that these conceptualizations may be overly simplistic.

Consequently, Carver, Scheier, and Weintraub (1989) have attempted to elucidate additional domains, such as appraisal-focused and avoidant-focused coping that focuses attention "on" or "away from," respectively, either the source of stress or one's psychological/somatic reactions to the stressor. Researchers have also attempted to conceptualize coping based on different theoretical orientations, motivating principles, and measurements, including adaptive (positive) and maladaptive (negative) strategies; optimism and pessimism; and active and passive strategies. Coping has been found to affect physiological, psychological, behavioral, and psychosocial adjustment outcomes. In addition, coping is conceptualized and empirically supported as a mediator between the severity of a chronic illness or disability and psychosocial outcomes (Chronister, Johnson, & Lin, 2009).

Research indicates that coping strategies play an important role in adaptation to epilepsy (Livneh, Wilson, Duchesneau, & Antonak, 2001; Oosterhuis, 1999; Tedman et al., 1995; Upton & Thompson, 1992). Central to the process of coping are self-generated core beliefs, forming the basis of how effective an individual with epilepsy perceives himself or herself to be in dealing with the everyday problems of life (Tedman et al., 1995). Oosterhuis (1999) reports that people with epilepsy are viewed as having coping strategies different from those of the general population: in general, they tend to use fewer active strategies in coping with their problems. The choice of coping strategies is determined by personal factors, by the social environment, and probably most importantly, by the nature of the stress it is aimed at (Oosterhuis, 1999; Lazarus, 1981). Research on coping with epilepsy strongly suggests that the engagement-type coping strategies of problem solving and cognitive restructuring are associated with better psychosocial adaptation (Livneh, et al, 2001).

This study utilized Carver and colleagues' (1989) conceptualization of coping. These authors have identified 14 coping strategies that include both empirically and theoretically derived responses: active coping, planning, acceptance, positive reframing, instrumental support, religion, humor, emotional support, self-distraction, venting, denial, substance use, behavioral disengagement, and self-blame. Some researchers (e.g., Meyer, 2001) have treated the first eight aforementioned strategies as adaptive coping and the remaining six as maladaptive coping. For this study, the first five strategies listed above (i.e., active coping, planning, acceptance, positive reframing, instrumental support) were employed and classified them as adaptive coping.

Self-efficacy. Self-efficacy refers to a person's belief in his or her capability to successfully perform a particular task (Bandura, 1977). It is largely developed through observation, comparison, trial, and learning. Together with the goals that people set, self-efficacy is one of the most powerful motivational predictors of how well a person performs in almost any endeavor. Self-efficacy is a strong determinant of effort, persistence, and strategizing as well as subsequent training and job performance (Heslin & Klehe, 2006). People with limited self-efficacy are unlikely to produce outcomes they desire. Bandura (1986) considered self-efficacy as the primary thought that affects functioning included in social cognitive theory. Perceived self-efficacy beliefs not only affect adaption but also change other determinants of behaviors/adaption (Bandura, 1997). Such beliefs influence whether people think pessimistically or optimistically and in ways that are self-enhancing or self-hindering. For instance, people with low self-efficacy are less likely to engage in positive psychological coping, because they lack confidence in their ability to engage in necessary coping strategies. Therefore, self-efficacy is regarded as the foundation of a person's motivation, accomplishment, and subjective well-being (Bandura, 1997).

Bandura (1986) postulated that an individual's behavior is determined and maintained by the interaction of personal factors (e.g., biological, cognitive, affective), behavior, and environment. Personal factors, as well as environmental factors, are responsible for desired outcomes. However, one can still decide to try overcoming barriers and attaining a desired outcome, despite environmental discouragement or disadvantage. The consequence of this action could increase perceptions of personal capability and foster confidence toward oneself. As such, optimistic estimates of self-efficacy are believed to increase effort and persistence and to promote accomplishment in challenging circumstances (Bandura, 1997).

The sense of lack of control and uncertainty is central to the subjective experience of people with epilepsy. This uncertainty applies to seizures and the associated lack of bodily control, dependency on medication, and help provided by significant others (Gehlert, 1994;

Snyder, 1990). In this study, self-efficacy was conceptualized as the general belief of people with epilepsy that they can control the course of their lives in spite of their medical condition. DiIorio et al. (2004) have demonstrated that self-efficacy has direct effects on both coping and the predisposition to seek appropriate help for emotional needs. They also found that self-efficacy has a high positive correlation with epilepsy self-management behaviors (Dilorio, Faherty, & Manteuffel, 1992a, 1992b). People with epilepsy who maintain high levels of self-efficacy and positive attitudes toward their chronic illness experience fewer psychosocial problems (Amir, Roziner, Knoll, & Neufeld, 1999; DiIorio, Shafer, Letz, Henry, Schomer, & Yeager, 2003, 2004; Kobau & DiIorio, 2003).

People are inclined to become anxious or depressed when they perceive themselves as unable to manage adverse events or gain what they value highly. In a dynamic work context, belief in the ability to manage medications, seizures, and lifestyles is likely to affect employment-related abilities such as finding employment, communicating with supervisors and coworkers, and career planning. Thus, self-efficacy is also related to the experience of work stress and occupational burnout. Specifically, low self-efficacy can readily lead to a sense of helplessness and hopelessness about one's capability to learn how to cope more effectively with the challenges and demands of one's work. When this occurs, low self-efficacy can be distressing and depressing, thereby preventing even highly capable people from succeeding. This study measured the different aspects of efficacy in the self-management of epilepsy based on the construct of self-efficacy as defined by Bandura (1986).

Self-esteem. Self-esteem refers to a positive or negative orientation toward oneself, an overall evaluation of one's worth or value. People are motivated to have high self-esteem, and having it indicates positive self-regard, not egotism. Self-esteem is only one component of the self-concept, which Rosenberg (1965) defines as totality of the individual's thoughts and feelings with reference to himself or herself as an object. In addition to self-esteem, self-efficacy or mastery and self-identity are important parts of the self-concept.

Belgrave & Walker (1991) found self-esteem to be significant in predicting employment status, with higher self-esteem predicting better outcomes. Studies reveal that people with epilepsy are prone to have poorer self-esteem, to experience higher levels of anxiety and depression, and to have a higher risk of developing psychopathology in comparison with the general population (Collings, 1990; Jacoby et al., 1996). Because people with epilepsy can appear "normal," many of them have low self-esteem problems because they are afraid of being stigmatized if they disclose their disability (Tedman et al., 1995). This fear imposes unique stress on the person with epilepsy with respect to self-perception and emotional adjustment. Lower self-esteem can result from perceptions of oneself as less competent than others and categorization of oneself as an "epileptic" with the consequent perception of stigma (Wright, 1983). The negative impact of social attitudes and unemployment can result in a lower socioeconomic status, lower self-esteem, poor self-image, lessened well-being, and a lower quality of life (Bishop, 2002; Lee, 2005).

Implications. Smeets et al. (2007) suggested that self-efficacy, self-directed activities, and active coping strategies are crucial for people with epilepsy in adapting to the disorder and in finding and maintaining employment (Upton & Thompson, 1992). As a result, treatment for people with epilepsy should focus on training that emphasizes the acquisition of active, problem solving-oriented, and goal-directed coping skills that can assist the individual with epilepsy in pursuing personal, social, and vocational goals (Livneh, et al., 2001; Feste & Anderson, 1995).

Role of Environmental Factors on Employment

Stigma. The label "epilepsy" can override what one has and almost defines who one is (Baker, Brooks, Buck, & Jacoby, 2000). People with epilepsy who are stigmatized can endure devastating consequences, including lower self-esteem, social anxiety, discrimination, isolation, reduced access to care and resources, and lower health status. Some studies suggest a relationship among stigma and poorer seizure control, psychopathology, and reduced quality of life (Jacoby, 1994; Jacoby et al., 2005; Whatley et al., 2010). Further, it is well documented that stigma is associated with poor psychosocial and vocational outcomes for people with epilepsy (Austin, MacLeod, Dunn, Shen, & Perkins, 2004; Jacoby & Austin, 2007; Jacoby et al., 2005; MacLeod & Austin, 2003). Previous studies indicate that stigmatizing perceptions, negative attitudes, and misperceptions about people with epilepsy remain a powerful barrier (Bishop, 2002; Cooper, 1995; Jacoby et al., 2005) and have a significant negative impact on finding and maintaining employment (Baker, 2002, Chaplin, 2005; Lee, Yoo, & Lee, 2005; Livneh & Antonak, 1997).

Scheid (2005) argues that one of the most critical determinants of employment is the degree of social acceptance or stigma in the workplace. Researchers have found that employers' attitudes regarding employment of people with epilepsy include a high level of concern that epilepsy could lead to work absenteeism and potential dangers of work-related accidents (Harden, Kossoy, & Vera, 2004; Jacoby et al., 2005). Other common concerns include fear of witnessing a seizure, concerns about the safety and comfort of workers, disruption of work flow, increased liability insurance costs, and increased expenses for work-related accommodations (e.g., Bishop, Stenhoff, Bradely, & Allen, 2007; Harden et al., 2004; Hicks & Hicks, 1991;

Jacoby et al., 2005). These concerns can cause unnecessary restrictions; however, there is no empirical support for those concerns (Jacoby et al., 2005).

In the last several decades, survey research has found that attitudes are improving toward people with epilepsy. However, a somewhat different reality has been suggested, first, by researchers who have used indirect survey methods that are less susceptible to socially desirable responses (Antonak & Livneh, 1995; Baumann et al., 1995; Bishop & Slevin, 2004) and, second, by evidence that the level of unemployment for people with epilepsy and that employers' attitudes have both remained fairly constant over a 30-year period (Bishop, 2002; Jacoby et al., 2005).

Based on their 2005 survey of a representative random sample of UK employers, Jacoby and colleagues found that 26% of employers reported having employed individuals with epilepsy knowingly, 16% believed their company had no jobs suitable for individuals with epilepsy; 21% thought employing people with epilepsy would be "a major issue"; and epilepsy created high concern for about 50% (in part because of concerns about work-related accidents), although employers said they were willing to make accommodations for people with epilepsy. Further, a U.S. study among employers and human resources personnel suggested that hiring an individual with epilepsy was less likely than hiring people with any number of other disabilities, including cancer in remission, depression, a history of heart problems, AIDS, mild intellectual disabilities, and spinal cord injury (Bishop et al., 2007).

Because of this potential for discrimination, people with epilepsy are often hesitant to disclose their epilepsy status to employers (Bishop, 2002; Bishop & Allen, 2001; Bishop et al., 2007). In a survey of local Epilepsy Foundation affiliates, none of the organizations reported that they counsel people to be open about their condition either on applications or in initial interviews, and more than half of respondents indicated that if an open discussion about the condition is necessary, they would advise that it should be done after being hired (Bishop & Allen, 2001). Not only does stigma result in discriminatory reactions, but people with epilepsy may also have internalized these community attitudes and come to expect rejection from others.

Self-perceived stigma, as opposed to actual stigma, is an even larger problem for many people with epilepsy (Jacoby, 1994). In a large-scale study of adults with recently diagnosed epilepsy, 70% reported that they expected to experience stigma and discrimination at work (Chaplin, Yepez-Lasso, Shorvon, & Floyd, 1992). They were ashamed of their condition and afraid to be open about it because of the negative reactions they anticipated. It appears, however, that there is a real and quantitative difference between perceived or expected stigma and discrimination, and the experience of “enacted” (actual) or “felt” (self-perceived) stigma and discrimination. The perceived stigma is often associated with a lack of seizure freedom, and it increases when current depression, epilepsy-related injuries, and other chronic diseases are present (Baker, Jacoby, Buck, Stalgis, & Monnet, 1997; Baker et al., 2000). This increase is due partly to the unpredictable and uncontrollable nature of seizures, which often arouses fear and concern in the immediate environment (Jacoby et al., 1996; Jacoby, Snape, & Baker, 2005). There is a clear relationship between self-perceived stigma, seizure frequency, and degree of illness. Quality of life is subsequently affected by learned helplessness, depression and anxiety, impaired physical health status, increased somatic symptoms and other health problems, and compromised self-esteem and life satisfaction (Jacoby & Austin, 2007).

Social support. Social support refers to provision of resources by other persons that may serve to help an individual cope with stresses/adverse events and/or protect the individual from the negative effects of stress (Cohen, Kamarck, & Memelstein, 1983; Cohen, Memelstein, Kamarck, & Hoberman, 1985). Generally, social support is conceptualized as comprising three constructs: supportive behavior, perceived social support, and support network (Vaux, 1988). Supportive behaviors are defined as acts or resources that other people are able to provide in coping, while perceived social supports are the perception of other people's assistance (Chwalisz & Vaux, 2000). A social network is composed of an individual's supportive relationships.

Research suggests three primary types of social support: (a) emotional support (someone to talk to, to share with, to make one feel loved and esteemed, and to provide a sense of belonging); (b) instrumental support (tangible aid, material goods and services); and (c) informational support (guidance, feedback, counseling) (Cobb, 1976; Cohen et al., 1983, 1985). Social support can be assessed by measuring the actual support system (e.g., quantity of friends, frequency of contacts, marital status) and by the individual's perception of his or her support network.

Perceived social support includes the individual's subjective evaluation of his or her social support network and the individual's confidence in the adequacy of and satisfaction with that support network (Cohen et al., 1983, 1985; Sarason et al., 1991; Vaux, 1988). Brandt and Weinert (1981) conceptualized perceived social support as having five underlying dimensions based on the relational functions proposed by Weiss (1974), including: (a) the indication that one is valued (worth); (b) the sense that one is an integral part of a group (social integration); (c) the provision for attachment/intimacy (intimacy); (d) the opportunity for nurturance (nurturance); and (e) the availability of information, and emotional and material help (assistance). Perceived social support may be global, reflecting an evaluative synthesis of a person's relationship with the network as a whole, or focused, reflecting a particular component of network relationships (e.g., spouse, friend, or coworker) or a particular type of support (e.g., emotional, informational, or instrumental) or a particular relational function (e.g., worth, social integration intimacy, nurturance, or assistance). This study measured the perceived availability of social support with respect to Weiss's definition of social support.

A number of studies have demonstrated positive associations between social support and rehabilitation-related outcomes, such as adjustment to disability, quality of life, psychological well-being, employment, treatment compliance, and survival rates in people with disabilities and chronic illnesses (Chronister et al., 2009). Kaplan (1988) found a significant positive correlation between social support and employment outcomes of persons with traumatic brain injury (TBI); and McShane and Karp (1993) found that social support has a significant direct path to employment status of persons with spinal cord injury. Compared with other chronic diseases (e.g., cancer, arthritis, diabetes), the research concerning epilepsy and social support has been relatively scarce. Studies have suggested that the negative effect of stigmatization are moderated when social support is stronger. Furthermore, a positive relationship has been reported between social support and self-management of the disease (Dilorio et al., 1992a, 1992b). Positive and significant correlations have been found between social support and several psychological variables, such as self-esteem, emotional stability, and perceived influence of the disease in general (e.g., Collings, 1990a, 1990b).

Implications. Epilepsy is a hidden disability, which means that the degree to which the general society is exposed to epilepsy as a disease is partly dependent on the role of epilepsy in that society. This role is determined by social and cultural attitudes toward epilepsy, and if these attitudes are negative, the diagnosis of epilepsy can carry a stigma. Misconceptions and negative stereotypes often place people with epilepsy in a position where they have to cope with the fears of stigma and discrimination. The public's perception, especially employers' attitudes toward people with epilepsy, can be improved through educational outreach that may include workshops, access to Internet sites with information about epilepsy, and informative mailings.

Overall Implications

There is growing interest in better meeting the employment needs of people with epilepsy; however, less is known about the different factors affecting employment outcomes. An understanding of how people manage their epilepsy and the impact of environment on their lives is critical and essential to the provision of effective support in finding and maintaining employment. Many studies point to the need for effective training programs in finding and obtaining employment for people with epilepsy (Bishop, 2002, 2004; Chaplin, 2005). Literature shows that coping strategies, self-efficacy, and social support play important roles in helping people with epilepsy accept and manage the psychosocial consequences or effects of having epilepsy. A logical step in understanding the role of self-efficacy, coping strategies, and social support in finding and maintaining employment would be the implementation of an effective, efficacious, and efficient rehabilitation intervention designed to promote self-efficacy and active coping strategies in people with epilepsy. This study informs the need for vocational rehabilitation programs for those people who require extra assistance when it comes to gaining or retaining employment, which would be beneficial not only for people with epilepsy but for state governments, society, and taxpayers as well.

Evidence of Application of the ICF Model

Recently, the ICF has gained wide acceptance among international rehabilitation health researchers and professionals as a framework that can be used to support a systematic approach for understanding chronic illness and disability across cultures (Chan, Keegan, et al., 2009; Chan, Sasson et al., 2009). Research findings for the ICF have been encouraging. For instance, Dixon et al. (2008) used structural equation modeling within the ICF to predict walking limitations in 190 patients awaiting hip or knee replacement surgery. The findings revealed that the impairment factor in the ICF predicted activity limitations. The significant relationship between impairment (in the form of pain) and activity limitations (limitation in walking) lent support to this portion of the ICF.

Rybski (2010) also conducted a study by using structural equation modeling to elucidate the second-order relationships among the ICF conceptual model components for people who have experienced a stroke. Rybski concluded that the component *body functions and structures* is more associated with *activities and participation* than with *environmental factors* and *personal factors* in the ICF. *Personal factors* is not a separate contextual component as proposed by the ICF. Rybski's study supported the associations among the components of the ICF and also identified important gaps in the ICF measures that relate to the amount and distribution of impairments associated with stroke in the United States.

Hollingsworth and Gray (2010) conducted a study with 604 people with mobility limitations in the community. The researchers examined the linkages between the constructs of *participation* and the *environment* for a set of leisure activities (attending concerts, attending movies, attending sporting events), and concluded that the model could provide guidance for community-based interventions and person-based therapies.

The ICF has been validated for people with chronic illness and disability with encouraging results. It can be used to develop intervention strategies for people with chronic illnesses and disabilities. However, the ICF has not been validated as an employment model for use with people with epilepsy. The primary purpose of this study was to formulate and test a model of employment outcome specific to individuals with epilepsy. The proposed model used four sets of predictor variables (functioning/severity, activities, personal factors, and environmental factors) with work participation as the outcome. Hierarchical regression analysis was used to evaluate the ICF as a comprehensive employment model for people with epilepsy by examining the relationships between ICF constructs and work participation.

CHAPTER THREE

Method

This chapter provides the details of the research design, study procedures, sampling plan, participant characteristics, information about and psychometric properties of selected instruments, and statistical techniques.

Design

A quantitative descriptive design utilizing multiple regression and correlational analysis was used to evaluate the ICF as a comprehensive employment model for people with epilepsy (Heppner, Wampold, & Kivlighan, 2008). Specifically, hierarchical multiple regression was used to determine the unique contribution of each individual ICF construct (i.e., functioning/severity, activities, personal factors, and environment factors) on work participation of individuals with epilepsy and how the ICF factors interact with each other.

Procedures

The investigator completed the required Human Subjects Protection Training for the University of Wisconsin–Madison (UW–Madison) Institutional Review Board (IRB) and obtained study approval from the IRB (see Appendix A). Following IRB approval, community-based support groups serving people with epilepsy were identified and contacted and then study information was sent along with invitations to participate in research collaboration. Participants were recruited from various state affiliates of the Epilepsy Foundation of the Americas across the country. To be eligible for inclusion in the study, participants had to meet the following criteria: (a) between 18 and 65 years of age; (b) diagnosed with chronic epilepsy for at least one year prior to survey completion; (c) a self-report 6th grade reading level or above; and (d) living in the community. Participants who were diagnosed with traumatic brain injury or profound intellectual disabilities, or those who lived in a residential setting were excluded from the study.

Upon agreement, written permission (letter of support) was obtained from each affiliate regarding advertising the research study to their members (see Appendix B for example). Then, information about the research project was disseminated electronically to each affiliate’s mailing list or posted on each affiliate’s website/social network page to recruit members as research participants (see Appendix C-E). To further promote the study, the researcher also attended some regular meetings and annual events organized by the affiliates of the Epilepsy Foundation.

Data were collected via an online survey platform (http://www.surveymonkey.com/). Interested participants were provided with the link to the online survey. All participants were informed of the voluntary nature of the research, their rights as a research participant, and the potential effects and benefits from participating in the study. The email address and telephone number of the investigator were given to participants for questions/assistance. In addition, participants were given the phone numbers of the investigator’s research advisor and the UW–Madison Social and Behavioral Science IRB. Participants were asked to read and endorse the informed consent form (see Appendix F) before they proceeded to complete the subsequent demographic questionnaire and set of measures. All responses were kept confidential. Participants were informed of the opportunity to obtain a $20 gift card via U.S. mail by signing up and providing contact information upon completing and returning the survey (see Appendix G). To protect confidentiality, the personal information of those participants was separated from their responses to the questionnaire. All materials, instruments, and procedures were pilot tested with the first 15 participants to determine instrument error or procedural difficulties. Five editing errors were identified by the participants and were corrected. The average completion time was approximately 30-45 minutes.

Sample

Participants

A total of 338 individuals with epilepsy attempted the online survey. Of those surveys, 19 (5.6%) did not meet the inclusion criteria and 49 (14.5%) provided incomplete data. The final study sample included 270 (79.9%) participants. Ninety-three (34.4%) of the participants were from Wisconsin and 177 (65.6%) were from 22 other states including 72 from California; 42 from Minnesota; 16 from Texas; 12 from Kentucky; 10 from Michigan; 5 from New York; 2 each from Nebraska, Florida, Illinois, and Indiana; and 1 each from Alaska, Louisiana, Maryland, Maine, North Carolina, North Dakota, New Hampshire, New Jersey, Nevada, Oregon, Pennsylvania, and South Carolina.

Sample Characteristics

Descriptive data for the participants are presented in Table 3.1. Participants ranged in age from 18 to 65 years (*M*=38.23, *SD*=12.14). The breakdown by gender was 186 (68.9%) females and 84 (31.1%) males. The majority of the participants described themselves as Caucasians (84.4%); 2.2% described themselves as African American, 7.0% as Hispanic/Latino, 1.9% as Asian American, and 4.4% as other/combined. A majority of the participants were either single (42.6%) or married (45.6%); 7.2% were divorced, and 11.8% were divorced, separated, widowed, or cohabitating. For employment status, 34.1% of the participants were employed full-time, 30.8% were unemployed, 22.2% were employed part-time, 6.7% were students, 3.3% were retired, and 3.0% were volunteers. The average earnings per week was $511.15 (*SD* = 520.20, *Median* = 400) in U.S. dollars, and the average number of hours worked per week was 30.02

(*SD*=13.86, *Median* = 36). The educational breakdown of the participants was as follows: 16.3% completed high school, 17.4% had post-secondary education (but not a degree), 18.5% completed an associate degree or vocational school, 35.2% completed college, 10.0% completed graduate study, and 2.3% had special education or no formal education. About 29% of the participants received cash benefits (11.1% received SSI, 15.6% received SSDI, and 2.2 received TANF); however, 71.1% did not receive any SSI/SSDI/TANF. About 37% of the participants had public insurance (Medicare: 5.9%, Medicaid: 3.3%, Medicare and Medicaid: 7.4%, public insurance from other source: 7.4%), 7.4% had private insurance, 27.0% had insurance though their own employer, 20.4% had insurance through their family's employer, and 8.3% had combined types of insurance.

Disability-Related Characteristics

Participants' mean age at first seizure was 16.90 years (*SD*=12.28), and the average number of years of active seizures was 21.46 years (*SD*=13.89). Among the different types of seizures that the participants experienced, 65.2% were tonic-clonic (grand-mal), 2.6% were absence (petit mal), 22.6% were complex partial, 2.2% were simple partial, 1.1% were myoclonic/atonic/tonic, 0.7% were secondarily generalized, and 4.4% were other types. Regarding the frequency of seizures that the participants experienced, 7.8% had seizures daily, 14.8% had seizures weekly, 28.1% had seizures monthly, 16.7% had seizures yearly, and 31.1% had not had seizures in more than 2 years. A majority of the participants took one (39.3%) to two (34.8%) types of antiepileptic drugs (AEDs), 16.3% took three to four types of AEDs, 4.4% took five or more types of AEDs, and 5.2% did not need to take any AEDs. Of all participants, 38.9% did not have other comorbid medical conditions or health issues besides epilepsy.

Table 3.1
Participant Demographic and Disability Characteristic (*N* = 270)

Demographic Covariates	*n* (%)	*Mean* (*SD*)
Age		38.23 (12.14)
Gender		
Men	84 (31.1%)	
Women	186 (68.9%)	
Race		
European American	228 (84.4%)	
African American	6 (2.2%)	
Hispanic	19 (7.0%)	
Asian American	5 (1.9%)	
Other/Combined	12 (4.4%)	
Marital status		
Single	115 (42.6%)	
Married	123 (45.6%)	
Divorced/Separated/Widowed	24 (8.8%)	
Cohabitating	8 (3.0%)	
Education		
< high school	7 (2.6%)	
High school graduate	44 (16.3%)	
Some post-secondary education	47 (17.4%)	
Associate degree	50 (18.5%)	
Bachelor’s degree	95 (35.2%)	
Master’s degree or above	27 (10.0%)	
Employment Status		
Full-time employed	92 (34.1%)	
Part-time employed	60 (22.2%)	
Unemployed	83 (30.8%)	
Student	18 (6.7%)	
Volunteer	8 (3.0%)	
Retired	9 (3.3%)	
Average earnings per week		511.15 (520.20)
Average working hours per week		30.02 (13.86)
Average years of employment		6.05 (7.42)
Cash benefits (SSI/SSDI/TANF)		
Yes	78 (28.9%)	
No	192 (71.1%)	
Medical benefits (Medicaid/Medicare)		
Yes	65 (37.4%)	
No	205 (62.6%)	

Disability-related Variables	*n* (%)	*Mean* (*SD*)
Average age at first seizure		16.90 (12.28)
Average years of active seizure		21.46 (13.89)
Type of Seizure		
Tonic-clonic (grand mal)	176 (65.2%)	
Absence (petit mal)	7 (2.6%)	
Complex partial	61 (22.6%)	
Simple partial	6 (2.2%)	
Myoclonic/Atonic/Tonic	3 (1.1%)	
Secondary generalized	2 (0.7%)	
Other	15 (4.4%)	
Frequency of Seizure		
Daily	21 (7.8%)	
Weekly	40 (14.8%)	
Monthly	76 (28.1%)	
Yearly	45 (16.7%)	
No seizure in >2 years	84 (31.1%)	
Number of antiepileptic drugs		
0	14 (5.2%)	
1	106 (39.3%)	
2	94 (34.8%)	
3-4	44 (16.3%)	
>5	12 (4.4%)	
Comorbid disabilities		
None	105 (38.9%)	
Cognitive	33 (12.2%)	
Mental	22 (8.1%)	
Substance abuse	42 (15.9%)	
Physical	3 (1.1%)	
Combined	64 (23.7%)	

However, 12.2% had comorbid cognitive impairment, 8.1% had comorbid mental illness, 15.9% had comorbid alcohol and substance abuse issues, 1.1% had physical impairment, and 23.7% had some combination of the above issues.

Measures

The dependent variable (DV) investigated in this study was work participation. The independent variable (IV) comprised the four major components proposed in the ICF framework: (1) *body functions and body structures* (consisting of seizure severity, cognitive deficits, depression, and anxiety); (2) *activities* (consisting of abilities/skills specific to work); (3) *personal factors* (consisting of positive coping, self-efficacy, and self-esteem); and (4) *environmental factors* (consisting of perceived stigma and social support).

Demographic Questionnaire

The demographic questionnaire was developed specifically to obtain general socio-demographic and epilepsy-related information (see Appendix H). Questions included: age, gender, race/ethnicity, education, marital status, Social Security Administration (SSA) beneficiary status, employment status, weekly working hours, weekly earnings, and employer-based health insurance, if applicable. Epilepsy-related questions included: age at onset, type of seizure, frequency of seizure, number of years of active epilepsy, and number of antiepileptic drugs (AEDs).

Instrumentation for Predictor Variables

Along with the socio-demographic and epilepsy-related questions, additional pre-existing instruments with well-documented validity and reliability are also selected in order to measure the constructs represented in the ICF framework. The descriptive statistics were listed in Table 3.2.

Table 3.2
Descriptive Statistics for Study Measures (*N* = 270)

ICF Constructs	# of Items	Instruments	Resp. Range	Mean (SD)	Cronbach's *α*
Predictor Variables					
Severity/functioning	Seizure severity (9 items)	- Seizure Severity Scale (SSS)	0-3	0.90 (0.73)	.879
	Cognitive deficits (14 items)	- Cognitive Failures Questionnaire (CFQ)	0-4	1.82 (0.87)	.926
Psychiatric comorbidity	Depression (6 items)	- Neurological Disorders Depression Inventory for Epilepsy (NDDI-E)	1-4	2.32 (0.80)	.897
	Anxiety (7 items)	- General Anxiety Disorder (GAD-7)	1-4	2.05 (0.89)	.938
Work Activity	Work skills (30 items)	- Life Skill Inventory-30 (LSI-30)	1-5		
		○ General Employability		3.94 (0.84)	.887
		○ Work Tolerance		3.89 (0.88)	.873
		○ Work Communication		3.90 (0.89)	.885
		○ Self-Care		4.08 (0.77)	.843
		○ Self-Direction		3.67 (0.90)	.857
		○ Total		3.90 (0.75)	.960
Personal Factors	Coping strategies (16 items)	- Brief COPE	1-4	3.00 (0.66)	.896
	Self-efficacy (33 items)	- Epilepsy Self-Efficacy Scale (ESES-2000)	0-10	7.49 (1.75)	.915
	Self-esteem (10 items)	- Rosenberg Self-Esteem Scale (RSES)	0-3	1.95 (0.62)	.901
Environmental Factors	Social Support (15 items)	- Personal Resource Questionnaire (PRQ-2000)	1-7	5.44 (1.17)	.932
	Perceived Stigma (10 items)	- Epilepsy Stigma Scale (ESS)	1-5	3.05 (1.02)	.935
Outcome Variable					
Outcome	Work Participation (9 items)	- Stages of Change-Work Participation (SOC-WP)	0-4		
		○ Contemplation		20.11 (6.14)	.748
		○ Action		14.23 (5.32)	.846

Functioning/Severity. Functioning/severity was measured by the *Seizure Severity Scale* (Austin, MacLeod, Dunn, Shen, & Perkins, 2004), a seizure severity measure; the abbreviated version of the *Cognitive Failures Questionnaire* (Broadbent, Cooper, FitzGerald & Parkes, 1982), a measure of subjective cognitive deficits; the *Neurological Disorders Depression Inventory for Epilepsy* (Gilliam, Barry, Hermann, Meador, Vahle, & Kanner, 2006), a measure of depressive symptoms; and the *General Anxiety Disorder* scale (Spitzer, Kroenke, Williams, & Löwe, 2006), a measure of anxiety symptoms.

Seizure severity. The *Seizure Severity Scale* (SSS) is an abbreviated version of the self-administered 20-item *Liverpool Seizure Severity Scale* (LSSS), which was originally developed by Baker, Smith, Dewey, Morrow, Crawford, and Chadwick (1991) to measure the extent of seizures and the degree to which seizures disrupt everyday life for adults with epilepsy. Austin, MacLeod, Dunn, Shen, and Perkins (2004) further revised the LSSS and developed the SSS. The SSS consists of items regarding nine clinical features or symptoms of seizures over a 4-week period. The respondents rate each item on a 4-point Likert-type scale (0 = Never; 1 = Sometimes; 2 = Usually; 3 = Always), with the total scores ranging from 0 to 27 (Baker, Smith, Jacoby, Hayes, & Chadwick, 1998). Higher scores indicate greater severity. Items reflect intrusiveness of the seizure (e.g., incontinence, loss of consciousness), disruptiveness of the seizure (e.g., bizarre movements, undressing self), and effects of the seizure (e.g., injury, confusion, sleepiness). Other items measure time of disruption and time until resuming normal activities after the seizure. The internal consistency (Cronbach's α) was .79 for population with chronic illness. Internal consistency for the scale was estimated with the present sample, and a Cronbach's alpha of .88 was found.

Cognitive deficits. The original version of the *Cognitive Failures Questionnaire* (CFQ) was developed by Broadbent, Cooper, Fitzgerald, and Parkes (1982). It is a measure of self-reported deficits in the completion of simple everyday tasks that a person should normally be capable of completing without error; it includes failures in attention, memory, perception, and motor function over the last 6 months (e.g., “Do you bump into people?” or “Do you find you forget appointments?”). It is composed of 25 items and uses a 5-point Likert scale (0 = Never; 1 = Very rarely; 2 = Occasionally; 3 = Quite often; 4 = Very often). The highest possible total score is 100, with a higher score indicating a higher incidence of cognitive failures, and a lower score indicating better mental functioning. The CFQ was developed to determine general cognitive failure, so it does not have any subscale score for a specific cognitive failure (Broadbent et al., 1982). The CFQ has high internal consistency (Cronbach’s alpha=.91) and has been found to be stable over 2 months, with a test-retest reliability rate of .82 (Wallace, Kass, & Stanny, 2002). Nonetheless, continuing arguments have been made to challenge the unidimensional structure of the CFQ. For example, Wallace et al. (2002) found a four-factor solution for the CFQ in which each item had a loading of .40 or above on its respective factor. The internal consistency of each subscale was considered acceptable (Cronbach’s α = .76 to .86). The Cronbach’s alpha for total scores for the sample in the present study was .93.

Depression. The *Neurological Disorders Depression Inventory for Epilepsy* (NDDI-E) was developed by Gilliam, Barry, Hermann, Meador, Vahle, and Kanner (2006) specifically for people with epilepsy. It is composed of 6 items to identify symptoms of depression that are differentiated from common comorbid cognitive deficits or adverse effects of antiepileptic drugs. Each item is rated on a 4-point Likert scale (1 = Never; 2 = Rarely; 3 = Sometimes; 4 = Always or often), and the total score ranges from 6 to 24, with higher scores indicating higher severity.

Internal consistency reliability of the NDDI-E has been estimated as .85 and test-retest reliability over 2 weeks as .78. An NDDI-E score of more than 15 had a specificity of 90%, sensitivity of 81%, and positive predictive value of .62 for a diagnosis of major depression. A validation study by Gilliam et al. (2006) showed that the model of association of major depression and the NDDI-E was not affected by adverse effects of antiepileptic medication, whereas models for depression and generic screening instruments often are. The Cronbach's alpha for total scores for the sample in the present study was found to be .90.

Anxiety. The *General Anxiety Disorder* scale (GAD-7) is a brief 7-item self-report anxiety scale developed by Spitzer, Kroenke, Williams, and Löwe (2006) to identify symptoms of general anxiety disorder over a 2-week period. The GAD-7 was validated with a large national probability sample. Sample items for the GAD-7 include: "Feeling nervous, anxious or on edge," "Not being able to stop or control worrying," and "Worrying too much about different things." Each item is rated on a 4-point Likert scale (1 = Not at all; 2 = Several days; 3 = More than half the days; 4 = Nearly every day), and the total score ranges from 7 to 28, with higher scores indicating higher severity. The internal consistency reliability estimate using Cronbach's alpha of .89 was reported for a general population (Löwe et al., 2008). A similar internal consistency estimate for the sample in the present study was found with a Cronbach's alpha of .94.

Activities: work skills/abilities. The *Life Skills Inventory* (LSI-30) was used to measure skills for work-related activities. The original version of the LSI was developed by Chan, Rubin, Lee, Miller, and Cheng (2003a) to operationalize life skills considered essential for assertive community living and work. The LSI is composed of 51 items with 5 subscales: (a) general employability skills (e.g., can get along with coworkers); (b) work-related communication skills (e.g., can interview effectively for jobs); (c) self-direction skills (e.g., can plan recreational activities); (d) self-care skills (e.g., can dress appropriately); and (e) work tolerance skills (e.g., can work an 8-hour day). Factorial validity of the LSI was established based on exploratory factor analysis, and life skills were found to correlate with quality of life (Cardoso, Blalock, Allen, Chan, & Rubin, 2004). Chan, Rubin, Lee and Pruett (2003b) reported that internal consistency for the 5 subscales was satisfactory (Cronbach's $\alpha = .85$ to .96). In order to have a smaller scale with similar measurement quality and a shorter testing time, only the consumer form of a brief version of LSI-30 was used. It is based on a review of factor loadings and logical analysis and includes 30 items. Participants were asked to rate their own ability using the same 5-point Likert scale (1 = Very low ability; 2 = Low ability; 3 = Moderate ability; 4 = High ability; 5 = Very high ability). The responses are summed over all the items to produce 5 subscale scores that range from 6 to 30 for each subscale, with higher scores indicating higher ability. Internal consistency for the composite scales was estimated with the present sample, and acceptable Cronbach's alphas were found, ranging from .84 to .96.

Personal factors. Personal factors were measured by the abbreviated version of the *Brief COPE* (Carver, 1997), a coping skills measure; the *Epilepsy Self-Efficacy Scale* (DiIorio & Yeager, 2003), a self-efficacy measure; and the Rosenberg Self-Esteem Scale (Rosenberg 1965), a self-esteem measure.

Coping style. The original version of *Brief COPE* was developed by Carver (1997) to measure conceptually distinct aspects of coping, and is an abbreviated version of the 60-item *COPE*. The *Brief COPE* is composed of 28 items with 14 subscales (2 items per subscale) and includes both potentially dysfunctional as well as adaptive strategies. These strategies are: active coping, planning, positive reframing, acceptance, humor, religion, using emotional support, using instrumental support, self-distraction, denial, venting, substance use, behavioral disengagement, and self-blame (Carver, 1997). Items are rated on a 4-point Likert scale (1 = I haven't been doing this at all; 2 = I've been doing this a little bit; 3 = I've been doing this a medium amount; 4 = I've been doing this a lot).

For this study, 5 subscales (10 items in total) of the *Brief COPE* were selected to represent positive (adaptive) coping styles. Some sample items of the 5 subscales are: "I've been taking action to try to make the situation better" (active coping); "I've been trying to come up with a strategy about what to do" (planning); "I've been looking for something good in what is happening" (positive reframing); "I've been learning to live with it" (acceptance); and "I've been getting help and advice from other people" (using instrumental support). The positive coping index was calculated by adding scores on all 10 items within five positive coping strategies to obtain a total score ranging from 10 to 40. Higher scores indicate that positive coping strategies are more frequently used. Internal consistency reliability estimates have been reported as follows: active coping (.68), planning (.73), positive reframing (.64), acceptance (.57), using instrumental support (.64). The scale was found to have satisfactory psychometric properties, and evidence of validity was demonstrated by correlations with a variety of personality measures (Lin, 2009). A Cronbach's alpha of .90 was found for the composite scale with the sample in the present study.

Self-efficacy. The *Epilepsy Self-Efficacy Scale* (ESES-2000) is an expansion of the earlier ESES (ESES-1992) to measure self-efficacy in terms of everyday management of epilepsy, and it focuses on individual confidence, awareness, and planning regarding self-management techniques (DiIorio & Yeager, 2003). The ESES-2000 assesses the degree of confidence that individuals have in their ability to successfully perform tasks in the areas of medication taking, seizure control, and general lifestyle management (DiIorio et al., 1992a, 1992b). Items for the scale are based on the construct of self-efficacy as defined by Bandura (1986). The original set of items was reviewed by a group of physicians, nurses, and people with epilepsy to assess face validity, and was reviewed by experts in self-efficacy, including Bandura (1986), to assess content validity (DiIorio et al., 1992a, 1992b). In 2000, 8 items were added to the 25-item ESES-1992 to further assess self-efficacy associated with lifestyle issues.

In order to have a smaller scale with similar measurement quality and a shorter testing time, 18 items were selected from the ESES-2000 version based on a review of factor loadings and logical analysis to examine the self-efficacy of participants in areas of medication adherence behaviors (e.g., “can stay on my seizure medication most of the time”), seizure control behaviors (e.g., “I can always keep my epilepsy under control”), and lifestyle management behaviors (e.g., “I can always find ways to do things that I enjoy to help me manage stress”). The participants were asked to rate each of the 18 items on an 11-point Likert scale, ranged from 0 (I cannot do it at all) to 10 (I am sure I can do it). The highest possible score for the ESES-2000 was 180. Higher scores correspond to higher levels of confidence in one’s ability to manage epilepsy. The internal consistency reliability has ranged from .89 to .94 with fair test-retest reliability coefficients over a 4-week period and construct validity documented through positive correlations with related measures of psychosocial well-being (DiIorio & Yeager, 2003; DiIorio, Shafer, et al., 2003, 2006). The self-efficacy scale also correlated in the predicted direction with self-management and social support, providing further evidence of construct validity. The Cronbach’s alpha for the sample in the present study was found to be .92.

Self-esteem. The Rosenberg Self-Esteem Scale (RSES) was developed by Rosenberg (1965) to measure self-esteem. It is composed of 10 items reflecting attitudes about self (e.g., “I take a positive attitude toward myself,” “I am able to do things as well as most other people,” and “I feel that I have a number of good qualities”) rated on a 4-point Likert scale (0 = Strongly disagree; 1 = Disagree; 2 = Agree; 3 = Strongly agree). Scores range from 0 to 30, with higher scores indicative of higher self-esteem. Studies using the RSES report test-retest reliabilities that range from .72 to .90 (Robins, Hendin, & Trzesniewski, 2001) and internal consistency reliabilities (Cronbach’s α) between .77 and .88 (Blascovich & Tomaka, 1993). The Cronbach’s alpha for the sample in the study was.90.

Environmental factors. Environmental factors were measured by the revised version of the *Epilepsy Stigma Scale* (DiIorio et al., 2004), a perceived stigma measure; and the *Personal Resource Questionnaire* (Weinert, 2003), a social support measure.

Perceived stigma. The *Epilepsy Stigma Scale* (ESS) is a revised version of the Parent Stigma Scale (PSS), developed by Austin, Macleod, Dunn, Shen, and Perkins (2004) for measuring perceived stigma in children with epilepsy and their parents. DiIorio and colleagues (2004) expanded and reworded the original 5-item scale to direct statements toward adults with epilepsy in order to assess the degree to which a person believes that epilepsy is perceived as negative and interferes with relationships with others. The modified scale is composed of 10 items, with each item rated on a 5-point Likert scale (1 = Strongly disagree; 2 = Disagree; 3 = Neither; 4 = Agree; 5 = Strongly agree). Higher scores reflect perceptions of greater stigma associated with the person having a seizure condition. The ESS showed good internal consistency reliability in studies of adults with epilepsy, with Cronbach’s α = .89 to .91 (e.g., DiIorio et al., 2004; Reisinger & DiIorio, 2009; Whatley, DiIorio, & Yeager, 2010). Most items on the ESS were found to be consistent with the literature and usable in this study. However, the wording of items was modified slightly so that the items were more appropriate and relevant to employment. For example, in one item the phrase “having trouble finding a relationship” was modified to "having trouble finding a job." Moreover, the word "people" was replaced by "coworkers" or "employer" for each item in order to make it more workplace focused. The Cronbach's alpha was found to be .94 for the sample in the present study.

Social support. The *Personal Resource Questionnaire* (PRQ-2000) is a revised version of the self-administered PRQ-85-2, which was developed by Weinert (1987, 2003) to measure perceived level of social support. This measure of social support was conceptualized using Weiss's definition of support, which is multidimensional and includes items reflecting intimacy, assistance, affirmation of worth, social integration, and nurturance. The original PRQ-85-2 has been used extensively in a variety of research projects, including studies of people with chronic diseases such as multiple sclerosis (Long & Weinert, 1992) and epilepsy (DiIorio et al., 1992a, 1992b, 1994; DiIorio, Henessy, & Manteuffel, 1996). The PRQ-2000 consists of 15 items with a 3-factor structure. Each item is rated on a 7-point Likert scale (1 = Strongly disagree; 2 = Disagree; 3 = Somewhat disagree; 4 = Neutral; 5 = Somewhat agree; 6 = Agree; 7 = Strongly agree). Total scores range from 15 to 105, with higher scores indicating higher levels of perceived social support.

Construct validity was assessed by examining the relationship between the PRQ-2000 and other mental health measures such as the Center for Epidemiologic Studies Depression Scale (Radloff, 1977). The correlations were appreciable and in the predicted directions. Weinert et al. (2003) reported that the internal consistency reliability remained stable and adequate, ranging from Cronbach's α = .87 to .93 for a variety of samples with chronic illness and disability. A Cronbach's α of .93 was reported in a sample of people with epilepsy (Bishop, Berven, Hermann, & Chan, 2002). A similar internal consistency estimate was found the sample in the present study with a Cronbach's alpha of .93.

Instrumentation for Outcome Variables

Work participation. The *Stages of Change–Work Participation Scale* (SOC-WP) was used to measure the perceived participation related to paid or voluntary work. It was adapted from two related instruments that were empirically derived from the Stages of Change (SOC) Model (Prochaska et al., 1992). These two instruments were the Lam Assessment on Stages of Employment Readiness (LASER), developed by Lam et al. (2010), and the University of Rhode Island Change Assessment for Vocational Counseling (URICA-VC), developed by Mannock, Levesque, and Prochaska (2002). The LASER was developed to assess welfare recipients' employment readiness; it consists of 14 items corresponding to Prochaska's SOC (Prochaska et al., 1992). The results of the confirmatory factor analysis supported the three factors structure corresponding to Prochaska's Precontemplation, Contemplation, and Action stages, and the cluster analysis classified the sample into three groups according to their LASER scores (Lam et al., 2010).

The URICA-VC was validated to measure the readiness of persons enrolled in vocational rehabilitation programs. The result of the cluster analysis identified three classifications—Reluctant, Reflective, and Participative—which relate to the Precontemplation, Contemplation, and Action scales defined by Prochaska and colleagues. Clusters were found to be significantly associated with continuance in counseling, χ^2 (2,155) = 7.56, $p < 0.05$, and return to work, χ^2 (2,155) = 15.06, $p < 0.001$ (Mannock et al., 2002). The URICA-VC had acceptable reliability coefficients, with Cronbach's α ranging from .66 for the Precontemplation and Contemplation scales to .93 for the Action scale. It was also validated within a sample of individuals with psychiatric disabilities seeking competitive employment to discriminate among individuals with varying levels of interest and involvement in vocational rehabilitation services.

The development of the SOC-WP was based on a comprehensive review of the literature, on the investigator's clinical knowledge, and after consultation with professionals in the vocational counseling and epilepsy fields. In addition, experts from the fields of rehabilitation counseling and epilepsy reviewed the instrument. Their revisions and suggestions helped the researcher finalize the questionnaire. The SOC-WP is composed of 20 items (4 items per hypothesized stages of change). The items address the individual's dissatisfaction in being unemployed and his or her contemplation or action toward becoming employed. The participants were asked to respond by indicating the extent to which they agree or disagree with each item on a 5-point Likert-type scale (0 = Strongly disagree; 1 = Disagree; 2 = Undecided; 3 = Agree; 4 = Strongly agree). The items are grouped to form 4 subscales labeled *Precontemplation*, *Contemplation*, *Preparation*, and *Action/Maintenance*. Some examples of items include "I am not able to work" (Precontemplation), "I am thinking about what kind of job is right for me" (Contemplation), "I am currently applying and interviewing for jobs" (Preparation), and "I am working hard to keep my job" (Action/Maintenance). The item scores are summed to produce two subscale scores. These scores are then converted into T-scores and used to create a profile that identifies an individual's Stages of Change as being either Contemplation or Action.

Data Analysis

Scores on all measures were computed as the mean item responses for each instrument in order to facilitate understanding and interpretation of the meaning of scores in terms of participant responses. The Statistical Package for Social Sciences (SPSS) 20.0 for Windows was used to manage raw data and perform all data analyses. Data was analyzed using descriptive statistics, preliminary screening procedures, and hierarchical regression to test research hypotheses. Descriptive statistics were computed for all IVs and DVs to examine the shape of the distribution (normal, skewness, kurtosis), central tendency (mean, median, mode), and dispersion (range, variance, standard deviation). Frequencies, percentages, means, and standard deviations were used to summarize demographic characteristics and measured variables of participants. All data were screened for missing information, outliers (Mahalanobis distances), and multicollinearity. Tests of regression assumptions, including normality (kurtosis and skewness), linearity, and homoscedasticity, were examined for both IVs and DVs. Coefficient alphas were used to estimate internal consistency of scores on each measure.

Sample size. An *a priori* power analysis was conducted for the total R^2 value for a multiple regression analysis with 23 predictor variables, power = .90, and alpha = .01. G^*POWER (Faul, Erdfelder, Lang, & Buchner, 2007; Faul, Eedfelder, Buchner, & Lang, 2009), a software tool for general power analysis, yielded a sample size of 259 for a medium effect size (f^2 =.15; Cohen, 1988). The 23 IVs consist of five demographic characteristics (gender, race/ethnicity, education level, cash benefits, and medical benefits); eight disability-related characteristics (age at onset, type of seizure, frequency of seizure, number of AEDs, seizure severity, cognitive deficits, depression, and anxiety); three dimensions of personal factors (positive coping, self-efficacy, and self-esteem); two dimensions of environmental factors (perceived stigma and social support); and five dimension of work skills/abilities (general employability, work tolerance, work communication, self-care, and self-direction skills). This sample size would be adequate for testing a regression model where the constructs were at least moderately correlated and the reliability of the measures was adequate.

Regression analyses. The hypothesized relationships among constructs was tested using regression analyses (Cohen, Cohen, West, & Aiken, 2003). Regression analysis is a method appropriate for examining the predictive power of sets of predictor variables and the contribution of each predictor variable with the DV (Hoyt, Imel, & Chan, 2008). This set of statistical procedures has been popular in counseling and rehabilitation research (Hoyt et al., 2008; Hoyt, Leierer, & Millington, 2006). Hoyt et al. (2008) pointed out that the technique allows researchers to address various research questions in rehabilitation. More specifically, the theory-testing function and its contribution in informing theories in applied settings are often particularly useful. The result of regression analysis is an equation that represents the best prediction of a DV from several continuous (or dichotomous) IVs.

Hierarchical regression analyses. Hierarchical regression analysis (HRA) was used to determine the correlation of each predictor set and to determine the unique contribution and predictive ability of each predictor variable to the variance of the criterion variable. HRA is particularly beneficial when, as in this study, there is more than one IV measuring a construct (Hoyt et al., 2008), because the change in R^2 (ΔR^2) shows the combined contributions of the set of IVs in the same construct in explaining variance in the criterion variable, while sr^2 indicates the unique variance shared by the specific IV.

A predetermined order of the IVs or set of IVs should be entered into the regression model according to the theory on which the hypothesized relationships are based. In this study, hierarchical multiple regression analysis was used to examine the relationships between the ICF constructs and work participation of people with epilepsy. Each set of IVs that belonged to the same ICF construct was entered into the regression model in an order based on the theoretical expectations of the ICF framework to influencing employment of people with epilepsy and assessed in terms of what it adds to the equation at its own point of entry (Tabachnick & Fidell, 2001). The significance was set at alpha = .05. The HRA included the following *a priori* specifications.

- In *Step 1*, a set of *demographic covariates* was entered, which included gender, race/ethnicity, education level, cash benefits, and medical benefits.
- In *Step 2*, the ICF factors related to *functioning/severity* variables was entered, which included age at onset, type of seizure, frequency of seizure, number of AEDs, seizure severity, cognitive deficits, and mental health (depression and anxiety). In this step, the effects of functioning/severity on work participation were determined, after controlling for the effect of demographic covariates.
- In *Step 3*, one of the ICF contextual factors, *personal factors* (positive coping, self-efficacy, and self-esteem), was entered. In this step, the effects of personal factors on work participation were determined, after controlling for the effect of the demographic covariates and functioning/severity.
- In *Step 4*, the other ICF contextual factor, *environmental factors* (perceived stigma and social support), was entered. In this step, the effects of environmental factors on work participation were determined, after controlling for the effect of demographic covariates, functioning/severity, and personal factors.
- In *Step 5*, the ICF factors related to *activities* (work-related skills/abilities) variables was entered. In this step, the effects of work-related skills on work participation were determined, after controlling for the effect of demographic covariates, functioning/severity, personal factors, and environmental factors.

Mediation and moderation analysis. Several multiple regressions were used to test the mediator and moderator hypotheses related to the effect of contextual (personal and environment) factors on the relationship between activities and work participation as well as the interaction effects between contextual factors and activities on work participation.

Mediation analysis. Testing mediator hypotheses is critical to theory building as well as clinical application (Hoyt et al., 2008). The mediator is an intervening variable caused by the IV, which in turn causes the DV, leading to a change of magnitude of the effect of the IV on the DV, partially or completely. By providing information about the underlying mechanisms for change, mediators enable researchers to understand “why” or “how” the IV predicts or causes the DV. Mediation analyses were conducted to examine the effects of activities (i.e., general employability, work tolerance, and work communication skills) as mediators between contextual (i.e., personal and environmental) factors and work participation. In the first mediation analysis, self-esteem was the IV, each of the activities was the mediator, and work participation was the DV. In the second mediation analysis, perceived stigma was the IV, each activity again was the mediator, and work participation was the DV.

Moderation analysis. A moderator variable is a third variable that affects the strength and/or direction of association between an IV and a DV. Moderators enable researchers to understand “when” (i.e., under what condition) or “for whom” the IV predicts or causes the DV. Moderation analyses were conducted to examine the interaction effects between contextual factors and each of the activities on work participation. In the moderation analysis, perceived stigma was the IV, each activity was the moderator, and work participation was the DV.

CHAPTER FOUR

RESULTS

The purpose of this study was to evaluate the ICF framework as an employment model for people with epilepsy. Hierarchical regression analysis was used to determine the amount of variance in work participation that could be accounted for by sets of predictors representing functioning/severity, activities (i.e., work-related skills/abilities), personal factors, and environmental factors of the ICF constructs. Specifically, a hierarchical multiple regression analysis was conducted to identify predictors of ICF constructs for work participation. In addition, mediation analyses were conducted to examine the mediating effect of work-related skills/abilities (i.e., general employability, work communication, and work tolerance skills) on the relationship between contextual (i.e., personal and environmental) factors and work participation. Then, moderation analyses were conducted to examine the interaction effect of work-related skills/abilities and perceived stigma on work participation. Finally, logistic regression analysis was used to examine the effect of the ICF predictors on employment outcome. This chapter describes the results of the statistical analyses used to evaluate the four research questions and the follow-up analysis.

Preliminary Data Screening and Analysis

Data for all predictor and criterion variables were screened using SPSS 20.0 for accuracy, data entry, multivariate outliers, and normality. Frequency tables were used to identify cases in which data had been entered in error. The presence of multicollinearity was assessed by examining the variance inflation factors (VIF) and tolerance. None of the VIF values exceeded 10 for any variables in the analyses (range, 1.02 to 4.17), and none of the tolerance values were less than .10 (range .24 to .98), suggesting that there is no multicollinearity in the data and that no large changes in coefficient would result from adding or deleting variables from the dataset. With the use of 23 predictors and $p < .01$ criterion for Mahalanobis distance, eight outliers were deleted from the hierarchical multiple regression analysis, resulting in a sample size of 262. Histograms, scatter plots of the residuals, and skewness and kurtosis statistics were used to assess normality and linearity; the assumptions of multivariate analyses were found to be met. An a *priori* power analysis was conducted for the total R^2 value for a multiple regression analysis with 23 predictor variables, power = .90, and an alpha = .01. G^*Power 3 (Faul et al., 2007), a software tool for general power analysis, yielded a sample size of 259 for a medium effect size ($f^2 = .15$; Cohen, 1988). With 23 predictors in the study, the sample size of 262 was adequate for regression analysis.

Factor Analysis of Stages of Change-Work Participation

Stages of change for work participation (SOC-WP) was the primary criterion variable in this study. Exploratory factor analysis on the *Stages of Change–Work Participation Scale* (SOC-WP) scores using principal component extraction and varimax rotation revealed a total of three latent factors having ≥ 1.0 eigenvalues (Total variance = 54.15%, *KMO* = .811). The eigenvalues of two latent factors were markedly higher (4.32 and 3.43) than the other (1.45). The result of a scree plot also revealed that the prominent number of components to be extracted was three. Items having factor loadings ≥ .40 were regarded as having a good fit to the latent factors (Nunnally & Bernstein, 1994) (Table 4.1).

Six out of 16 scores loaded onto Factor 1, including four scores that originally belonged to the action subscale and two reversed scores initially belonging to the precontemplation subscale. For the rest of the 10 scores loaded onto Factor 2, four scores originally belonged to the contemplation subscale and two reversed scores originally belonged to the precontemplation subscale. Items 1 had double factor loadings ≥ .40 that loaded negatively onto Factor 2 but positively onto Factor 3.

Table 4.1
Explorative factor analysis on SOC-WP items.

Item #	Items in Original SOC-WP	Factor 1	Factor 2	Factor 3
7	I am performing well on my job. (A)	.877*		
8	I am working hard to keep my job. (A)	.793*		
2	I get along with my coworkers and my supervisor at work. (A)	.785*		
9	I am not able to work. (PC)	.653		.344
16	No one will hire me because of my disability. (PC)	.561		.343
15	I am motivated to work hard to get ahead. (A)	.520*		
12	I am thinking about what kind of job is right for me. (C)		.730*	
3	I probably should look for a job. (C)		.716*	
11	I am beginning to see the value of having a job. (C)		.652*	
13	I am currently applying and interviewing for jobs. (P)		.642	-.312
10	I will have a better life if I have a job. (C)		.616*	
14	I have received or am currently receiving the education and training that can lead to a job. (P)		.555	
4	I am not interested in going to work if it means losing my disability or other benefits (e.g., SSI/SSDI). (PC)			.746
6	The value of work is grossly exaggerated. (PC)			.742
5	I have joined a job club/support group for job-seeking skills training and support. (P)			.588
1	I have received or am currently seeking assistance from an employment agency/vocational rehabilitation agency to help me find a job. (P)		-.469	.503

Note: Method: principal component, orthogonal varimax rotation. Underlined factor loading refers to the variable (item #) loaded onto the designated latent factor (1 = action; 2 = contemplation). Factor loadings marked with asterisk refer to those ≥ .40 and loaded onto the latent factors similar to those stipulated in the SOC-WP.

Items 4, 5 and 6 had factor loadings ≥ .40 and were positively loaded onto Factor 3. The latent Factors 1 and 2 would appear to coincide with the action and contemplation factors (or subscales), respectively, as originally designated in the SOC-WP. Items 1, 4, 5, and 6 were eliminated for computation of the action and contemplation/preparation score. Scores of the SOC-WP were computed as two subscale scores (i.e., SOC-WP contemplation and SOC-WP action subscale scores). The mean scores of the SOC-WP contemplation and SOC-WP action subscales for the study sample were found to be 14.24 (*SD* = 5.32) and 20.11 (*SD* = 6.14), respectively. The internal consistency indices (Cronbach's *α*) for these two subscales were .85 and .75, respectively. Specifically for this study, the SOC-WP action subscale score was computed and used as an indicator for general work participation, with a higher score reflecting greater work participation (i.e., more motivated to participate in work).

Descriptive Statistics

More than half of participants (57%) reported having a job. The rest of the participants (*n* = 120) reported their employment status as unemployed (29%), student (8%), volunteer (3%), and retired (3%). Of those participants who were currently employed (*n* = 159), over half (59%) reported working in a full-time employment. Among those unemployed (*n* = 81), approximately two-thirds (67%) reported that they were in fact actively looking for work.

Correlational Analyses

The correlations among the dependent variable and the predictor variables ranged from small to large, with Pearson Product-Moment correlation coefficients in the .04 to .70 range. Correlations and descriptive statistics for the independent variable, mediator variables, and dependent variable are provided in Table 4.2. The relationship between SOC-WP contemplation score and SOC-WP action score was not significant ($r = .119$, $p < .05$).

Table 4.2
Correlations, Means, and Standard Deviations for Variables Used in Hierarchical Regression Analyses

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
1. SOC-WP contemplation	1	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--
2. SOC-WP action	.119	1	--	--	--	--	--	--	--	--	--	--	--	--	--	--
3. Seizure Severity	.013	$-.361^{**}$	1	--	--	--	--	--	--	--	--	--	--	--	--	--
4. Cognitive Deficits	.008	$-.321^{**}$	$.421^{**}$	1	--	--	--	--	--	--	--	--	--	--	--	--
5. Depression	.080	$-.365^{**}$	$.383^{**}$	$.625^{**}$	1	--	--	--	--	--	--	--	--	--	--	--
6. Anxiety	.028	$-.270^{**}$	$.375^{**}$	$.604^{**}$	$.690^{**}$	1	--	--	--	--	--	--	--	--	--	--
7. Positive Coping	$.172^{**}$	$.198^{**}$	-.081	-.075	$-.145^{*}$	-0.04	1	--	--	--	--	--	--	--	--	--
8. Self-Efficacy	.002	$.343^{**}$	$-.442^{**}$	$-.508^{**}$	$-.488^{**}$	$-.418^{**}$	$.333^{**}$	1		--	--	--	--	--	--	--
9. Self-Esteem	-.064	$.413^{**}$	$-.281^{**}$	$-.455^{**}$	$-.717^{**}$	$-.529^{**}$	$.258^{**}$	$.483^{**}$	1	--	--	--	--	--	--	--
10. Perceived Stigma	$.162^{**}$	$-.504^{**}$	$.365^{**}$	$.480^{**}$	$.534^{**}$	$.406^{**}$	$-.200^{**}$	$-.447^{**}$	$-.561^{**}$	1	--	--	--	--	--	--
11. Social Support	-.011	$.415^{**}$	$-.233^{**}$	$-.300^{**}$	$-.516^{**}$	$-.316^{**}$	$.288^{**}$	$.490^{**}$	$.594^{**}$	$-.409^{**}$	1	--	--	--	--	--
12. General Employability	.013	$.531^{**}$	$-.333^{**}$	$-.460^{**}$	$-.468^{**}$	$-.368^{**}$	$.278^{**}$	$.591^{**}$	$.462^{**}$	$-.470^{**}$	$.415^{**}$	1	--	--	--	--
13. Work Tolerance	.071	$.636^{**}$	$-.434^{**}$	$-.478^{**}$	$-.497^{**}$	$-.364^{**}$	$.187^{**}$	$.576^{**}$	$.456^{**}$	$-.458^{**}$	$.386^{**}$	$.727^{**}$	1	--	--	--
14. Work Communication	.070	$.452^{**}$	$-.366^{**}$	$-.448^{**}$	$-.432^{**}$	$-.322^{**}$	$.260^{**}$	$.541^{**}$	$.421^{**}$	$-.460^{**}$	$.321^{**}$	$.803^{**}$	$.724^{**}$	1	--	--
15. Self-Care	.021	$.417^{**}$	$-.409^{**}$	$-.469^{**}$	$-.461^{**}$	$-.332^{**}$	$.297^{**}$	$.690^{**}$	$.444^{**}$	$-.348^{**}$	$.456^{**}$	$.695^{**}$	$.721^{**}$	$.658^{**}$	1	--
16. Self-Direction	-.012	$.414^{**}$	$-.386^{**}$	$-.484^{**}$	$-.554^{**}$	$-.396^{**}$	$.303^{**}$	$.702^{**}$	$.541^{**}$	$-.497^{**}$	$.526^{**}$	$.688^{**}$	$.687^{**}$	$.680^{**}$	$.756^{**}$	1
Mean	14.23	20.11	0.90	1.82	2.32	2.05	3.00	7.49	1.95	3.05	5.44	3.94	3.89	3.90	4.08	3.67
SD	5.32	6.14	0.73	0.87	0.80	0.89	0.66	1.75	0.62	1.02	1.17	0.84	0.88	0.89	0.77	0.90
Min	0.00	0.00	0.00	0.00	1.00	1.00	1.00	0.83	0.00	1.00	1.13	1.17	1.00	1.33	1.50	1.50
Max	24.00	28.00	3.00	4.00	4.00	4.00	4.00	10.00	3.00	5.00	7.00	5.00	5.00	5.00	5.00	5.00

Note: $^{*}p \le .05$; $^{**}p \le .01$.

Work participation (represented by SOC-WP action score) was found to be inversely related to seizure severity ($r = -.361$, $p < .01$), cognitive deficits ($r = -.321$, $p < .01$), depressive symptoms ($r = -.365$, $p < .01$), anxiety symptoms ($r = -.270$, $p < .01$), and perceived stigma ($r = -.504$, $p < .01$). Work participation was also found to be positively correlated with positive coping ($r = .198$, $p < .01$), self-efficacy ($r = .343$, $p < .01$), self-esteem ($r = .413$, $p < .01$), and social support ($r = .415$, $p < .01$). In addition, work participation was moderately associated with all work-related skills, including general employability skills ($r = .531$, $p < .01$), work tolerance skills ($r = .636$, $p < .01$), work communication skills ($r = .452$, $p < .01$), self-care skills ($r = .417$, $p < .01$), and self-direction skills ($r = .414$, $p < .01$).

Social support was found to be inversely related to seizure severity ($r = -.233$, $p < .01$), cognitive deficits ($r = -.300$, $p < .05$), depressive symptoms ($r = -.516$, $p < .01$), anxiety symptoms ($r = -.316$, $p < .01$), and perceived stigma ($r = -.409$, $p < .01$). Social support was also found to be positively correlated with positive coping ($r = .288$, $p < .01$), self-efficacy ($r = .490$, $p < .01$), self-esteem ($r = .594$, $p < .01$), and work-related skills ($r = .321$ to $.526$, $p < .01$). Positive coping was found to be positively associated with self-efficacy ($r = .333$, $p < .01$), self-esteem ($r = .258$, $p < .01$), and work-related skills ($r = .187$ to $.303$, $p < .01$). Positive coping was found to be inversely related to depressive symptoms ($r = -.145$, $p < .05$) and perceived stigma ($r = -.200$, $p < .01$). Seizure severity was found to be moderately correlated with cognitive deficits ($r = .421$, $p < .01$), depressive symptoms ($r = .383$, $p < .01$), anxiety symptoms ($r = .375$, $p < .01$), and perceived stigma ($r = .365$, $p < .01$). Seizure severity was found to be inversely related to self-efficacy ($r = -.442$, $p < .01$), self-esteem ($r = -.281$, $p < .01$), and work-related skills ($r = -.333$ to $-.434$, $p < .01$).

Hierarchical Regression Analysis

Hierarchical regression analysis (HRA) was conducted to answer the primary research question with work participation as the dependent variable and five sets of ICF variables entered as predictors in sequential steps: (a) demographic covariates, i.e., gender, race/ethnicity, education level, and SSA beneficiary status (cash benefits or medical benefits); (b) functioning/severity, i.e., age at onset, type of seizure, frequency of seizure, number of AEDs, seizure severity, cognitive deficits, depression, and anxiety; (c) personal factors, i.e., positive coping, self-efficacy, and self-esteem; (d) environmental factors, i.e., perceived stigma and social support; and (e) activities, i.e., work-related skills/abilities.

HRA was used to examine the relative contributions of the four sets of ICF variables as predictors of work participation in persons with epilepsy. The results of the analysis, including values of change in R^2 (ΔR^2), along with unstandardized regression coefficients (B), standard errors (*SE B*), and standardized coefficients (β) for the predictor variables at each step and in the final model are presented in Table 4.3.

In the first step of the regression analysis, individual characteristics (i.e., age, gender, race/ethnicity, education level, cash benefits, and medical benefits) were entered. This set of demographic covariates accounted for a significant amount of variance in work participation scores, $R^2 = .256$, $F\ (5, 254) = 17.48$, $p < .001$. An examination of the standardized partial regression coefficients, cash benefits (SSI/SSDI/TANF) and medical benefits (Medicaid/ Medicare), found that they significantly contributed to the change in variance in work participation scores, with $\beta = –.360$, $t\ (260) = –5.29$, $p < .001$; and $\beta = –.162$, $t\ (260) = –2.38$, $p =$ .018, respectively. However, this relationship between SSA benefits and work participation was

Table 4.3
Hierarchical Multiple Regression Analysis for Prediction of Work Participation ($N = 262$)

			At Entry Into Model			Final Model		
Variable	R^2	ΔR^2	B	SE B	β	B	SE B	β
Step 1	.256	.256**						
Gender			-1.49	0.67	-.121	-1.08	0.59	-.088
Race			1.66	0.90	.100	0.87	0.76	.053
Education level			0.20	0.66	.017	0.85	0.59	.071
Cash benefits			-4.55	0.86	-.360**	-1.16	0.81	-.092
Medical benefits			-2.03	0.85	-.162*	-1.94	0.73	-.155*
Step 2	.346	.090**						
Age at onset			0.00	0.03	.000	-0.02	0.02	-.042
Type of Seizure			-0.33	0.64	-.027	-0.63	0.55	-.053
Frequency of Seizure			-0.32	0.72	-.028	0.02	0.62	.002
Number of AEDs			-0.78	0.67	-.068	-1.25	0.57	-.109*
Seizure Severity			-0.11	0.06	-.128*	-0.07	0.05	-.075
Cognitive Deficits			-0.01	0.03	-.024	0.02	0.03	.041
Depression			-0.19	0.09	-.162*	0.15	0.10	.124
Anxiety			-0.03	0.07	-.028	-0.05	0.06	-.050
Step 3	.388	.043**						
Positive Coping			0.05	0.05	.061	0.03	0.04	.039
Self Efficacy			0.01	0.01	.055	0.05	0.07	.058
Self Esteem			0.23	0.07	.247**	-0.02	0.01	-.106
Step 4	.448	.060**						
Perceived Stigma			-0.17	0.04	-.296**	-0.16	0.03	-.275**
Social Support			0.04	0.02	.121*	0.04	0.02	.119*
Step 5	.550	.102**						
General Employability			0.27	0.11	.216*	0.27	0.11	.216*
Work Tolerance			0.57	0.10	.500**	0.57	0.10	.500**
Work Communication			-0.32	0.09	-.281**	-0.32	0.09	-.281**
Self-Care			-0.15	0.10	-.120	-0.15	0.10	-.120
Self-Direction			0.00	0.09	-.004	0.00	0.09	-.004

Note. F (23, 236) = 12.55, $p < .001$ for full model; F (5, 254) = 17.48, $p < .001$, for Step 1; $\Delta F(8, 246) = 4.21$, $p < .001$ for Step 2; $\Delta F(3, 243) = 5.64$, $p < .001$ for Step 3; $\Delta F(2, 241) = 13.06$, $p < .001$ for Step 4; $\Delta F(5, 236) = 10.73$, $p < .001$ for Step 5.
$^{*}p \leq .05$, $^{**}p \leq .01$.

negative, indicating that people who received cash/medical benefits were associated with lower levels of work participation compared to those who did not receive cash/medical benefits.

Functioning/severity variables (i.e., type of seizure, frequency of seizure, number of AEDs, seizure severity, cognitive deficits, depression, and anxiety) were entered in the second step of the regression analysis. This set of variables accounted for a significant amount of additional variance in work participation scores beyond that explained by the demographics covariates entered in the first step, $R^2 = .346$, $\Delta R^2 = .090$, F (8, 246) = 4.21, $p < .001$. In this step, the standardized beta for cash benefits was reduced from –.360 to –.283 and the standardized beta for medical benefits was reduced from –.162 to –.139.

Despite the changes in standardized beta values, cash benefits and medical benefits both remained significant contributors to the variance in work participation. With the addition of functioning/severity variables in the equation, seizure severity and depression were found to contribute significantly to the change in variance in work participation scores, with $\beta = -.128$, t (260) = –1.99, $p = .047$; and $\beta = -.162$, t (260) = –2.05, $p = .041$, respectively. This result indicates that seizure severity and depression level were negatively associated with work participation and that each standard deviation unit increase on seizure severity was predicted to correspond to a 0.13 and 0.16 standard deviation unit decrease on work participation, respectively (if other demographic covariates and functioning/severity variables were held constant).

Personal factors (i.e., positive coping, self-efficacy, and self-esteem) were entered in the third step of the regression analysis. This set of variables accounted for a significant amount of additional variance in work participation scores beyond that explained by the demographic covariates and functioning/severity variables entered in previous steps, $R^2 = .388$, $\Delta R^2 = .043$, F

(3, 243) = 5.64, $p < .001$. Medical benefits, seizure severity and depression were no longer significant contributors to the variance in work participation. However, cash benefits still remained a significant contributor but to a somewhat lesser extent with the personal factors controlled for cash benefits, $\beta = –.271$, t (260) = –4.05, $p < .001$. Furthermore, self-esteem was found to significantly contribute to the change in variance in work participation scores, with β =.247, t (260) = 3.29, $p = .001$, respectively. The results indicate that self-esteem were positively associated with work participation, suggesting that higher self-esteem was associated with greater work participation.

Environmental factors (i.e., perceived stigma and social support) were entered in the fourth step of the regression analysis. This set of variables accounted for a significant amount of additional variance in work participation scores beyond that explained by the demographic covariates, functioning/severity, and personal factor variables entered in previous steps, R^2 = .388, $\Delta R^2 = .043$, F (3, 243) = 5.64, $p < .001$. Cash benefits remained significant contributors to the variance in work participation, but to a somewhat lesser extent with the environmental factors controlled for cash benefits, $\beta = –.243$, t (260) = –3.79, $p < .001$.

Furthermore, perceived stigma and social support were found to significantly contribute to the change in variance in work participation scores, with $\beta = –.296$, t (260) = –4.64, $p < .001$; and $\beta = .121$, t (260) = 196, $p = .050$, respectively. The results indicate that perceived stigma was negatively correlated with work participation, whereas social support was positively associated with work participation, suggesting that reduced perceived stigma or increased social support was associated with greater work participation. With the addition of perceived stigma and social support in the equation, self-esteem was no longer a significant contributor to the overall variance over and above the other variables entered into the analysis.

In the final step, work-related skills/abilities variables (i.e., general employability, work communication, work tolerance, self-care, and self-direction skills) were entered into the regression analysis. The addition of these five variables accounted for a significant amount of additional variance in work participation scores beyond that explained by the demographic covariates, functioning/severity variables, personal factors, and environmental factors entered in previous steps, $R^2 = .550$, $\Delta R^2 = .102$, $F\ (5, 236) = 10.73$, $p < .001$. General employability and work tolerance were found to contribute significantly to the change in variance in work participation scores, with $\beta = .216$, $t\ (260) = 2.57$, $p = .011$; and $\beta = .500$, $t\ (260) = 5.65$, $p < .001$, indicating that increased general employability and work tolerance were associated with greater work participation. However, work communication was found to contribute significantly to the change in variance in work participation scores, with $\beta = –.281$, $t\ (260) = –.3.35$, $p = .001$, indicating that increased work communication was associated with less work participation. Number of AEDs, perceived stigma, and social support remained significant contributors to the variance in work participation scores, with $\beta = –.109$, $t\ (260) = –2.18$, $p = .\ 030$; $\beta = –.275$, $t\ (260) = –4.56$, $p < .001$, and $\beta = .119$, $t\ (260) = 1.99$, $p = .047$, respectively. Medical benefits was significant ($p < .05$) in Step 1 and Step 2; whereas, its effect was mediated by personal and environmental factors in Step 3 and Step 4 (p = n.s.). However, with the inclusion of work-related skills/abilities variables in the regression analysis, medical benefits again became a significant predictor of work participation, $\beta = –.155$, $t\ (260) = –2.65$, $p = .009$.

The final regression model accounted for 55% of the variance in work participation. According to Cohen's standards for the behavioral sciences, this is considered a large effect size (Cohen, 1988; 1992). Once all other factors were controlled, medical benefits ($\beta = –.092$), number of AEDs ($\beta = –.109$), perceived stigma ($\beta = –.275$), social support ($\beta = .119$), general employability (β = .216), work tolerance (β = .500), and work communication (β = –.281) were found to be significant predictors of work participation in persons with epilepsy. Social support, general employability and work tolerance were positively associated with work participation, whereas medical benefits, number of AEDs, perceived stigma, and work communication were negatively related to work participation. In addition, work tolerance was found to be the strongest predictor in the model with its effect, r = .636, β = .500, on work participation.

Mediation Analyses

Work related skills (i.e., general employability, work tolerance, and work communication skills) were hypothesized to be mediators between contextual factors (i.e., personal factors and environmental factors) and work participation. In this study, only one personal factor (i.e., self-esteem) and one environmental factor (i.e., perceived stigma) were focused and three separate sets of mediation analyses were conducted. Baron and Kenny's (1986) application of multiple regression was used to test this hypothesis. Guidelines provided by Frazier and colleagues (2004) and Preacher and Hayes (2004) were followed in conducting the mediation analyses. This procedure involved three steps:

1. Regress the outcome (DV) onto the predictor (IV) to show that a causal relation is plausible.
2. Regress the mediator(s) onto the predictor (IV) to show it is plausible that the two variables can be causally linked.
3. Regress the outcome (DV) simultaneously onto the predictor (IV) and the mediator(s) to show that the mediator(s) is/are significantly related to the outcome (DV), even when the predictor (IV) is statistically controlled.

If the regression coefficients for Steps 1 and 2 are significant and if the partial regression coefficient for predicting the outcome variable from the mediator is significant in Step 3, a mediator hypothesis is supported (Baron & Kenny, 1986). In this study, a mediational hypothesis of the relationship between each of the work-related abilities/skills and work participation was assessed. To answer the second research question, "Do *work-related abilities/skills* <u>mediate</u> the relationship between *self-esteem* and *work participation*?", mediation analyses were computed to examine the role of each work-related skill (i.e., general employability, work tolerance, or work communication skill) as a mediator between self-esteem and work participation. To answer the third research question, "Do *work-related abilities/skills* <u>mediate</u> the relationship between *perceived stigma* and *work participation*?", mediation analyses were computed to examine the role of each of the three work-related abilities/skills as a mediator between perceived stigma and work participation. The results of the mediation analyses are presented in Table 4.4 and Table 4.5.

Test of indirect effect. A complement to Baron and Kenny's (1986) approach to testing mediator hypotheses is the test of the significance of the indirect effect of the IV on the DV through the mediator. Numerically, this indirect effect is equal to the product of the two path coefficients that compose the indirect path from the predictor (X) to the outcome variable (Y). A simple approach to testing whether this product differs significantly from zero was proposed by Sobel (1982). Sobel assumed a normal sampling distribution for the product and used an approximate standard error to create a CI or conduct a significance test. Unfortunately, the sampling distribution of the product does not usually approximate a normal distribution, and as a result, significance tests using Sobel's method are biased (Hoyt et al., 2008).

Table 4.4
Steps in Testing Self-Esteem as a Mediator between Work Skills/Abilities and Work Participation

Conditions for Mediator Model	**General Employability**			**Work Tolerance**			**Work Communication**		
	B	SE B	*β*	B	SE B	*β*	B	SE B	*β*
Condition 1									
Outcome: Work Participation									
Predictor: Self-esteem	0.38	0.05	.407**	0.38	0.05	.407**	0.38	0.05	.407**
Condition 2									
Mediator: Work-related Skills									
Predictor: Self-esteem	0.35	0.04	.469**	0.38	0.05	.464**	0.35	0.05	.422**
Condition 3									
Outcome: Work Participation									
Mediator: Work-related Skills	0.49	0.07	.388**	0.60	0.06	.529**	0.35	0.07	.307**
Predictor: Self-esteem	0.21	0.06	.225**	0.15	0.05	.162**	0.26	0.06	.277**
Overall Model	R^2	*F*	*p*	R^2	*F*	*p*	R^2	*F*	*p*
	.283	51.11	<.001	.385	81.12	<.001	.243	41.54	<.001
	z	*p*		*z*	*p*		*z*	*p*	
Sobel Test	5.20	<.001		6.36	<.001		4.26	<.001	
		95% CI			*95% CI*			*95% CI*	
	Δ	Lower	Upper	Δ	Lower	Upper	Δ	Lower	Upper
Bootstrap Test	.171	.111	.246	.231	.164	.315	.122	.070	.193

$^{*}p < .05$, $^{**}p < .01$.

Table 4.5
Steps in Testing Perceived Stigma as a Mediator between Work Skills/Abilities and Work Participation

Conditions for Mediator Model	**General Employability**			**Work Tolerance**			**Work Communication**		
	B	SE B	*β*	B	SE B	*β*	B	SE B	*β*
Condition 1									
Outcome: Work Participation									
Predictor: Perceived Stigma	-0.28	0.03	-.485**	-0.28	0.03	-.485**	-0.28	0.03	-.485**
Condition 2									
Mediator: Work-related Skills									
Predictor: Perceived Stigma	-0.20	0.03	-.434**	-0.22	0.03	-.432**	-0.21	0.03	-.427**
Condition 3									
Outcome: Work Participation									
Mediator: Work-related Skills	0.44	0.07	.349**	0.55	0.06	.485**	0.30	0.07	.265**
Predictor: Perceived Stigma	-0.19	0.03	-.333**	-0.16	0.03	-.276**	-0.21	0.03	-.372**
Overall Model	R^2	*F*	*P*	R^2	*F*	*P*	R^2	*F*	*p*
	.334	64.85	<.001	.426	96.28	<.001	.293	53.55	<.001
	z	*p*		*z*	*p*		*z*	*p*	
Sobel Test	-4.86	<.001		-5.95	<.001		-3.94	<.001	
		95% CI			*95% CI*			*95% CI*	
	Δ	Lower	Upper	Δ	Lower	Upper	Δ	Lower	Upper
Bootstrap Test	-.086	-.125	-.054	-.119	-.164	-.082	-.064	-.102	-.030

$^{*}p < .05$, $^{**}p < .01$.

Several alternative tests have been proposed (MacKinnon et al., 2002), and a consensus is emerging that the bootstrap test provides the strongest statistical properties (Hoyt et al.). The indirect effect for the mediation model was tested using an SPSS macro for conducting bootstrap tests of multiple-mediator models downloaded from Kristopher Preacher's website (www.people.ku.edu/preacher/).

Mediation analyses between self-esteem and work participation. The first mediation analysis was computed to examine the role of general employability as a mediator between self-esteem and work participation. The first step was to establish a significant relationship between the predictor and outcome variables by regressing work participation on self-esteem. Self-esteem (predictor) was found to be significantly associated with work participation (outcome), $\beta = .407$, $t\,(260) = 7.18$, $p < .001$, satisfying the first condition. In the second step, general employability (mediator) was regressed on self-esteem (predictor). Self-esteem was significantly related to general employability, $\beta = .469$, $t\,(260) = 8.56$, $p < .001$. Finally, the putative mediator was significantly related to the outcome variable, while statistically controlling for the predictor variable (Step 3). The relevant analysis was a simultaneous regression of work participation (outcome) on self-esteem (predictor) and general employability (mediator). The model accounted for 28% of the variance in work participation, $R^2 = .283$, $F\,(2, 259) = 51.11$, $p < .001$, and is considered a large effect size (Cohen, 1988; 1992). In a test of the third condition, the mediator was significantly associated with the outcome variable. The relationship between general employability and work participation, while the effect of self-esteem was controlled, was found to be significant, $\beta = .388$, $t\,(260) = 6.51$, $p < .001$, satisfying the final condition for mediation. In summary, the results in all three steps were significant, as predicted, yielding support for the proposed mediation model. Furthermore, the findings conform to the predictions of a model in which self-esteem is associated with work participation indirectly through its association with general employability.

In addition, the association between self-esteem and work participation in the final (two-predictor) regression equation was also found statistically significant, $\beta = .225$, $t\ (260) = 3.78$, $p < .001$. The β for self-esteem was reduced from .407 to .225 after controlling for the effect of the mediator. Thus, while the intervening variable (general employability) helps to explain the link between self-esteem and work participation, it does not completely explain the relationship. This pattern of findings, with a significant indirect effect through a mediator accompanied by a significant direct effect, is not uncommon and was characterized by Baron and Kenny (1986) as a case of partial mediation. To determine the significance of the indirect effect in this partially mediated model, the modified version of the Sobel (1982) test by Baron and Kenny (1986), which includes an additional denominator term to calculate z-values, was used to create 95% confidence intervals around the estimate of the indirect effect. Results indicate the presence of mediation through general employability, $z = 5.20$, $p < .001$. Across bootstrapped samples, the mean indirect effect from self-esteem, through general employability, to work participation was .171, $CI_{.95} = .111, .246$, indicating that the indirect effect was significantly different from zero, $p < .05$, and supporting the hypothesis that general employability mediates the positive relationship between self-esteem and work participation.

The second mediation analysis was computed to examine the role of work tolerance as a mediator between self-esteem and work participation. In the first step, self-esteem (predictor) was found to be significantly associated with work participation (outcome), $\beta = .407$, $t\ (260) = 7.18$, $p < .001$, satisfying the first condition. In the second step, self-esteem (predictor) was found to be significantly related to work tolerance (mediator), $\beta = .464$, $t\ (260) = 8.44$, $p < .001$.

Finally, work participation (outcome) was regressed simultaneously on self-esteem (predictor) and work tolerance (mediator). The model accounted for 39% of the variance in work participation, $R^2 = .385$, F (2, 259) = 81.12, $p < .001$, and is considered a large effect size (Cohen, 1988; 1992). In the test of the third condition, the relationship between work tolerance and work participation, while the effect of self-esteem was controlled, was found to be significant, $\beta = .529$, t (260) = 9.62, $p < .001$, satisfying the final condition for mediation. In summary, the results in all three steps were significant, as predicted, yielding support for the proposed mediation model. Furthermore, the findings conform to the predictions of a model in which self-esteem is associated with work participation indirectly through its association with work tolerance.

In addition, the association between self-esteem and work participation in the final (two-predictor) regression equation was also found statistically significant, $\beta = .162$, t (260) = 2.94, $p = .004$. The β for self-esteem was reduced from .407 to .162 after controlling for the effect of the mediator. Thus, while the intervening variable (work tolerance) helps to explain the link between self-esteem and work participation, it does not completely explain the relationship. Results of the Sobel test indicated the presence of mediation through work tolerance, z = 6.36, $p < .001$. Across bootstrapped samples, the mean indirect effect from self-esteem, through work tolerance, to work participation was .231, $CI_{.95}$ = .164, .315, indicating that the indirect effect was significantly different from zero, $p < .05$, and supporting the hypothesis that work tolerance mediates the positive relationship between self-esteem and work participation.

The third mediation analysis was computed to examine the role of work communication as a mediator between self-esteem and work participation. In the first step, self-esteem (predictor) was found to be significantly associated with work participation (outcome), $\beta = .407$,

t (260) = 7.18, $p < .001$, satisfying the first condition. In the second step, self-esteem (predictor) was significantly related to work communication (mediator), $\beta = .422$, t (260) = 7.51, $p < .001$. Finally, work participation (outcome) was regressed simultaneously on self-esteem (predictor) and work communication (mediator). The model accounted for 24% of the variance in work participation, $R^2 = .243$, F (2, 259) = 41.54, $p < .001$, which is considered a medium-to-large effect size (Cohen, 1988; 1992). In the test of the third condition, the relationships between work communication and work participation, while the effect of self-esteem was controlled, was found to be significant, $\beta = .307$, t (260) = 5.14, $p < .001$, satisfying the final condition for mediation. In summary, the results in all three steps were significant, as predicted, yielding support for the proposed mediation model. Furthermore, the findings conform to the predictions of a model in which self-esteem is associated with work participation indirectly through its association with work communication.

In addition, the association between self-esteem and work participation in the final (two-predictor) regression equation was also found statistically significant, $\beta = .277$, t (260) = 4.65, $p < .001$. The β for self-esteem was reduced from .407 to .277 after controlling for the effect of the mediator. Thus, while the intervening variable (self-esteem) help to explain the link between work communication and work participation, it does not completely explain the relationship. Results of the Sobel test indicated the presence of mediation through work communication, z = 4.26, $p < .001$. Across bootstrapped samples, the mean indirect effect from self-esteem, through work communication, to work participation was .122, $CI_{.95}$ = .070, .193, indicating that the indirect effect was significantly different from zero, $p < .05$, and supporting the hypothesis that work communication mediates the positive relationship between self-esteem and work participation.

Mediation analyses between perceived stigma and work participation. The first mediation analysis was computed to examine the role of general employability as a mediator between perceived stigma and work participation. The first step was to establish a significant relationship between the predictor and outcome variables by regressing work participation on perceived stigma. Perceived stigma (predictor) was found to be significantly associated with work participation (outcome), $\beta = -.485$, $t\ (260) = -.894$, $p < .001$, satisfying the first condition. In the second step, general employability (mediator) was regressed on perceived stigma (predictor). Perceived stigma was significantly related to general employability, $\beta = -.434$, $t\ (260) = -7.77$, $p < .001$. Finally, the putative mediator was significantly related to the outcome variable, while statistically controlling for the predictor variable (Step 3). The relevant analysis was a simultaneous regression of work participation (outcome) on perceived stigma (predictor), and general employability (mediator). The model accounted for 33% of the variance in work participation, $R^2 = .334$, $F\ (2, 259) = 64.85$, $p < .001$, and is considered a large effect size (Cohen, 1988; 1992). In a test of the third condition, the mediator was significantly associated with the outcome variable. The relationship between general employability and work participation, while the effect of perceived stigma was controlled, was found to be significant, $\beta = .349$, $t\ (260) = 6.19$, $p < .001$, satisfying the final condition for mediation. In summary, the results in all three steps were significant, as predicted, yielding support for the proposed mediation model. Furthermore, the findings conform to the predictions of a model in which perceived stigma is associated with work participation indirectly through its association with general employability.

In addition, the association between perceived stigma and work participation in the final (two-predictor) regression equation was also found statistically significant, $\beta = -.333$, $t\ (260) = -$

5.92, $p < .001$. The β for general employability was reduced from –.485 to –.333 after controlling for the effect of the mediator. Thus, while the intervening variable (general employability) helps to explain the link between perceived stigma and work participation, it does not completely explain the relationship. Results of the Sobel test indicate the presence of mediation through general employability, z = –4.86, $p < .001$. Across bootstrapped samples, the mean indirect effect from perceived stigma, through general employability, to work participation was –.086, $CI_{.95}$ = –.125, –.054, indicating that the indirect effect was significantly different from zero, $p < .05$, and supporting the hypothesis that general employability mediates the negative relationship between perceived stigma and work participation.

The second mediation analysis was computed to examine the role of work tolerance as a mediator between perceived stigma and work participation. In the first step, perceived stigma (predictor) was found to be significantly associated with work participation (outcome), β = –.485, t (260) = –8.94, $p < .001$, satisfying the first condition. In the second step, perceived stigma (predictor) was found to be significantly related to work tolerance (mediator), β = –.432, t (260) = –7.71, $p < .001$. Finally, work participation (outcome) was regressed simultaneously on perceived stigma (predictor) and work tolerance (mediator). The model accounted for 43% of the variance in work participation, $R^2 = .426$, F (2, 259) = 96.28, $p < .001$, and is considered a large effect size (Cohen, 1988; 1992). In a test of the third condition, the relationship between work tolerance and work participation, while the effect of perceived stigma was controlled, was found to be significant, β =.485, t (260) = 9.30, $p < .001$, satisfying the final condition for mediation. In summary, the results in all three steps were significant, as predicted, yielding support for the proposed mediation model. Furthermore, the findings conform to the predictions of a model in which perceived stigma is associated with work participation indirectly through its association with work tolerance.

In addition, the association between perceived stigma and work participation in the final (two-predictor) regression equation was also found statistically significant, $\beta = -.276$, $t\ (260) = -5.28$, $p < .001$. The β for general employability was reduced from –.485 to –.276 after controlling for the effect of the mediator. Thus, while the intervening variable (work tolerance) helps to explain the link between perceived stigma and work participation, it does not completely explain the relationship. Results of the Sobel test indicate the presence of mediation through work tolerance, $z = -5.95$, $p < .001$. Across bootstrapped samples, the mean indirect effect from perceived stigma, through work tolerance, to work participation was –.119, $CI_{.95} = -.164, -.082$, indicating that the indirect effect was significantly different from zero, $p < .05$, and supporting the hypothesis that work tolerance mediates the negative relationship between perceived stigma and work participation.

The third mediation analysis was computed to examine the role of work communication as a mediator between perceived stigma and work participation. In the first step, perceived stigma (predictor) was found to be significantly associated with work participation (outcome), $\beta = -.485$, $t\ (260) = -9.30$, $p < .001$, satisfying the first condition. In the second step, perceived stigma (predictor) was found to be significantly related to work communication (mediator), $\beta = -.427$, $t\ (260) = -7.62$, $p < .001$. Finally, work participation (outcome) was regressed simultaneously on perceived stigma (predictor) and work communication (mediator). The model accounted for 29% of the variance in work participation, $R^2 = .293$, $F\ (2, 259) = 53.55$, $p < .001$, and is considered a large effect size (Cohen, 1988; 1992). In a test of the third condition, the relationships between work communication and work participation, while the effect of perceived stigma was controlled, were found to be significant, $\beta = .265$, $t\,(260) = 4.59$, $p < .001$, satisfying the final condition for mediation. In summary, the results in all three steps were significant, as predicted, yielding support for the proposed mediation model. Furthermore, the findings conform to the predictions of a model in which perceived stigma is associated with work participation indirectly through its association with work communication.

In addition, the association between perceived stigma and work participation in the final (two-predictor) regression equation was also found statistically significant, $\beta = -.372$, $t\,(260) = -6.43$, $p < .001$. The β for work communication was reduced from –.485 to –.372 after controlling for the effect of the mediator. Thus, while the intervening variable (work communication) helps to explain the link between perceived stigma and work participation, it does not completely explain the relationship. Results of the Sobel test indicated the presence of mediation through work communication, $z = -3.94$, $p < .001$. Across bootstrapped samples, the mean indirect effect from perceived stigma, through work communication, to work participation was –.064, $CI_{.95} = -.102, -.030$, indicating that the indirect effect was significantly different from zero, $p < .05$, and supporting the hypothesis that work communication mediate the negative relationship between perceived stigma and work participation.

Moderation Analyses

To answer the last research question “Do *work-related abilities/skills* moderate the relationship between *perceived stigma* and *work participation*?”, moderation analysis was computed. The recommendations of Aiken and West (1991) and Frazier, Tix, and Barron (2004) were followed in order to examine the role of each work-related skill (i.e., general employability, work tolerance, or work communication skill) as a moderator between perceived stigma and work participation. The predictor and moderator variables were standardized and measured on a continuous scale of z-scores, creating multiplicative interaction terms. One of the advantages of centering or standardizing predictors is to reduce the problems associated with multicollinearity among the variables in the regression equation (Aiken & West, 1991). Standardizing variables also makes it easier to plot significant moderator effects (Frazier, Tix, & Barron, 2004). Variables in sets were entered into the regression equation, the incremental *F*-test of the difference in R^2 between the sets of variables was computed, and the presence of a significant change in the total R^2 after each new set of predictors was added to the model was examined (Cohen et al., 2003). At Step 1, the centralized scores of perceived stigma and one of the work-related skills were entered. At Step 2, a set of two-way interaction between perceived stigma and specific work-related skills was entered. Overall, after the main effect of perceived stigma and specific work-related skill was controlled, none of the interaction effects between any of the perceived stigma and specific work-related skills on work participation was found significant (p = n.s.). The results indicated that work-related skills/abilities do not moderate the relationship between perceived stigma and work participation.

Secondary Analysis

Employment status (i.e., employed vs. unemployed) is always considered as an employment outcome, while the results of this study indicated that work participation is positively correlated with employment status (Spearman's rho $r = .468$, $p = <.001$). Thus, a logical follow-up analysis would be to determine whether the five sets of variables in the ICF model can predict employment status. Logistic regression analysis was used to examine the effect of demographic covariates, functioning/severity, personal factors, environmental factors, and work-related abilities/skills on employment outcome (i.e., employed vs. unemployed). This secondary analysis can provide useful information to rehabilitation health professionals on helping people with epilepsy to obtain employment. The results of this secondary analysis are presented in Table 4.6.

The omnibus test for the logistic regression model was found to be statistically significant, χ^2 (23, N = 262) = 90.45, $p < .001$. The Nagelkerke R^2 was computed to be .384, indicating a relatively large effect size. The Hosmer and Lemeshow goodness of fit test was not significant, χ^2 (8, N = 262) = 8.83, $p = .357$, indicating that the model fits the data reasonably well. In the final step, only race/ethnicity, medical benefits (i.e., Medicaid/Medicare), frequency of seizure, perceived stigma, social support, general employability, work tolerance, and work communication skills were found to be significant predictors. Individuals who are white had an increase in odds of being employed compared to those who are non-white, odds ratio (*OR*) = 3.37, 95% *CI*: 1.36, 8.37. However, individuals who received medical benefits had a reduction in odds of being employed compared to those who did not receive benefits, *OR* = 0.34, 95% *CI*: 0.15, 0.76. In addition, individuals who experienced more frequent seizures had a reduction in odds of being employed compared to those who experienced less frequent seizures, *OR* = 0.43, 95% *CI*: 0.21, 0.89. Environmental factors were significantly associated with employment status (perceived stigma: *OR* = 0.94, 95% *CI*: 0.90, 0.98; social support: *OR* = 1.03, 95% *CI*: 1.00, 1.05), indicating that individuals who had higher perceived social support or lower perceived stigma had an increase in odds of being employed. Furthermore, general employability, *OR* = 1.12, 95% *CI*: 1.00, 1.26, and work tolerance, *OR* = 1.15, 95% *CI*: 1.03, 1.28, were positively correlated with employment status. Similarly, work communication was also found to be inversely correlated with employment status, with *OR* = 0.86, 95% *CI*: 0.77, 0.96. The results indicate that individuals who had higher general employability, higher work tolerance, or lower work communication skills had an increase in odds of being employed.

Table 4.6
Hierarchical Logistic Regression Analysis for Prediction of Employment Status (*N* = 262)

Variable	*B*	SE *B*	Wald	df	*p*	*OR*	95% CI	
							Upper	Lower
Step 1								
Gender	-0.40	0.35	1.35	1	.245	0.67	0.34	1.32
Race	1.22	0.46	6.85	1	.009	3.37^{**}	1.36	8.37
Education level	0.36	0.34	1.07	1	.302	1.43	0.73	2.80
Cash benefits	-0.34	0.45	0.55	1	.457	0.71	0.29	1.73
Medical benefits	-1.09	0.42	6.82	1	.009	0.34^{**}	0.15	0.76
Step 2								
Age at onset	0.01	0.01	0.66	1	.416	1.01	0.98	1.04
Type of Seizure	-0.08	0.33	0.06	1	.805	0.92	0.49	1.75
Frequency of Seizure	-0.83	0.37	5.14	1	.023	0.43^{*}	0.21	0.89
Number of AEDs	0.40	0.35	1.32	1	.251	1.50	0.75	2.99
Seizure Severity	0.03	0.03	1.08	1	.300	1.03	0.97	1.09
Cognitive Deficits	0.01	0.02	0.56	1	.455	1.01	0.98	1.05
Depression	0.06	0.06	0.92	1	.338	1.06	0.94	1.19
Anxiety	-0.02	0.04	0.21	1	.644	0.98	0.92	1.06
Step 3								
Positive Coping	-0.02	0.03	0.47	1	.495	0.98	0.93	1.03
Self Efficacy	-0.01	0.01	1.06	1	.304	0.99	0.98	1.01
Self Esteem	-0.04	0.04	1.32	1	.250	0.96	0.89	1.03
Step 4								
Perceived Stigma	-0.06	0.02	9.03	1	.003	0.94^{**}	0.90	0.98
Social Support	0.03	0.01	4.88	1	.027	1.03*	1.00	1.05
Step 5								
General Employability	0.12	0.06	3.78	1	.050	1.12*	1.00	1.26
Work Tolerance	0.14	0.06	6.66	1	.010	1.15^{**}	1.03	1.28
Work Communication	-0.15	0.06	7.12	1	.008	0.86^{**}	0.77	0.96
Self-Care	0.04	0.06	0.37	1	.543	1.04	0.92	1.17
Self-Direction	-0.04	0.06	0.50	1	.480	0.96	0.86	1.07

Note. OR = odds ratio; 95% *CI*=95% confidence intervals; Nagelkerke R^2 = .384.
$^{*}p \leq .05$, $^{**}p \leq .01$.

CHAPTER FIVE

Summary, Discussion, Implications

In this chapter, a summary of the study findings, followed by a discussion and possible explanations for the major findings, is provided. Limitations of this study that might impact the interpretation and generalizability of research results are then considered. Finally, implications and suggestions for clinical rehabilitation practice and future research are discussed.

Major Study Findings

Unemployment and underemployment continue to be profound problems for people with epilepsy (Smeets et al., 2007). Known consequences of unemployment and underemployment include depression and anxiety, alcohol and other drug abuse, low self-esteem, and poor quality of life. However, in spite of numerous employment-related services offered by various organizations, research has shown that there has been no material change in the employment rate for individuals with epilepsy in over three decades (Bishop & Chiu, 2011; Smeets et al., 2007). Smeets et al. indicated that problematic employment situations associated with epilepsy are the result of a set of adverse internal (personal) and external (environmental) factors interacting with each other in a complex manner. Rehabilitation health researchers have advocated for theory-driven research that would give them a better understanding of these complex factors and their interaction effects in order to comprehend the dynamics of epilepsy and employment. Recently, the International Classification of Functioning, Health and Disability (ICF) model has become widely used as a framework that can support a systematic approach to the understanding of chronic illness and disability across cultures (Chan, Keegan, et al., 2009; Chan, Sasson, et al., 2009). Within the ICF framework, functioning and disability are viewed as complex interactions among the health condition of the individual and the context of personal and environmental factors. As such, the ICF framework could be used to study the complex internal and external factors associated with employment outcomes of individuals with epilepsy. Subsequently, efficacious, effective, and efficient employment interventions can be developed to tangibly improve employment outcomes and work participation for people with epilepsy.

The primary goal of this study was to evaluate the ICF framework as a multidimensional, comprehensive employment model and to investigate its ability to predict work participation for people with epilepsy through the use of hierarchical regression analysis. Specifically, the relationships among the variables of different ICF components (i.e., functioning/severity, activities, personal, and environmental factors) were examined as they apply to people with epilepsy and their engagement in work. An additional aim of this study was to investigate the relationship between contextual factors (i.e., personal and environmental factors) and work participation. An examination of the possible mediating role of work-related skills/abilities (i.e., general employability, work tolerance, and work communication) on the relationship between personal factors (i.e., self-esteem) and work participation as well as between environmental factors (i.e., perceived stigma) and work participation was also conducted. Based on the initial study findings, an additional analysis was conducted to evaluate the ability of the ICF model to predict employment status as the outcome variable.

This study is novel because it is the first study to use the Stages of Change Model in its investigation of work participation for individuals with epilepsy in the community and is the first to adopt the ICF model as a guiding framework in its consideration of potential factors impacting work participation for individuals with epilepsy.

Relationships Between ICF Predictors and Work Participation

In this study, a correlational analysis was conducted to evaluate the relationships between the 23 predictor variables and 1 outcome variable from the ICF framework. Several significant relationships were found. Medium-to-large positive relationships were observed between work participation and the following ICF predictors: self-efficacy, self-esteem, positive coping, social support, general employability, work tolerance, work communication, self-care, and self-direction skills. Several medium negative relationships were observed between work participation and these ICF predictors: seizure severity, cognitive deficits, depression, anxiety symptoms, and perceived stigma. Also notable were medium-to-large relationships involving the personal and environmental factors of positive coping, self-efficacy, self-esteem, perceived support, and social support. It is not surprising that people with greater work participation have higher self-esteem and self-efficacy, use more positive coping strategies, and perceive less stigma in the work environment. Finally, strong relationships were found among the various work-related skills. The findings indicate that some variables may overlap but not to such a degree that the variables appear to measure the same construct.

Factors Contributing to Work Participation

In the primary analyses, hierarchical regression analysis (HRA) was used to investigate how different ICF variable sets may contribute to work participation for people with epilepsy. The predictor variables of the ICF model were divided into four major groups, matching the different components of the model, and HRA was used to assess the contribution of each construct. Specifically, it was hypothesized that the five sets of variables—demographic covariates, functioning/severity variables, work-related skills/abilities, personal factors, and environmental factors—would each contribute significantly to a prediction of work participation.

Overall, the final regression model accounted for 55% of the variance in work participation scores, which is considered a large effect size according to Cohen's (1988) standards and provides good support for the use of the ICF model in predicting work participation for people with epilepsy. The results suggested that demographic variables (medical benefits), functioning/severity variables (number of antiepileptic drugs [AEDs]), environmental variables (perceived stigma and social support), and work-related skills/abilities (general employability, work tolerance, and work communication skills) accounted for the variance in work participation; however, personal variables were not found to be significant factors.

Discussion. Evaluating a multidimensional model such as ICF posed some challenges. In an effort to limit the number of items in the survey so as not to make it too onerous for participants, shorter measures were usually selected; a choice that may not assess as many aspects of a construct. In addition, the variables of the two ICF constructs, *activities* and *participation*, were not as clearly defined as other variables in the model, which presents some challenges in the lack of reliable measures from them. Therefore, the instruments chosen for this study might not adequately capture and measure all the aspects under different constructs.

There appears to be considerable overlap of predictor variables used in different studies to examine the determinants of employment outcome among people with epilepsy. However, the included predictors varied across studies regarding definition of terms and selection criteria of participants, making it sometimes quite difficult to draw conclusions about the effect of the variables in various studies. Unfortunately, no previous research study has been done by using a theory-driven model (e.g., ICF) to understand the factors that affect the employment outcome of people with epilepsy. It is important to continue efforts to clarify definitions of the different ICF variables. This will lessen confusion between similar ICF variables and enhance the ability to accurately measure the constructs.

Nonetheless, the current study provides some support for the structure of the ICF. The fact that the functioning/severity, personal, and environmental factors, which were derived from the four ICF domains, predict work participation, which was derived from the four stages in the Stages of Change theory (Prochaska et al., 1992), provides support for the combination of the two theories. Several variables in the ICF were not found to be significant contributors to prediction; the various reasons for this are discussed in the following sections.

Demographic characteristics. The first step of the regression model consisted of demographic covariates—specifically, gender, race/ethnicity, education level, and SSA beneficiary status (cash benefits or medical benefits)—that have shown associations with employment and epilepsy in the extant literature. The results indicated that demographic characteristics accounted for 26% of the variance in work participation scores for this sample of individuals with epilepsy. At the initial entry into the model, receipt of SSA benefits, both cash benefits (SSI/SSDI/TANF) and medical benefits (Medicaid/Medicare), independently accounted for the work participation variance over and above the other demographic characteristics, suggesting that receiving cash/medical benefits was related to lower levels of work participation. However, when the next set of predictors was entered into the equation, the cash/medical benefits contribution to the variance in work participation was reduced, although it remained significant. The receipt of medical benefits was found to be a significant contributor in the final regression model. These relationships have been consistently reported across studies.

The finding that work disincentives, such as receiving cash or medical benefits, could significantly impede employment outcomes is consistent with other vocational rehabilitation studies. In this study, work disincentives were found to affect work participation. One explanation could be that people who receive benefits might have more severe seizure conditions that negatively impact their work ability and participation. In addition, individuals with epilepsy are prone to relying on medical management including antiepileptic medications. Therefore, their concerns about losing medical benefits are reasonable and can be expected. The receipt of medical benefits did not only serve as a proxy of seizure severity but also created a disincentive for employment, because people who receive benefits might be less motivated to work. Legislative initiatives, such as the Ticket to Work and the Work Incentives Improvement Act of 1999, have attempted to minimize the disincentives of disability benefit programs. There is some evidence to suggest that knowledge of these work incentive initiatives does impact a recipient's employment decisions. Specifically, Hennessey (1997) found that if SSDI recipients had knowledge of the trial work period and the extended period of benefits eligibility under new laws, as well as assurance that they would continue receiving Medicare/Medicaid benefits, the effect of work disincentives dissipated. Rehabilitation counselors providing services to clients with epilepsy should become familiar with benefits counseling and financial planning/counseling services offered by the SSA and state vocational rehabilitation agencies.

Disabilities-related characteristics. In the second step of the analysis, functioning/severity variables—age at first seizure, type of seizure, frequency of seizure, number of AEDs, seizure severity, cognitive functioning, and mental health (depression and anxiety)—were entered into the regression equation. The results indicated that disability-related characteristics accounted for 9% of the variance in work participation beyond that accounted for by demographic characteristics. In the preliminary analyses, the correlation matrix (see Table 4.1) showed small-to-medium negative correlations between work participation and disability-related characteristics, including seizure severity, cognitive deficits, depression, and anxiety (*r* = –.270 to –.365). Only seizure severity and depression independently accounted for the work participation variance over and above the other disability-related characteristics, suggesting that increased severity of one's seizures (e.g., intrusiveness, disruptiveness, effects) and depressive symptoms were related to lower levels of work participation. However, when the next set of predictors was entered into the equation, the contribution of seizure severity and depression to the variance in work participation were no longer significant. Even though seizure severity and depression did not remain significant in the final regression model, the number of AEDs did become a significant contributor in the final model. The results, in fact, concurred with the study conducted by Bishop (2004) examining the determinants of employment status among a community-based sample of people with epilepsy. The predictors of employment in Bishop's (2004) study were the number of antiepileptic drugs, seizure frequency, and possession of a driver's license.

With respect to the impact of seizures on work participation and employment status, this study indicated that work participation was associated with the number of AEDs (an indicator of seizure severity), with a higher number of AEDs reflecting higher seizure severity. Seizures, depending on their severity, can negatively affect one's employment outcome. As a result, both medication and seizure control are crucial factors when it comes to not only finding and maintaining employment but also improving quality of life. Seizures can impair one's ability to obtain an education, to drive, and to develop and maintain employment (Fisher et al., 2000). Good employability is related to the perceptions that epilepsy has little or no effect on job prospects and that people with epilepsy have good experiences with colleagues and management, have low seizure severity, and have good seizure control. Across studies, seizure type, frequency, and severity were found to be predictors of employment in people with epilepsy. Seizure severity is also associated with an increased risk for any injury. Several cross-sectional studies indicate higher rates of unemployment among individuals with more severe seizures (Chaplin et al., 1998; Jacoby et al., 1996; Yagi, 1998).

Personal characteristics. In the third step of the analysis, personal characteristics—positive coping, self-efficacy, and self-esteem—were entered into the regression equation. This group of variables accounted for a significant amount of additional variance in work participation (4%) over and above that already explained by demographic and disability-related factors. With the addition of this predictor set, the independent contribution of cash/medical benefits was reduced; in addition, the contribution of seizure severity and depression to the variance in work participation was no longer significant. In the preliminary analyses, the correlation matrix (see Table 4.1) showed medium-to-large positive correlations between work participation and personal characteristics, i.e., positive coping, self-efficacy, and self-esteem (r = .198 to .413). However, only self-esteem independently accounted for a significant amount of the variance in work participation over and above all the other variables entered into the model, suggesting that increased self-esteem was related to higher levels of work participation. Positive coping and self-efficacy did not independently contribute to variance in work participation over and above other factors, which is surprising given their significant correlation with work participation. One possible explanation is that the selected instruments, the Brief COPE and the Epilepsy Self-Efficacy Scale (ESES), used for assessing positive coping and self-efficacy did not adequately capture and measure the construct in this study. It might be because only items of the Brief COPE that represented positive (adaptive) coping were included and computed as a positive coping index. According to Carver (1997), aggregation of subscales for generating "adaptive" and "maladaptive" composites were less well-defined under the construct of coping style. Future research should use each individual scale separately to examine its relationship to other variables. Another recommendation would be that researchers further explore and determine the composition of the higher-order factors among the scales so that those factors can be used as predictors independently. Furthermore, because the ESES was designed to assess self-efficacy regarding management of seizures, medication, and lifestyle instead of work-related factors, it might be less sensitive to measuring the target construct. It might be possible that work-related self-efficacy may directly or indirectly impact work participation. Future research should investigate this further and aim to distinguish between these constructs and their impact on work participation.

Overall, this study supported the finding that psychosocial factors play a significant role in the relationship between epilepsy and employment. Previous studies (e.g., Smeets et al, 2007) have shown that coping and self-esteem help people with epilepsy manage the psychosocial consequences or effects of having epilepsy. Literature has also shown that self-esteem, depression, and anxiety are highly correlated, suggesting that self-esteem belongs to a negative affect/physiological construct rather than being an individual characteristic. Nonetheless, the results revealed that there is unique variance for self-esteem in the final regression model after controlling for the negative affect (i.e., anxiety and depressive symptoms), indicating some unique contribution of self-esteem in work participation. As a result, improved self-esteem could be considered as a proxy of disability acceptance and successful psychosocial adaptation to the disorder. For example, the literature on coping with epilepsy strongly suggests that enhancement of self-esteem, engagement-type coping strategies of problem solving, and cognitive restructuring are associated with better psychosocial adaptation (e.g., high level of self-efficacy, self-directed activities, and social support resources), higher acceptance of disabilities, and more success in seeking, securing, and maintaining employment (Livneh et al., 2001; Smeets et al., 2007; Upton & Thompson, 1992).

Because psychosocial factors are highly diverse and often difficult to define, specifying the interactions between psychosocial variables and the employment factor of people with epilepsy is challenging. Furthermore, the complexity of behavioral factors, internal/personal factors, and environmental factors makes it even more difficult to determine the exact impact of psychosocial factors on work participation. This study is a novel study examining the precise interactions between psychosocial variables and work participation of people with epilepsy.

Environmental characteristics. In the fourth step of the analysis, environmental characteristics—perceived stigma and social support—were entered into the regression equation. This group of variables accounted for a significant amount of additional variance in work participation (6%) over and above that already explained by demographic, disability-related, and personal factors. With the addition of this predictor set, the independent contribution of cash/medical benefits and self-esteem were reduced. In the preliminary analyses, the correlation matrix (see Table 4.1) showed large negative correlations between work participation and perceived stigma ($r = -.504$), whereas the relationship between work participation and social support ($r = .415$) was positive. Both perceived stigma and social support independently accounted for a significant amount of the variance in work participation over and above all the other variables entered into the model, suggesting that decreased perceived stigma and increased social support were related to higher levels of work participation.

As expected, stigma was found to be a significant predictor of work participation. Stigma is so prevalent that people with epilepsy may experience “felt” stigma, being ashamed of their condition and afraid to be open about it because of the negative reactions they anticipate may ensue. Stigma adds to the burden of the condition, while the stigmatizing nature of epilepsy and its associated psychological distress can have a significant impact on employment and quality of life. However, these observations have not been consistently reported across studies, and perceived stigma has not consistently been found among people with epilepsy (Chaplin, 2005; DiIorio et al., 2003; Harden et al., 2004; Lee et al., 2005). Cross-sectional findings indicate that people with epilepsy often feel stigmatized by their disorder, although this perception does not always correlate with the presence of prejudice (Smeets et al., 2007). A study by Ryan et al. (1980) demonstrated that people with epilepsy do not universally feel stigmatized by their disorder. Of the 445 respondents, 81% felt that they had been treated fairly in society and 70% felt neither unreasonably limited nor treated differently because of their epilepsy. This may explain why environmental factors were not found to be significant contributors to work participation, especially when other socio-demographic and personal factors were taken into account.

In this study, the set of social support variables also accounted for unique variance in work participation after controlling for the variance explained by other ICF variables. The results of this study were consistent with other studies that have found that social support contributed unique variance in psychosocial adaptation to chronic illness and disability (e.g., Livneh & Wilson, 2003). When the sources of stress are all-encompassing in a person’s life, social support compared to other psychosocial factors (e.g., coping strategy) has a significant effect in motivating people with epilepsy to obtain or keep a job. Positive associations between social support and rehabilitation-related outcomes have been shown in previous studies, such as adjustment to disability and employment in people with disabilities and chronic illnesses

(Chronister et al., 2009). Studies have suggested that the negative effects of stigmatization were moderated when social support was stronger. Furthermore, a positive relationship has been reported between social support and self-management of the disease (Dilorio et al., 1992a, 1992b).

Work-related characteristics. In the final step, measures of work-related skills/abilities—general employability, work tolerance, work communication, self-care, and self-direction skills—were entered into the regression equation. These variables accounted for a significant amount of additional variance (10%) in work participation over and above that already explained by previous sets of variables. With the addition of this predictor set, the independent contributions of medical benefits, number of AEDs, perceived stigma, and social support were reduced, and the contributions of cash benefits, seizure severity, depression, and self-esteem were no longer significant in the overall regression model. All work-related skills/abilities (i.e., general employability, work tolerance, work communication skills) were found to contribute significantly to the variance in work participation, with work tolerance skills being the most significant predictor. The term "work tolerance skills" refers to the physical, cognitive, and psychological ability to effectively perform job requirements with or without accommodations and meet the demands of participating in work-related activities (e.g., how long and under what conditions can the individual work). Low work tolerance, which can be caused by many factors (e.g., side effects of medications, fatigue), may negatively impact the work capacity of people with epilepsy and prevent them from becoming involved in work activities (e.g., full-time job) as well as reduce their motivation to be engaged in work.

In contrast, work communication skills were found to be negatively correlated with work participation in the final regression model. This phenomenon can be explained by the suppressor effect, which was tested by the reduced model. In this study, items included in the work communication scale are more related to job application skills (e.g., “Read a want ad”; “Write a resume”; “Complete a job application blank”; “Read work diagrams”). In contrast, items included in the work tolerance scale are more related to on-the-job skills (e.g., “Perform major job tasks at an acceptable pace”; “Handle the physical demands of my job”; “Work an 8-hour day”; “Show up regularly for work”; “Perform my job well”). A suppressor relationship suggests that there might be at least two sources of variance that contribute to work communication skills. First, the work communication scale is correlated with the work tolerance scale, which implies that work communication skills carry some variance attributable to work tolerance/on-the-job skills (even though the focus of the work communication scale is on job application skills). Second, when work tolerance variance is controlled, the residual variance (work communication variance that cannot be predicted from work tolerance scores) might be attributable to some other stable characteristic (e.g., non–on-the-job skills) that is negatively associated with work participation.

The suppressor effect suggests that the residual variance is not just error variance but has some substantive meaning. For example, a lower work participation score usually indicates that a person is at the contemplation stage of being employed (i.e., looking for a job). Individuals at this stage are probably attending vocational training or interviewing for jobs. They are hopeful about finding a job and tend to perceive themselves as having a higher level of job application skills than would correspond to their level of actual job skills. In contrast, a higher work participation score usually indicates that a person is at the action stage of being employed (i.e., working in a job). Individuals at this stage have gone through the job searching process and are currently working in a position. They are hopeful about keeping the job and tend to perceive themselves as having a higher level of actual job skills than would correspond to their level of job application skills. As a result, if a person is claiming a higher level of job application skills than would correspond to his or her level of actual job skills, the positive residual score (i.e., work communication – work tolerance) might reflect less work participation.

Given the important role of work-related skills/abilities, secondary mediation analyses were conducted to look further at the possible mediating effect of each of the work-related skills on the relationship between self-esteem and work participation as well as the relationship between perceived stigma and work participation. The results indicated that each work-related skill was indeed a mediator between self-esteem and work participation as well as between perceived stigma and work participation.

Mediating Factors Between Contextual Factors and Work Participation

Findings from the primary HRA in this study suggested that work-related skills (i.e., general employability, work tolerance, and work communication skills) accounted for a significant portion of variance in work participation, while other variables were shown to have bivariate association with work participation and are hypothesized as predictors of employment. Self-esteem showed a positive contribution to variance in work participation scores, whereas perceived stigma showed a negative contribution in the final regression model. In an effort to explore these findings and to better understand their complex nature, the relationships among contextual factors (i.e., personal and environmental factors) and work participation were investigated. Mediator analyses were conducted to evaluate the hypotheses about the possible mediating effect of work-related skills (i.e., general employability skills, work tolerance skills, and work communication skills) between contextual factors (i.e., self-esteem and social support) and work participation. Rationale and findings for each analysis are discussed below.

In the first set of mediation analyses, each of the work-related skills was hypothesized to mediate the relationship between self-esteem and work participation. Taken together, the three mediation analyses provided support for the hypotheses. All work-related skills were found to be partial mediators between self-esteem and work participation, indicating that improvement in self-esteem did play a role in increasing work-related skills, which in turn improved work participation for people with epilepsy.

In the second set of mediation analyses**,** each of the work-related skills was hypothesized to mediate the relationship between perceived stigma and work participation. Taken together, the three mediation analyses provided support for the hypotheses. All work-related skills were found to be partial mediators between perceived stigma and work participation, indicating that a reduction in perceived stigma did play a role in increasing work-related skills, which in turn improved work participation for people with epilepsy.

Therefore, findings from this study reveal that the effect of personal and environmental factors on work participation can be partially mediated by work-related skills. This finding suggests that self-esteem was positively related to work participation whereas perceived stigma was negatively associated with work participation, while improvements in work-related skills increased the odds of work participation. In fact, the mediational effect of work-related skills on the relationship between each of the contextual factors and work participation was large in this study. Research indicates that self-esteem is associated with work-related competency, higher employment outcomes, and health-related quality of life. Conversely, an individual's perception of social stigma impacts work-related competency and employment outcome (Smeets et al., 2007). Therefore, when working with people with epilepsy, rehabilitation counselors must consider not only job readiness training but also other interventions that can improve work-related competency, self-esteem, and perceived stigma.

Limitations

Several limitations should be considered when interpreting the results of the present study. First, the generalizability of the findings was limited by the use of an online survey format and non-random convenience sample through support groups (via Epilepsy Foundation). This sample was composed predominantly of well-educated White persons with well-controlled seizure conditions and who were associated with Epilepsy Foundation networks, with majority of the participants recruited from Wisconsin States. It is possible to have sampling bias because people who have skills in using the Internet to access the survey are possibly a unique group of individuals with epilepsy. Also, individuals who know how to use community resources, such as the local chapter of the Epilepsy Foundation, may be different than people who are less aware of community resources. Consequently, individuals who are not seeking assistance for themselves will not be represented.

In addition, when compared to the demographic characteristic in the report published by the Institute of Medicine (2012), the seizure condition of the sample in this study is most likely better controlled; they also tend to be somewhat better educated, have a higher socioeconomic status, have a higher employment rate, and be less ethnically diverse than the true epilepsy population in the United States. Individuals associated with the Epilepsy Foundation may be at different stages of change for work participation and may not represent the larger population of individuals with epilepsy. Furthermore, because it is hard to know how many people were invited to participate and how many of them actually met eligibility criteria, it is difficult to discern the exact response rate. Nonetheless, it can be assumed that a large proportion of eligible individuals chose not to participate. While the exclusion criteria specified severe traumatic brain injury and intellectual disability, it is likely that individuals with more significant functional limitations, such as issues related to fatigue, memory, vision, or comprehension, had difficulty completing the long survey. Therefore, these findings may not generalize to other samples with epilepsy.

Second, the variables of the two ICF constructs, *activities* and *participation*, were somewhat similar and not as clearly defined as other variables in the model. The overlapping variables can be a major issue because they create ambiguity within the ICF constructs. The lack of reliable measures posed challenges in collecting information for the predictor variables that is different from the outcome variables. Hence, the inclusion of instruments in this study might not adequately capture and measure all the aspects under different constructs. Although the survey asked individuals to answer items about their work participation, it is possible that the items selected also covered some portion of work skills and competencies.

Third, these surveys relied on self-reported data, making the results vulnerable to error and bias (Kobau et al., 2008). For example, self-reported epilepsy may overestimate the presence of epilepsy within the sample, because individuals may report seizures that are not epilepsy seizures (Kelvin et al., 2007). Also, it is possible that the physical and cognitive limitations associated with epilepsy impacted an individual’s ability to respond to survey items. Gathering information directly from individuals who have experienced epilepsy offers opportunities to gain additional insights. On the other hand, because the questions are based on self-report, the results might not correspond to more objective indicators. For example, subjective work participation rather than objective conventional employment status or wage was selected to represent employment outcome for people with epilepsy. Potential biases might exist due to the subjectivity of the participants' perception on their work participation. It is challenging to know the extent to which study findings accurately reflect the true state of the construct being measured. Furthermore, when environmental factors (i.e., perceived stigma and social support) were measured, there are assumptions that self-perceived stigma and social support are a accurate estimates of actual stigma and social support in the environment.

Fourth, the reduction of some variables to broad dimensions (e.g., coping strategies) may obscure potential differential relationships among various subdimensions (e.g., problem-focused coping strategies and emotion-focused coping strategies) and work participation. In addition, the number of items for a variable was shortened to control the length of the survey and to not overwhelm the respondents. For example, the instrument that measured coping strategies included only 10 out of 16 selected items. The short forms may cause some measurement problems.

Fifth, although an a priori analysis deemed the sample size appropriate for the primary regression analyses, the study may have been underpowered and unable to detect specific independent contributions of variables. For instance, with a larger sample, environmental factors may have been found significant in the fourth step of the analysis. An inadequate sample size may have limited the power to detect a small effect size in the moderation analysis. In addition, the limited sample size prevented the use of more statistically advanced methodologies, such as hierarchical linear modeling, path analysis, or structural equation modeling.

Finally, the research design is a descriptive correlational study that uses cross-sectional data, and therefore, the directionality of the effects of causality among variables cannot be determined. Consequently, associations between independent and dependent variables cannot be deemed causal, because the study did not actively manipulate variables. For reasons based on the

ICF framework and on Stages of Change theories, assumptions were made about various aspects of directionality with regard to functioning/severity, skills/abilities, personal factors, environmental factors, and ultimately, work participation. However, it is possible that assumptions regarding directionality should be reversed.

Clinical Implications in Rehabilitation Counseling Practice

Epilepsy is a complex disorder that requires the active involvement of the person with epilepsy, family, friends, and other caregivers; the time and expertise of many health care providers; and the knowledge and skills of varied community services providers. The use of the ICF framework in understanding the work participation of people with epilepsy incorporates a biopsychosocial approach that acknowledges the multidimensional interactions of demographic factors (e.g., receipt of medical benefits), physiologic factors (e.g., seizure severity), psychosocial factors (e.g., positive coping strategies), and vocational factors (e.g., work skills/abilities) that can have an impact on an individual's symptoms, behaviors, and outcomes (e.g., work participation) (Borrell-Carrio et al., 2004; Engel, 1977). This study was the first to look at work participation for individuals with epilepsy. The findings extend the literature related to promoting successful employment outcomes for individuals with epilepsy, and contribute to the ongoing investigation of Stages of Change theory for work participation in the rehabilitation psychology field in several ways. The theoretical model emphasizes the dynamic and synergistic relationships that occur in a disorder such as epilepsy and can shed light on the clinical implications in rehabilitation counseling practice.

This study suggests the importance of considering work participation as a potentially viable employment-related outcome measure, alongside traditional measures that assess employment status (i.e., employed vs. unemployed). In this study, work participation levels ranged across individuals, indicating that some people with epilepsy feel a strong sense and strong need of looking for or keeping a job, whereas others only contemplate the prospect of obtaining a job. Whereas this study investigated specifically work participation, treatments for facilitating seizure control, reducing seizure severity, promoting self-managing, and encouraging self-advocacy might be helpful in order to improve employment as well as quality of life. Rehabilitation counselors in vocational rehabilitation programs frequently work to help individuals with epilepsy achieve personal, social, psychological, and vocational goals; or counselors may be employed in hospitals and schools to assist people with psychosocial adjustment and coping or benefits planning as well as educational and vocational planning and services. Following are discussions of several possible clinical practices for rehabilitation counselors to assist people with epilepsy in increasing work participation and enhancing employment outcome as well as quality of life.

Specialized vocational training. In this study, work-related skills/abilities were found to be the most significant predictor of work participation. The results shed light on the importance of job training and related vocational services. Research indicates that employment training programs designed specifically for people with epilepsy generally achieve better results than generalized disability programs. For example, the state-federal vocational rehabilitation (VR) program provides services to assist people with disabilities to seek, obtain, and retain employment. Although this general disability program can be a valuable resource for people with epilepsy (Goodall, Lawyer, & Wehman, 1994; Mount, Johnstone, White, & Sherman, 2005), the placement rates of state VR agencies for people with epilepsy consistently fall below those of specialized employment programs (Fraser, Trejo, & Blanchard, 1984). Bishop, Tschopp, and Mulvihill (2000) concluded that there is a need for specialized training, information, and resources for rehabilitation counselors who work with people with epilepsy. Vocational rehabilitation programs that focus on establishing workplace accommodations, providing work-related skills, increasing clients' self-confidence and self-efficacy in dealing with work-related problems, and providing training aimed at job retention have been found to be effective (Varekamp, Verbeek, & van Dijk, 2006). Rehabilitation counselors should develop specialized services and innovative techniques for effectively assisting people with epilepsy with the employment barriers they face in their areas. Components of these programs may include neuropsychological assessment, vocational training, interviewing preparation and disclosure counseling, specialized placement services, and follow-along services. Further, counselors should establish programs that bring employers and individuals with epilepsy into direct contact, such as through negotiated short-term work experience placements (Jacoby et al., 2005).

Seizure control. Given the impact of seizure severity and the importance of seizure control, rehabilitation counselors must have an understanding of the client's perspective toward taking medications before they can develop strategies to promote adherence and, ultimately, to improve seizure control and reduce seizure severity. Among the most commonly reported fears expressed by people with epilepsy are concern about having side effects from taking seizure medications (Fisher et al., 2000; Kucukarslan, Reeves, & McAuley, 2008) and forgetting to take the medication or not having it available (Hovinga et al., 2008). Rehabilitation counselors might work with clients on methods of managing medications that are critical self-management tools. Such methods may include tracking pill taking, using pill dispensing boxes, using reminders and alarms, modifying lifestyles to make medication taking easier, and participating in counseling to identify and overcome other barriers to medication side effects. Furthermore, research in sports and exercise suggests that regular physical activity—in addition to its well-known positive psychosocial and physiologic benefits—can reduce the frequency and severity of seizures as well as improve seizure control (Arida et al., 2009, 2010; Conant et al., 2008; Eriksen et al., 1994; Nakken et al., 1990, 1997). Physical activity also can improve attention, mood, and physical health and may have a role in minimizing depression in people with epilepsy (Arida et al., 2011). Rehabilitation counselors may assist clients with epilepsy to design appropriate physical activity programs that match with severity and related fears.

Self-management. Certain types of behavioral therapy can also be considered a form of self-management (the strategies people use to manage their epilepsy and its effects on their daily life). A behavioral therapy is usually intended to change an unhealthy behavior or promote a positive or healthy behavior. For example, trigger management involves teaching people how to recognize or identify possible seizure triggers by observing environmental, personal, or lifestyle factors (such as lack of sleep, flashing lights, fever, or excessive alcohol consumption) that appear to increase susceptibility to seizures. For many people, seizure control can improve if these triggers are avoided. Teaching about trigger management and lifestyle modifications is a frequent component of epilepsy care provided by rehabilitation professionals (Legion, 1991; Shafer, 1994). Other behavioral approaches include seizure control through the use of relaxation, yoga, biofeedback, and counseling; self-control approaches or acceptance and commitment therapy using individual and group sessions; and mind-body techniques (Andrews & Schonfeld, 1992; Lundgren et al., 2008a, 2008b; Wagner et al., 2010). Relaxation treatment studies, while limited in number, generally show positive results in reducing seizures and improving quality of life (Dahl et al., 1987; Puskarich et al., 1992; Rousseau et al., 1985). All such approaches need rigorous review. Other behavioral treatments frequently taught to people with epilepsy and their families focus on knowledge about safety and adapting behaviors to prevent injuries (Shafer, 1998).

Positive coping. An understanding of how clients manage their epilepsy and the impact it has on their lives is critical to the provision of effective support in vocational rehabilitation. The stages of change for work participation is particularly relevant for individuals who experience significant life changes, such as being diagnosed with epilepsy or developing an additional disability, in which motivation to work may be altered. A person who sustains a chronic illness or disability, or change in functional status, may experience physical and social barriers or negative beliefs regarding his or her ability to engage in gainful employment. Treatment for clients with epilepsy should focus on training that emphasizes the acquisition of active, problem solving–oriented, and goal-directed coping skills that can assist the client to pursue personal, social, and vocational goals. Positive coping strategy plays an important role in the acceptance and management of the psychosocial consequences or effects of having epilepsy. Rehabilitation counselors can assist individuals with epilepsy in coping with stress. This study found positive coping to be correlated with work participation, and as a result, improvements in positive coping may lead to improved employment outcome. Rehabilitation counselors must first understand how a client copes with stress and what type of support the client uses both inside and outside the workplace. It may prove helpful to include an individual’s social support network in stress-coping activities in order to provide additional reinforcement and accountability. Rehabilitation counselors can also facilitate a discussion of benefits of and barriers to stress coping as well as potential available social support.

Self-advocacy. Epilepsy education helps people with epilepsy become self-confident, competent in self-management, aware of their needs, and able to access resources to meet their needs—in other words, it helps them become better partners in client-centered care. Moreover, having accurate, in-depth information about epilepsy helps people better understand the disorder, prevents misconceptions, and reduces concerns about stigma. Rehabilitation counselors can assist individuals with epilepsy and their families to have access to relevant and usable knowledge to meet their individual needs; to request work accommodations; to participate effectively in client-centered care; to be competent in the management of their epilepsy; and to attain the highest possible physical and emotional well-being. Thus, rehabilitation counselors should become familiar with educational materials and programs, support groups, and counseling resources that can help individuals with epilepsy and their families successfully cope with stigma and related concerns, for example, the fear of having a seizure in public.

Implications for Future Research

The findings from this study provide support for the use of the ICF framework as an employment model for people with epilepsy. However, because this study is a descriptive correlational study, the causality of the relationships between predictor and outcome variables could not be verified. To test the actual causal relationships and to investigate the mediating relationships among variables of interest, further longitudinal research is necessary. In addition, this employment model can be evaluated as a predictor for other rehabilitation outcomes for people with epilepsy in future studies, such as health-related quality of life. It can also be evaluated as a predictor for employment outcome, as well as other work-related behaviors, for other neurological disability populations, such as people with traumatic brain injury or spinal cord injury.

Given the biopsychosocial nature of the ICF model, it is considered to be a comprehensive and holistic framework to guide empirical studies, especially disability-related research. However, more conceptual and theoretical studies than empirical studies have been conducted. Considerable overlaps and ambiguities exist in the variables used within the ICF components. Future research could more clearly distinguish the differences or similarities between constructs, which could be further validated and operationalized. Future research could also develop and validate effective and efficient ICF-based measures for several of the variables in the ICF model. Subjective measurement of work participation for people with disabilities remains a challenge in research. Movement toward a more uniform understanding of the constructs of work participation and the subsequent development of sound measurement instruments is warranted. Also, better definitions and measures of the variety of overlapping work-related activities and work participation would be beneficial for future studies.

The measures of social support could be expanded to better capture the effect of the work of rehabilitation professionals by including the higher recall of lifestyle and vocational advice from health professionals. Adding Stages of Change concepts may improve the predictability of the ICF model. Future research could extend the validation of the ICF model to a full range of employment, health, and quality-of-life factors for people with epilepsy. Importantly, the study of cultural factors, that is, the intersection between culture and disability related to stages of change for work participation, may shed light on person-environment interaction “P X E” issues for people with epilepsy from racial and ethnic and socioeconomic minority backgrounds. Given the unique incorporation of P X E factors in the ICF model, this study may be useful for validating the ICF model as a culturally sensitive health promotion model for people with epilepsy. Finally, this study can be used to design vocational training interventions for people with epilepsy, and the efficacy of an ICF-based vocational intervention can be evaluated through randomized controlled trials.

Conclusion

This study is novel in that it was the first to apply the ICF model to a sample of individuals with epilepsy in order to better understand their work participation in the community. Overall, the study provides good support for the usefulness of the ICF framework as an interactive and holistic employment model for people with epilepsy, suggesting that the concept of employment outcome needs to rely on multiple factors, including demographics, functioning/severity, activities, personal factors, and environmental factors. Individual characteristics, disability-related characteristics, psychosocial characteristics, and work-related characteristics accounted for 45% of the variance in work participation scores in this study. In particular, work tolerance skills were the strongest independent predictor of work participation in the final regression model. This finding supports the validation of the model as a predictor of work participation for people with epilepsy and supports the use of this model in the development of effective, efficacious, and efficient vocational interventions for people with epilepsy. Subsequent mediation analyses provide support for the possible indirect effect of work-related skills/abilities on work participation through positive coping and perceived stigma. Further research is needed to explain the complex relationships of factors impacting work participation for people with epilepsy.

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APPENDIX A

INSTITUTIONAL REVIEW BOARD NOTICE OF APPROVAL

Notice of Action

University of Wisconsin–Madison
Institutional Review Board (IRB)

Principal Investigator:	Fong Chan, Ph.D.
Department:	Rehabilitation Psychology and Special Education
Co-Investigator:	Ying Yuk Sung
Point of Contact:	Ying Yuk Sung
Protocol Title:	Evaluating the WHO ICF framework as an employment model for people with epilepsy
Protocol Number:	SE-2011-0614
IRB:	Social & Behavioral Sciences IRB (Contact: 263-2320)
Committee Action:	Approved on: **October 18, 2011** Expires: **September 22, 2012**

We have received the information you sent regarding the above named protocol. This information complies with the modifications required by the Institutional Review Board, and your protocol is now approved. You may begin collecting data at any time.

Thank you for your cooperation.

Special Notes or Instructions: Researcher has complied with the modifications set forth by the IRB. This protocol is now approved per the recommendation of the full IRB as a minimal risk study. Research seeks to collect baseline information about employment status and to identify factors affecting employment rates employment quality of people with epilepsy in Wisconsin. When research intervention and consent process is delivered in person, signed written consent will be obtained. If participants decide to do the research intervention online, requirement for signed, written consent waived per 45.CFR.46.117(c) as impracticable. Participants will indicate their willingness to participate by clicking "I have read the above information and agree to participate in this study". Protocol is minimal risk.

INVESTIGATOR RESPONSIBILITIES:

Unless this protocol is exempt, or the IRB specifically waived the use of written consent, an approved consent form that is stamped with approval and expiration dates can be found on IRB WebKit. To find the stamped consent form, go to IRB WebKit at https://rcr.gradsch.wisc.edu/irbwebkit/Login.asp. Login and open this protocol number. The link to the consent form can be found on the left side of the page. All copies of the form must be made from this original. Any changes to the consent form must be approved in advance by the IRB.

Any changes to the protocol must be approved by the IRB before they are implemented.

Any new information that would affect potential risks to subjects, any problems or adverse reactions must be reported immediately to the IRB contact listed above.

If the research will continue beyond the expiration date indicated above, a request for renewal/continuing review must be submitted to the IRB. You must obtain approval before the current expiration date. If you do not obtain approval by the expiration date noted above, you are not authorized to collect any data until the IRB re-approves your protocol.

Signed consent forms must be retained on campus for seven years following the end of the project.

If you are continuing to analyze data, even though you are no longer collecting data, you should keep this protocol active.

APPENDIX B
LETTER OF SUPPORT – FROM WISCONSIN AFFILIATE

EPILEPSY FOUNDATION®
SOUTHERN WISCONSIN
Not another moment lost to seizures™

1302 MENDOTA STREET #100
MADISON, WI 53714

August 16, 2011

Ms Connie Sung
Department of Rehabilitation Psychology and Special Education
University of Wisconsin-Madison
461 Education Building
1000 Bascom Mall
Madison, WI 53706

Dear Ms Sung:

Congratulations on your successful application to the Epilepsy Foundation Research Initiative. The Epilepsy Foundation affiliates in Wisconsin, including the Southern Wisconsin affiliate and the Central & Northeast Wisconsin affiliate, are very excited to collaborate with you and support this important study. Under-employment and unemployment continue to be among the most critical issues that we address every day with our consumers.

We have participated in statewide research projects in the past. One way we will be able to assist you is to use our substantial mailing lists, email list-serves and websites to help recruit our members as respondents in your study. Because employment problems are so important to our consumers, I know there will be a great deal of enthusiasm about participating in your project.

Between the four Epilepsy Foundation affiliates in Wisconsin we have mailing lists totaling nearly 10,000 people with epilepsy or family members. We can promote the project through links on our website, www.epilepsywisconsin.org, and by utilizing a list-serve of over 1,200 email addresses we have collected in Southern Wisconsin.

I look forward to working with you on this important research. I'm delighted that you will be able to join us at the end of August at our annual adult retreat. We will begin by introducing you and your project to the 50 adults with epilepsy in attendance, from all parts of Wisconsin.

Sincerely,

Arthur J Taggart
Executive Director

608.442.5555 • 800.693.2287 • FAX 608.442.7474 • ataggart@wisc.edu
www.epilepsywisconsin.org

LETTER OF SUPPORT – FROM KENTUCKIANA AFFILIATE

October 5, 2011

Connie Sung
PhD Candidate
Department of Rehabilitation Psychology and Special Education
University of Wisconsin-Madison
415 Education Building
1000 Bascom Mall
Madison, WI 53706

Dear Ms. Sung:

The Epilepsy Foundation of Kentuckiana (EFKY) is honored to be involved with your epilepsy/employment-related research project, entitled "Evaluating the WHO ICF framework as an employment model for people with epilepsy". The EFKY applauds you for your work in this area, as we fully understand the significant challenges many adults with epilepsy face regarding employment.

To support this very important project, the EFKY will work to recruit participants involved with our organization throughout our service area of Kentucky and southern Indiana that meet the necessary requirements. While more than 5,000 people are included on our mailing list, we estimate about a quarter of these individuals to be impacted by epilepsy.

Again, thank you for inviting the Epilepsy Foundation of Kentuckiana to take part in your epilepsy employment study. We are hopeful our involvement will be beneficial in the recruitment process, which is essential to successfully completing your project.

I look forward to hearing back from you to proceed with the recruitment process. In the meantime, feel free to call me at 502- 637-4440 ext. 13, if I can offer any other support.

Sincerely,

Debbie McGrath

Deb McGrath
Executive Director/Co-Founder

APPENDIX C
PROMOTIONAL FLYER

What is the purpose of the study?

The purpose of this study is to collect baseline information about employment status and to identify factors affecting employment rates and employment quality of people with epilepsy. Results of this study can help rehabilitation and health professionals develop effective vocational rehabilitation services to help people with epilepsy find jobs and to promote career opportunities for those who are underemployed. This study is sponsored by the Epilepsy Foundation of America. This study will be conducted from now through **[exact date]**.

Who are we?

We are a group of researchers in the Department of Rehabilitation Psychology and Special Education at the University of Wisconsin-Madison and working on research projects related to employment directed by Fong Chan, PhD and Connie Sung, MPhil.

Am I eligible to participate in the study?

You are eligible to participate in this study if you are:

(1) diagnosed with **epilepsy**;
(2) between **ages of 18 and 65**; and
(3) **can read/write at a 6th grade level or above**.

How can I participate in the study?

You can participate in this study by completing a survey comprising several psychosocial and vocational questionnaires which will **take about 30-45 minutes**. The survey can be accessed by clicking the link: https://www.surveymonkey.com/s/Epilepsy-Employment; or requesting the hardcopy of survey packet from a local affiliate office of the Epilepsy Foundation.

What will I get after participating in this study?

You will receive a **$20 Target Gift Card** upon completion of the survey. The gift card will be sent to you via mail at the end of **[exact date]**.

If I have questions, whom should I contact?

If you have questions about this study, please contact Connie Sung (Phone: 608-320-5163; E-mail: ysung4@wisc.edu). Thank you very much for your participation!

APPENDIX D
EMAIL INVITE TO PARTICIPATE IN WEB-BASED SURVEY

Employment Study in Epilepsy – Research Participants Wanted!

Dear Epilepsy Foundation Member:

High rates of unemployment and underemployment have been a major challenge facing individuals with epilepsy. We are conducting a research study about employment in epilepsy from now on until **[exact date]**. As a member of the Epilepsy Foundation Wisconsin Affiliates, you have been selected to participate in this study to help us collect baseline information about employment status and identify factors affecting employment rates and employment quality of people with epilepsy in Wisconsin.

You are eligible to participate in this study if you are an individual with epilepsy between the ages of 18 and 65 who can read/write at a 6th grade level or above. You can participate by completing a survey comprising several psychosocial and vocational questionnaires which will **take about 30-45 minutes**.

Please complete the online survey by clicking on the following link:

https://www.surveymonkey.com/s/Epilepsy-Employment

We would like to thank you in advance for your participation in this important study. In addition, findings from this study will also help rehabilitation and health professionals develop effective vocational rehabilitation services to help people with epilepsy find jobs and to promote career opportunities for those who are underemployed.

In recognition of your contributions and participation in this study, you will receive a **$20 Target Gift Card** upon completion of the survey. The gift card will be sent to you via email at the end of **[exact date]**.

For more information, please refer to the attached flyer. If you prefer to fill in the survey in hardcopy, you may also request a survey packet from us and we are happy to mail it to you. This study is sponsored and fully supported by the Epilepsy Foundation of America.

Thank you very much for your participation!

Sincerely,
Connie Sung, M.Phil.
Doctoral Candidate
Department of Rehabilitation Psychology and Special Education
University of Wisconsin-Madison
Tel: 608-320-5163
Email: ysung4@wisc.edu

APPENDIX E
EMAIL REMINDER

Just A Reminder – 2 Weeks Left!

Employment Study in Epilepsy – Research Participants Wanted!

Dear Epilepsy Foundation Member:

We are following up on our request to ask you to participate in an important research project about employment in epilepsy. If you have already completed the survey we made available to you two weeks ago, we want to sincerely thank you for your highly valued contribution to this critical study.

If you have not yet participated, we would strongly urge you to complete the survey (see link below) within the next two week. **The study will be open through [exact date]**. Your input is absolutely critical to this study and your responses will help rehabilitation and health professionals develop effective vocational rehabilitation services to help people with epilepsy find jobs and to promote career opportunities for those who are underemployed. As you know, we are also awarding **a $20 Target Gift Card** for your valued participation. Please help us on this important research initiative.

Please complete the online survey by clicking on the following link:

http://www.surveymonkey.com/epilepsy-employment

For more information, please refer to the attached flyer. If you prefer to fill in the survey in hardcopy, you may also request a survey packet from us and we are happy to mail it to you. This study is sponsored and fully supported by the Epilepsy Foundation of America.

Thank you very much for your participation!

Sincerely,
Connie Sung, M.Phil.
Doctoral Candidate
Department of Rehabilitation Psychology and Special Education
University of Wisconsin-Madison
Tel: 608-320-5163
Email: ysung4@wisc.edu

APPENDIX F
STUDY INFORMATION AND CONSENT FORM

University of Wisconsin-Madison

Research Participant Information and Consent

Title of the Study: Evaluating the WHO ICF Framework as an Employment Model for People with Epilepsy

Principal Investigator: Professor Fong Chan (608-262-2137; chan@education.wisc.edu)

Student Researcher: Connie Sung (608-320-5163; ysung4@wisc.edu)

DESCRIPTION OF THE RESEARCH

You are cordially invited to participate in a research study about the employment situations of individuals with epilepsy. The research is being conducted by Ms Connie Sung as a part of her doctoral study in rehabilitation psychology at the University of Wisconsin-Madison, under the supervision of Professor Fong Chan. It is being sponsored by the Epilepsy Foundation and endorsed by the Epilepsy Foundation Wisconsin Affiliates. You have been asked to participate because you are a member of Epilepsy Foundation (EF).

The purpose of this study is to collect baseline information about employment status and to identify factors affecting employment rates and employment quality of people with epilepsy in Wisconsin. We are very interested in your experiences and perspectives related to employment, as indicated by your responses on the questionnaires. **You are eligible to participate in the study if you are an individual with epilepsy between the ages of 18 and 65 who live in the community and can read or write at a 6th grade level or above.**

WHAT WILL MY PARTICIPATION INVOLVE?

We very much hope that you will participate in the study, however, participation is completely voluntary. Also, your responses will be completely confidential as no identifying information is requested on any of the questionnaires. Thus, no one will know how you have answered any of the items or even whether you have chosen to participate by completing the questionnaires.

If you decide to participate, you will be asked to complete a series of 13 self-report questionnaires. We hope that you will respond to all items, which will take approximately 30-45 minutes in total. However, if you find any items to be too personal or objectionable in any way, you are certainly free to skip them. As long as you do not lose your internet browser connection, you should be able to take breaks as you are completing the survey and go backward to change your answers if needed.

ARE THERE ANY RISKS TO ME?

We do not anticipate any risks to you through your participation in this study.

ARE THERE ANY BENEFITS TO ME?

We anticipate no direct benefits to you through participating in this study. However, the results of this study can help rehabilitation and health professionals develop effective vocational rehabilitation services to help people with epilepsy find jobs and to promote career opportunities for those who are underemployed. Thus, your participation will contribute to helping people with epilepsy enhance their employment and improve their quality of life. We plan to provide a summary of the results of the study to people associated with EF through articles included in EF newsletters and/or posted on the EF website.

WILL I BE COMPENSATED FOR MY PARTICIPATION?

Upon completion of all the questionnaires, you will receive a $20 Target Gift Card for participating in this study. You will have an option to sign up for the gift card. **If you choose to, your mailing address will be required for us to send you the gift card. Please note that your names and mailing addresses will be obtained separately from your responses to the questionnaire.**

HOW WILL MY CONFIDENTIALITY BE PROTECTED?

If you choose to participate, your responses will be completely confidential. Neither your name nor any other identifiable information will be recorded. When the survey is successfully completed, you will have the option to click on a link and sign up for a $20 Target Gift Card. In order to receive the gift card, you will be asked to provide a name and mailing address, but this information is separate from the responses you will provide in the survey, so your answers will still remain confidential. In addition, your contact information will be kept in secure login and password protected web account until all gift cards are sent out. The dataset will be managed and used only by the investigator and co-investigator of this study. Only group information and aggregated results will be included in any reports from the study.

WHOM SHOULD I CONTACT IF I HAVE QUESTIONS?

You may ask any questions about the research at any time. If you have questions about the research, you should contact either the principal investigator (Professor Fong Chan) or student researcher (Ms Connie Sung) at the phone numbers or email addresses above. If you are not satisfied with any responses from the research team, have more questions, or want to talk with someone about your rights as a research participant you should contact the Education Research and Social & Behavioral Science Institutional Review Board (IRB) Office at the University of Wisconsin-Madison (608-263-2320; ormangelli@LS.Admin.wisc.edu). If it is inconvenient to make these phone or email contacts, please contact the EF office, and they will get word to us to contact you. **If you have any question about your health problems or mental health concerns, please contact your health professional consultants or others as suggested in the resource list.**

Again, your participation is completely voluntary and confidential. If you decide not to participate or to withdraw from the study, it will have no effect on any services or treatment you are currently receiving or are entitled to. If you choose to participate, please proceed to the survey. Your completed online survey will indicate that you have read and understand the description of what you are being asked to do. And, you voluntarily consent to participate in this research study.

Thank you very much for your time and participation in this study!

Sincerely,
Connie Sung, M.Phil.
Doctoral Candidate
Department of Rehabilitation Psychology and Special Education
University of Wisconsin-Madison

***__Please check the box for starting the survey.__**

☐ I have read the above information and I agree to participate the study.

APPENDIX G

INCENTIVE FORM

Thank you for completing our survey!

If you are interested in receiving a **$20 Target Gift Card**, please copy and paste the website address below in your web browser address line above and provide your contact information.

http://www.surveymonkey.com/survey-giftcard

The purpose for using a separate link is to assure that your personal information will not be linked in any way to your survey responses to protect confidentiality.

If you have any difficulty entering the information for receiving a gift card, you can email me at ysung4@wisc.edu and put "Survey Gift Card" in the title line and provide your name and address.

Thank you again for your time and effort in completing the survey!

Please fill in the following information in order for us to send you a $20 Target gift card:

First Name: ____

Last Name: ____

Mailing Address: ____

Email Address or Phone Number: ____

APPENDIX H
STUDY QUESTIONNAIRE

Employment Study in Epilepsy – Survey

Over the course of this survey you will be asked to complete the questionnaire which consists of 13 sections, in which we are interested in understanding your experiences and expectations regarding your employment. We are interested only in ***what you*** do or think, not what and how ***other people*** do and think. There is ***no right or wrong*** answer to any of these items.

Please read each question carefully and circle or fill in the blanks as appropriate. Please also note that the rating scales sometimes change from one section to another. Try to rate each item separately from the others. It is very important that ***all questions be completed to the best of your ability***. Please read each question carefully and circle or fill in the blanks as appropriate. Please also note that the rating scales sometimes change from one section to another. Try to rate each item separately from the others. It is very important that all questions be completed to the best of your ability.

We encourage you to complete the questionnaire in one session. However, if necessary, you can complete your survey in several sessions as long as you are using the same computer.

Finally at the end of the survey, after you have completed all of the items, you will be able to sign up for a ***$20 Target Gift Card*** you have earned as one of our participants.

Thank you very much for your time!

Are you a person with epilepsy between the ages of 18 and 65 who live in the community?
☐ **Yes** *[If yes, the participant will be asked to continue with the survey.]*
☐ **No** *[If no, the participant will be asked to discontinue.]*

Section 1: Demographic Information

Instructions: Please check or fill in the blanks as best descriptions as your situations.

		Personal Information
1.	Age:	
2.	Gender:	☐ Male ☐ Female
3.	Race/Ethnicity:	☐ Caucasian (White) ☐ African American ☐ Hispanic/Latino ☐ Asian American & Pacific Islanders ☐ Native/Indian American ☐ Others (specify): _______________________________________
4.	Marital status:	☐ Single ☐ Married ☐ Divorced ☐ Widowed ☐ Separated ☐ Cohabitating
5.	Education level:	☐ No formal education ☐ Elementary education (grades 1-8) ☐ Secondary education, no high school diploma (grades 9-12) ☐ Special education certificate of completion/diploma or in attendance ☐ High school graduate or equivalency certificate ☐ Post-secondary education, no degree ☐ Associate degree or vocational/technical certificate ☐ Bachelor's degree ☐ Master's degree or higher
6.	Size of city/town:	☐ Urban ☐ Suburban ☐ Rural ☐ Others (specify): _______________________________________
7.	**State** of Residency:	
	County of Residency:	
8.	SSA beneficiary (mark all that apply):	☐ Supplemental Security Income (SSI) ☐ Social Security Disability Insurance (SSDI) ☐ None ☐ Others (specify): _______________________________________

		Employment-related
9.	Employment status:	☐ Full-time employed ☐ Part-time employed ☐ Retired ☐ Student ☐ Volunteer ☐ Unemployed but actively looking for job ☐ Unemployed and not looking for job
10.	Current position:	☐ Laborer ☐ Student ☐ Service worker ☐ Operator ☐ Craftsman ☐ Clerical sale ☐ Manager ☐ Professional ☐ Others (specify):______________
11.	Job title:	*(If you are only a student, enter "STUDENT" as your answer) (If you DO NOT currently have a job, enter "N/A" as your answer)*
12.	How long have you been working at your CURRENT job?	*(If you DO NOT currently have a job, how long has it been since your LAST job?)* Year(s):______________ Month(s):_____________
13.	Average earnings per WEEK:	*(If you DO NOT currently have a job, answer based on your LAST job)* Amount($):_____________
14.	Average number of hour(s) worked per WEEK:	*(If you DO NOT currently have a job, answer based on your LAST job)* Hour(s):_____________
15.	Health insurance (mark all that apply):	☐ No insurance at all ☐ Medicare ☐ Medicaid ☐ Public insurance from other source ☐ Insurance through your own employer ☐ Insurance through your spouse's or another family member's employer ☐ Private insurance purchased by you or other family members ☐ Others (specify):____________________________________

		Epilepsy-related
16.	Age at first seizure:	
17.	Type of seizure (mark all that apply):	☐ Simple partial ☐ Complex partial ☐ Absence (petit mal) ☐ Tonic-clonic (grand mal) ☐ Myoclonic/Atonic/Tonic ☐ Secondarily generalized ☐ Others ☐ Unknown ☐ Not sure *If you choose "Others", "Unknown" or "Not sure", briefly describe your seizure:*
18.	Frequency of seizure:	☐ None ☐ Daily ☐ Weekly ☐ Monthly ☐ Yearly ☐ No seizure in >2 years ☐ No seizure in >5 years ☐ No seizure in >10 years
19.	When was your last seizure?	*(How many years/months/days ago? If your last seizure was TODAY, enter "1" in the day box)* Year(s):______________ Month(s):_____________ Day(s):_____________
20.	Number of antiepileptic drugs (AEDs):	☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 or more *List the type of AEDs (please specify)*

21.	Do you have any other conditions or health issues? (mark all that apply)	☐ Do not have any ☐ Physical disability (e.g., require assistance [cane, wheelchair, walker] to walk) ☐ Cognitive disability (e.g., memory problem, attention problem) ☐ Mental illness (e.g., depression, anxiety) ☐ Alcohol and other drug abuse ☐ Others (specify):____
22.	Your epilepsy may **interfere** your daily activities (e.g., confusion, forgetfulness, fatigue), whether you have had a seizure on that day or not. Using the following **interference** rating scale to describe in general the level of **interference**. No **interference** … Interference as much as you can **imagine** 0 1 2 3 4 5 6 7 8 9 10	
23.	You may experience some **stress** in daily life. Using the following **stress** rating scale to describe in general the level of **stress**. No **stress** … Stress as much as you can **imagine** 0 1 2 3 4 5 6 7 8 9 10	

Section 2: SSS-9

Instructions: Please rate the following 9 clinical features or symptoms of seizures over the **previous FOUR WEEKS** on 4-point Likert scales.

		Never	**Sometimes**	**Usually**	**Always**
1.	Loss of consciousness	0	1	2	3
2.	Movements (Bizarre movements)	0	1	2	3
3.	Confusion	0	1	2	3
4.	Sleepiness	0	1	2	3
5.	Loss of bladder/bowel control	0	1	2	3
6.	Injure self (Injury)	0	1	2	3
7.	Undressing self	0	1	2	3
8.	Time of seizures (Seizure length)	< 1 min	1-2 mins	2-5 mins	> 5 mins
9.	Recovery time	< 1 min	2-5 mins	5 mins-1 hr	> 1 hr

Section 3: CFQ

Instructions: The following questions are about minor mistakes, which everyone makes from time to time, but some of which happen more often than others. We want to know how often these things have happened to you in the **past SIX MONTHS**. Please select the appropriate answer.

		Never	**Very rarely**	**Occasi -onally**	**Quite often**	**Very often**
1.	Do you read something and find you haven't been thinking about it and must read it again?	0	1	2	3	4
2.	Do you find you forget why you went from one part of the house to the other?	0	1	2	3	4
3.	Do you find you forget whether you've turned off a light or a fire or locked the door?	0	1	2	3	4
4.	Do you fail to hear people speaking to you when you are doing something else?	0	1	2	3	4
5.	Do you lose your temper and regret it?	0	1	2	3	4
6.	Do you leave important letters unanswered for days?	0	1	2	3	4
7.	Do you find you forget which way to turn on a road you know well but rarely use?	0	1	2	3	4
8.	Do you find yourself suddenly wondering whether you've used a word correctly?	0	1	2	3	4
9.	Do you have trouble making up your mind?	0	1	2	3	4
10.	Do you find you forget appointments?	0	1	2	3	4
11.	Do you daydream when you ought to be listening to something?	0	1	2	3	4
12.	Do you find you forget people's names?	0	1	2	3	4
13.	Do you start doing one thing at home and get distracted into doing something else (unintentionally)?	0	1	2	3	4
14.	Do you find you forget what you came to the shops to buy?	0	1	2	3	4

Section 4: NDDI-E

Instructions: Please select the answer that best describes you within the **past TWO WEEKS**.

		Never	**Rarely**	**Sometimes**	**Always or often**
1.	Everything is a struggle	1	2	3	4
2.	Nothing I do is right	1	2	3	4
3.	Feel guilty	1	2	3	4
4.	I’d be better off dead	1	2	3	4
5.	Frustrated	1	2	3	4
6.	Difficulty finding pleasure	1	2	3	4

Section 5: GAD-7

Instructions: How often have you been bothered by any of the following problems over the last **TWO WEEKS**? Please select the answer that best describes you.

	How often have you been bothered by any of the following problems?	**Not at all**	**Several days**	**More than half the days**	**Nearly every day**
1.	Feeling nervous, anxious or on edge	1	2	3	4
2.	Not being able to stop or control worrying	1	2	3	4
3.	Worrying too much about different things	1	2	3	4
4.	Trouble relaxing	1	2	3	4
5.	Being so restless that it is hard to sit still	1	2	3	4
6.	Becoming easily annoyed or irritable	1	2	3	4
7.	Feeling afraid as if something awful might happen	1	2	3	4

Section 6: LSI-30

Instructions: The 30 life skills items below cover five life skill domains: 1) General employability skills, 2) Work-related communication skills, 3) Self-direction skills, 4) Self-care skills, and 5) Work tolerance skills. Please use the 5-point ability rating scale to rate your ability to perform these life skills.

		Very low ability	Low ability	Moderate ability	High ability	Very high ability
1.	Perform major job tasks at an acceptable pace. (WT)	1	2	3	4	5
2.	Read a want ad. (WC)	1	2	3	4	5
3.	Plan recreational activities. (SD)	1	2	3	4	5
4.	Handle the physical demands of my job. (WT)	1	2	3	4	5
5.	Express dissatisfaction effectively when mistreated. (SD)	1	2	3	4	5
6.	Work an 8-hour day. (WT)	1	2	3	4	5
7.	Perform my job well. (WT)	1	2	3	4	5
8.	Understand oral instructions. (WC)	1	2	3	4	5
9.	Understand consequences of my workplace behavior. (GE)	1	2	3	4	5
10.	Get along with co-workers and supervisors. (GE)	1	2	3	4	5
11.	Read work diagrams. (WC)	1	2	3	4	5
12.	Adjust to unexpected changes in the routine of a job. (GE)	1	2	3	4	5
13.	Handle stress associated with my job. (GE)	1	2	3	4	5
14.	Write a resume. (WC)	1	2	3	4	5
15.	Recognize when people are unhappy with you. (GE)	1	2	3	4	5
16.	Practice good grooming and hygiene. (SC)	1	2	3	4	5
17.	Eat right and exercise. (SC)	1	2	3	4	5
18.	Take prescribed medications as directed. (SC)	1	2	3	4	5
19.	Deal with physical pain associated with disability. (WT)	1	2	3	4	5
20.	Seek emotional support from family and friends. (SD)	1	2	3	4	5
21.	Show up regularly for work. (WT)	1	2	3	4	5
22.	Shop for necessities. (SC)	1	2	3	4	5
23.	Get around at home and in the community. (SC)	1	2	3	4	5
24.	Follow safety rules in the workplace. (GE)	1	2	3	4	5
25.	Complete a job application blank. (WC)	1	2	3	4	5
26.	Obtain medical care when needed. (SD)	1	2	3	4	5
27.	Communicate your accommodation needs to others. (SD)	1	2	3	4	5
28.	Obtain psychological services when needed. (SD)	1	2	3	4	5
29.	Understand written instructions. (WC)	1	2	3	4	5
30.	Keep home clean. (SC)	1	2	3	4	5

Note: GE = General Employability, WT = Work Tolerance, WC = Work Communication, SC = Self-care, SD = Self-direction.

Section 7: Brief COPE-10

Instructions: These items deal with ways how you cope with stressful situation in your life. There are many ways to try to deal with problems. Please circle the point on the 4-point rating scale to indicate what you generally do and feel in a stressful event.

		I haven't been doing this at all	**I've been doing this a little bit**	**I've been doing this a medium amount**	**I've been doing this a lot**
1.	I've been concentrating my efforts on doing something about the situation I'm in.	1	2	3	4
2.	I've been taking action to try to make the situation better.	1	2	3	4
3.	I've been getting help and advice from other people.	1	2	3	4
4.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4
5.	I've been trying to come up with a strategy about what to do.	1	2	3	4
6.	I've been looking for something good in what is happening.	1	2	3	4
7.	I've been accepting the reality of the fact that it has happened.	1	2	3	4
8.	I've been trying to get advice or help from other people about what to do.	1	2	3	4
9.	I've been learning to live with it.	1	2	3	4
10.	I've been thinking hard about what steps to take.	1	2	3	4

Section 8: ESES-2000

Instructions: Please select the answer for each of the 18 statements that is most appropriate for you.
(0=I cannot do at all, 10=Sure I can do)

		I cannot do at all				**Moderately sure I can do**					**Sure I can do**	
1.	I can stay on my seizure medication most of the time.	0	1	2	3	4	5	6	7	8	9	10
2.	I can always plan ahead so that I do not run out of my seizure medication.	0	1	2	3	4	5	6	7	8	9	10
3.	I can always get enough exercise.	0	1	2	3	4	5	6	7	8	9	10
4.	I can always manage my epilepsy in new situations.	0	1	2	3	4	5	6	7	8	9	10
5.	I can always tell when I am having side effects from my seizure medication.	0	1	2	3	4	5	6	7	8	9	10
6.	I can always eat healthy meals.	0	1	2	3	4	5	6	7	8	9	10
7.	I can always deal with any side effects from my seizure medication.	0	1	2	3	4	5	6	7	8	9	10
8.	I can always find ways to get enough sleep.	0	1	2	3	4	5	6	7	8	9	10
9.	I can always handle situations that upset me.	0	1	2	3	4	5	6	7	8	9	10
10.	I can always do what needs to be done if I miss a dose of my seizure medication.	0	1	2	3	4	5	6	7	8	9	10
11.	I can always find ways to do things that I enjoy to help me manage stress.	0	1	2	3	4	5	6	7	8	9	10
12.	I can always follow my seizure medication schedule.	0	1	2	3	4	5	6	7	8	9	10
13.	I can always keep my epilepsy under control.	0	1	2	3	4	5	6	7	8	9	10
14.	I can always avoid situations or activities that make my seizures worse.	0	1	2	3	4	5	6	7	8	9	10
15.	I can always drive or get a ride to the doctor's office when I need to see him or her.	0	1	2	3	4	5	6	7	8	9	10
16.	I can always get medical help when needed for my seizures.	0	1	2	3	4	5	6	7	8	9	10
17.	I can always carry personal identification in case I have a seizure.	0	1	2	3	4	5	6	7	8	9	10
18.	I can always get my seizure medication refilled when I need to.	0	1	2	3	4	5	6	7	8	9	10

Section 9: RSES

Instructions: Below are 10 statements dealing with your general feelings about yourself. Please select the answer that is most appropriate for you.

		Strongly disagree	**Disagree**	**Agree**	**Strongly agree**
1.	On the whole, I am satisfied with myself.	0	1	2	3
2.	At times, I think I am no good at all.	0	1	2	3
3.	I feel that I have a number of good qualities.	0	1	2	3
4.	I am able to do things as well as most other people.	0	1	2	3
5.	I feel I do not have much to be proud of.	0	1	2	3
6.	I certainly feel useless at times.	0	1	2	3
7.	I feel that I am a person of worth, at least on an equal plane (surface) with others.	0	1	2	3
8.	I wish I could have more respect for myself.	0	1	2	3
9.	All in all, I am inclined to feel that I am a failure.	0	1	2	3
10.	I take a positive attitude toward myself.	0	1	2	3

Section 10: ESS

Instructions: Please tell me how much you agree or disagree with each of the following 10 statements.

		Strongly disagree	Disagree	Neither	Agree	Strongly agree
1.	If coworkers know that I have a seizure condition, they would treat me differently.	1	2	3	4	5
2.	It really doesn't matter what I say to coworkers about my seizure condition, they usually have their minds made up.	1	2	3	4	5
3.	I always have to prove myself because of the seizure condition.	1	2	3	4	5
4.	Because of the seizure condition, I will have problems finding a job.	1	2	3	4	5
5.	In many coworkers' minds, a seizure condition attaches a stigma or label to me.	1	2	3	4	5
6.	I feel different from other coworkers because of my seizure condition.	1	2	3	4	5
7.	I feel embarrassed about my seizure condition.	1	2	3	4	5
8.	I feel ashamed to tell other coworkers about my seizure.	1	2	3	4	5
9.	If coworkers know that I have a seizure condition, they would be uncomfortable with me.	1	2	3	4	5
10.	If coworkers know that I have a seizure condition, they would prefer not to be with me.	1	2	3	4	5

Section 10: PRQ-2000

Instructions: Below are 15 statements with which some people agree and others disagree. Please read each statement and choose the response most appropriate for you. There is no right or wrong answer.

		Strongly disagree	**Disagree**	**Some what disagree**	**Neutral**	**Some what agree**	**Agree**	**Strongly agree**
1.	There is someone I feel close to who makes me feel secure	1	2	3	4	5	6	7
2.	I belong to a group in which I feel important	1	2	3	4	5	6	7
3.	People let me know that I do well at my work (job, homemaking)	1	2	3	4	5	6	7
4.	I have enough contact with the person who makes me feel special	1	2	3	4	5	6	7
5.	I spend time with others who have the same interests that I do	1	2	3	4	5	6	7
6.	Others let me know that they enjoy working with me (job, committees, projects)	1	2	3	4	5	6	7
7.	There are people who are available if I need help over an extended period of time	1	2	3	4	5	6	7
8.	Among my group of friends we do favors for each other	1	2	3	4	5	6	7
9.	I have opportunity to encourage others develop their interests and skills	1	2	3	4	5	6	7
10.	I have relatives or friends who will help me out even if I can't pay them back	1	2	3	4	5	6	7
11.	When I am upset, there is someone I can be with who lets me be myself	1	2	3	4	5	6	7

12.	I know that others appreciate me as a person	1	2	3	4	5	6	7
13.	There is someone who loves and cares about me	1	2	3	4	5	6	7
14.	I have people to share social events and fun activities with	1	2	3	4	5	6	7
15.	I have a sense of being needed by another person	1	2	3	4	5	6	7

Section 12: SOC-WP

Instructions: Each item below describes how a person might feel about going to work. Please indicate the extent to which you agree or disagree with each statement in describing your current situation. Base your response on how you are feeling or acting now. Please rate the following statements using the following 5-point rating scale.

		Strongly disagree	**Disagree**	**Undecided**	**Agree**	**Strongly agree**
1.	I have received or am currently seeking assistance from an employment agency/vocational rehabilitation agency to help me find a job. (P)	0	1	2	3	4
2.	I get along with my coworkers and my supervisor at work. (A)	0	1	2	3	4
3.	I probably should look for a job. (C)	0	1	2	3	4
4.	I am not interested in going to work if it means losing my disability or other benefits (e.g., SSI/SSDI). (PC)	0	1	2	3	4
5.	I have joined a job club/support group for job-seeking skills training and support. (P)	0	1	2	3	4
6.	The value of work is grossly exaggerated. (PC)	0	1	2	3	4
7.	I am performing well on my job. (A)	0	1	2	3	4
8.	I am working hard to keep my job. (A)	0	1	2	3	4
9.	I am not able to work. (PC)	0	1	2	3	4
10.	I will have a better life if I have a job. (C)	0	1	2	3	4
11.	I am beginning to see the value of having a job. (C)	0	1	2	3	4
12.	I am thinking about what kind of job is right for me. (C)	0	1	2	3	4
13.	I am currently applying and interviewing for jobs. (P)	0	1	2	3	4
14.	I have received or am currently receiving the education and training that can lead to a job. (P)	0	1	2	3	4
15.	I am motivated to work hard to get ahead. (A)	0	1	2	3	4
16.	No one will hire me because of my disability. (PC)	0	1	2	3	4
17.	Do you currently have a full- or part-time job?	Yes / No				
18.	Do you intend to look for a job in the **next 6 months**?	Yes / No				
19.	Do you intend to look for a job in the **next 30 days**?	Yes / No				
20.	Have you been working during the **past 6 months**?	Yes / No				

Note: PC = Precontemplation, C = Contemplation, P = Preparation, A = Action.

End of Survey