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## USING THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY, AND HEALTH TO PREDICT PARTICIPATION IN ADULTS WITH PARKINSON'S DISEASE: THE ROLE OF POSITIVE PSYCHOLOGICAL CAPITAL

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DISSERTATION

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A dissertation submitted in partial fulfillment of the  
requirements for the degree of Doctor of Philosophy in the  
College of Education at the University of Kentucky

By  
Bradley Wayne McDaniels

Lexington, Kentucky

Director: Dr. Malachy Bishop, Professor of Rehabilitation Counseling

Lexington, Kentucky

2018

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## ABSTRACT OF DISSERTATION

### USING THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY, AND HEALTH TO PREDICT PARTICIPATION IN ADULTS WITH PARKINSON'S DISEASE: THE ROLE OF POSITIVE PSYCHOLOGICAL CAPITAL

Participation is generally considered the ultimate rehabilitation outcome and, for individuals with progressive illnesses, elucidating the factors that impact participation is critical. Parkinson's disease (PD) is a chronic degenerative, neurological condition affecting nearly 1 million people in the United States, making PD the second most prevalent neurodegenerative disorder. PD has a profound negative effect on functioning and activity, but limited literature exists assessing the relationship between PD and community participation. The purpose of this study was to use the World Health Organization (WHO) International Classification of Functioning, Disability, and Health (ICF) as a framework for explaining how PD affects participation. Additionally, because the ICF explains the impact of chronic illness and disability as consisting of interactions between different contextual and disease-related factors, this investigation also addressed whether the personal factors, Positive Psychological Capital (PsyCap), mediated the relationship between functioning with PD and community participation.

A total of 114 individuals were surveyed from peer-led PD support groups in a Midwestern state. The study examined the individual and collective contributions of demographic characteristics, activities/functioning, environmental factors, and personal factors on community participation. Results from the hierarchical regression analysis suggest that demographic characteristics account for only 15% of the variance in participation, but when functioning was added to the model, 65% of the variance was accounted for. The addition of environmental and personal covariates did not result in any significant change in overall variance in participation. These results, along with the strong, positive linear correlations between functioning and participation ( $r = .78$ ), indicate that functioning largely predicts an individual's participation. The study also sought to identify any mediating effect of personal factors (PsyCap) on the relationship between functioning and participation. The results indicated that the completely standardized indirect coefficient was not significant,  $b = .065$ ,  $SE = .0617$ , 95%

$CI = -.213, .029$ , with 0 falling within the  $CI$ , which confirms no significant effect of the mediator PsyCap.

The study contributes new knowledge to the association between the symptoms associated with PD and one's community participation. Clearly, functioning is the primary predictor of participation. The lack of mediation of PsyCap, again, supports the strength of the relationship between functioning and participation. Although PsyCap did not mediate the relationship, implications for future research are discussed.

KEYWORDS: ICF, Parkinson's disease, Participation, PsyCap, Functioning

Bradley Wayne McDaniels

July 5, 2018

Date

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Date

## DEDICATION

To my wife, Kimberly. Thank you for your undying support, encouragement, and  
love. My gratitude abounds

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As I have labored assiduously through this dissertation, I have been reminded of how truly blessed I am to have had the unwavering support of so many. Before I begin, I want to thank God for equipping me with the strength, dedication, and ability to have successfully matriculated through my doctoral work and reached this milestone.

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I am forever grateful for my parents and my daughter. This day would have never come to pass without their continued love and support. Thank you, mom and dad, for engendering faith and resilience in me and providing encouragement, love, and patience,



which have been essential to my becoming the man I am today. Despite having to traverse some rocky roads, you have remained steadfastly in my corner. Thank you! Sydney, you have been a bright spot in my life, and I am grateful for your continued love. I love being your daddy and am excited to continue to watch you mature into a beautiful young woman.

Last but certainly not least, I want to thank my beautiful wife, Kimberly. This accomplishment is more yours than it is mine. You unselfishly afforded me the opportunity to pursue my dreams despite having to be responsible for many aspects of our life. Your love and support has never wavered throughout my graduate work. We have experienced both the peaks and the valleys, and I hope the best is yet to come. We are approaching the light at the end, and I am eager to see what God has in store for us next!

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## **CHAPTER ONE**

### **Introduction**

Parkinson's Disease (PD) is a chronic, degenerative, neurological condition that affects nearly every aspect of an individual's life. PD is characterized by motor symptoms, including tremor, bradykinesia, and gait disturbances; it is also frequently associated with psychiatric and cognitive symptoms including depression, anxiety, and decreased executive functioning (Alder, 2005; Barbas, 2006). Although there is a reasonable amount of literature documenting the negative correlation between the severity of both motor and non-motor features of PD and participation in specific activities (e.g., exercise, physical activity), no research could be located that specifically addressed how the sequelae of PD and individual personal factors impact overall participation (e.g., community engagement). This study will utilize the International Classification of Functioning, Disability, and Health (ICF; World Health Organization [WHO], 2001) framework to evaluate the effect of both functioning with PD and specific personal factors on participation. This study is focused on investigating two questions: (a) how does the decrease in body function associated with PD impact participation based on the ICF model, and (b) whether and to what degree personal factors, specifically the higher order construct of positive psychological capital (PsyCap), mediate the relationship between body function and participation in persons with PD. PsyCap was generated from the positive psychology movement and positive organizational behavior (Luthans, Luthans, & Luthans, 2004). Although there have been many studies using PsyCap in the business literature, it has yet to be utilized in disability or rehabilitation counseling research or in PD research.

## **Statement of the Problem**

The motor and non-motor symptoms of PD can significantly disrupt daily functions, roles, and activities (O'Sullivan, 2007). These functions, roles, and activities are all essential components to participation, defined by ICF as the patient's involvement in life situations (World Health Organization [WHO], 2001). For those with PD, the positive effects of remaining engaged in life activities can be exemplified by reports indicating that engagement in social activities has been positively correlated with well-being (Everard, Lach, Fisher, & Baum, 2000). Moreover, participation in valued activities has been shown to contribute to the maintenance of function and quality of life in older adults, which, given the typical age at diagnosis, includes the majority of individuals with PD (Berkman et al., 1993). Accordingly, focus must be given to those factors that can help individuals maintain meaningful participation in personally important life domains. Evidence supporting the influence of psychosocial factors on participation for people with disabilities can guide rehabilitation research and interventions that look beyond traditional functional remediation (Bent, Jones, Molloy, Chamberlain, Tennant, 2001).

### **PD and Participation**

Because of the association between activity engagement, quality of life, and well-being, it is essential to understand how a decrease in functioning associated with PD may impact participation. Importantly, researchers have demonstrated that functional health status and psychosocial factors are important determinants of participation level among individuals with disabilities (Bent et al., 2001). Participation is considered one of the most important rehabilitation outcomes, and many models of disability have included

participation as a primary construct (Heinemann, 2010). Participation is a complex construct affected by multiple factors (e.g., medical, personal, environmental) and largely captures the impact of chronic illness and disability (CID) on multiple life domains. The overriding goal of rehabilitation interventions is to help individuals return to both personally satisfying and meaningful life roles (Chan, Gelman, Ditchman, Kim, Chiu, 2009). The chronic course of PD requires researchers to examine factors that impact participation, which can guide interventions to help individuals live healthy, productive, and satisfying lives despite a PD diagnosis. A key consideration for rehabilitation and related professionals is the chronic, lifelong, and progressive course of PD. Accordingly, focus must be given to factors that can help individuals maintain active and meaningful life roles in their community. However, there is limited, if any, research examining participation for people with PD in the rehabilitation literature.

Participation influences quality of life (QOL), and, due to the scope of impairments associated with PD, the ability and/or desire to actively participate in once valued activities may negatively and potentially significantly affect QOL. PD is often associated with participation restrictions in interpersonal, domestic, vocational, and avocational activities, as well as in the ability to maintain general independence (Abudi, Bar-Tal, Ziv, & Fish, 1997; Brod, Mendelsohn, & Roberts, 1998; Schenkman, Cutson, Zhu, & Whetten-Goldstein, 2002; Scott, Borgman, Engler, Johnels, & Aquilonius, 2000). Therefore, individuals with PD may find themselves socially isolated, dependent on others, and/or dissatisfied with their social support networks (Abudi et al., 1997). Moreover, individuals with PD have frequently identified the social isolation associated with decreased participation as more concerning than the physical sequelae of the disease



(Schenkman et al., 2000). Variability in impairment and activity limitations affects the degree to which individuals experience PD-related participation restrictions (Abudi et al., 1997; Schenkman et al., 2000.; Scott et al., 2000). Over time, individuals with PD generally participate less, which is hypothesized to negatively impact subjective QOL (Chang & Coster, 2010).

Participation in valued life activities decreases as an inevitable consequence of aging, but having a chronic neurologic condition may significantly impact both the timing of when the decrease occurs and the overall amount of participation (Thordardottir, Nilsson, Iwarsson, & Haak, 2014). Although participation in activities deemed personally meaningful is critical to overall health and well-being (Chan, Cordoso, & Chronister, 2009; Chan, Chan, Ditchman, Phillips, & Chou, 2013; Kielhofner, 2008; Wilcock, 2006), a paucity of literature exists specifically examining the effects of PD on participation. Moreover, there are a lack of empirical studies assessing the impact that PD has on participation using the ICF framework as a guide. The absence of empirical research examining the effects of PD on participation as defined by the ICF provides the impetus for this investigation

An important consideration for the study of participation among individuals with PD is providing a specific definition of participation that can be adequately operationalized. For the purposes of this study, participation will be defined based on the description proposed by Scherer, Sax, and Glueckauf (2005): the individual's involvement in life situations and roles (e.g., parenting, interpersonal relationships, academic pursuits, employment, recreation, worship, political expression, volunteering). An important consideration is the ability to clearly differentiate between activities and

participation per the ICF, which is critical to achieving valid results for either domain independently. Therefore, activities will be considered one's functional abilities (e.g., activities of daily living, personal care) as posited by Fougeyrollas et al. (1998).

Research has clearly demonstrated the negative effects of the symptoms of PD, both motor and non-motor, on various life domains, and although these findings are important, little can currently be done to relieve the untoward symptoms and alter outcomes. Therefore, aside from the typical features of PD that most would assume negatively impact participation, little research (see Gruber-Baldini, Ye, Anderson, & Shulman, 2009), has been done seeking to identify individual characteristics that may play a role in an individual's ability and/or decision whether and to what degree to participate in life. Accordingly, the field of rehabilitation has looked for other factors (e.g., personal, environmental) beyond physical functioning that may improve the lives of people with disabilities. Researchers have identified that personality characteristics can interact with an individual's health condition to impact participation and QOL outcomes. Building on the positive psychology movement, rehabilitation researchers have sought to understand how positive personality characteristics (e.g., optimism, hope, self-efficacy) can improve well-being and assuage the negative aspects of disability (Chou et al., 2013; Seligman & Csikszentmihalyi, 2000; Sheldon & King, 2001).

There is a lack of literature assessing how the different domains of the ICF interact among individuals with PD. As has been stated, research supports the negative effects of PD symptoms on participation, but what is lacking is the association between the contextual factors (i.e., personal factors, environmental factors) and participation for individuals with PD.

## **International Classification of Functioning, Disability, and Health**

As a classification system, the International Classification of Functioning, Disability, and Health (ICF) was established in an attempt to provide a comprehensive system for the conceptualization of health in a holistic manner. Moreover, the ICF can be used to “provide a unified and standard language and framework for the description of health and health-related states” (WHO, p. 3). The ICF is a biopsychosocial model that integrates all of the useful aspects from the medical and social models. Rather than a singular focus on the underlying medical condition or the environmental barriers as contributors to disability, the ICF focuses on the interplay between psychological, biological, and social components and how they, collectively, affect an individual’s ability to function (Peterson, 2018). Origins of the bio-psychosocial framework can be traced to an article from the 1970s arguing for a new medical model for biomedicine (Engel, 1977). Accordingly, the ICF, as described by Peterson and Rosenthal (2005a), is “a classification system developed by the WHO that portrays health as a dynamic interaction between the individual’s functioning and disability within a given context” (p. 95). Furthermore, introduction of the construct of participation highlights that persons with disabilities do not necessarily have the same opportunities for participation as non-disabled peers (WHO, 2010). The key focus of the ICF is on the consequence of disability rather than the etiology.

The key idea of the ICF model is the focus on health as a whole of many parts that interact as either primary or secondary factors (Chan, Gelman, et al., 2009). The ICF model is made up of two parts. The first part, Function and Disability, is comprised of physical functions and structures, activity, and participation, and the second part,

Contextual Factors, is comprised of environmental factors and personal factors which, when all are taken into account define an individual's health and/or disability (Chan, Gelman, et al.; Chan, Tarvydas, Blalock, Strauser, & Adkins, 2009).

### **ICF and participation**

Despite being championed as an ideal outcome, there has been no comprehensive study of factors that impact participation for people with PD. Considering the wide variability in the presentation and progression of PD, the manner in which PD results in functional impairments is a highly individual matter; therefore, an understanding of contextual factors and personal dispositions related to participation is needed to make empirical claims. The sequelae of PD undoubtedly negatively affect a number of life domains, and participation is certainly among those impacted. Because the majority of the extant literature addresses mainly the functional impact of individuals with PD due to disease-related causes, gaining a clearer picture of how and to what degree different domains interact to effect outcomes is warranted. Although there may be different ways in which to systematically investigate these interactions, the ICF framework is well positioned, reliable, and valid. In particular, the ICF can serve as a useful conceptual framework for studying complex internal and external factors associated with participation for individuals with PD. Conceptual clarity with respect to these factors and their interaction effects on participation can assist researchers and clinicians to more thoroughly understand the dynamics of PD and develop novel interventions.

### **Psychological Capital**

Participation is likely affected by the functional difficulties associated with PD and the other components of the ICF, but the hypothesis that personal positive

psychological resources play a role is a unique proposition. In fact, a paucity of research is available assessing how any psychological components fit into Personal Factors of the ICF and, ultimately, affect participation in any chronic disease. One recent study that did address psychological factors and the ICF focused on the trait-like components of core self-evaluations (CSE; self-esteem, self-efficacy, locus of control, emotional stability or neuroticism), but participation was not directly measured (Yaghmaian, Smedema, & Thompson, 2017). Although the components of CSE would be a reasonable choice for this investigation, there is some question as to whether trait-like characteristics, which are inherently stable by nature, can be difficult to change and develop. PsyCap, however, is composed of trait-like characteristics that are all amenable to development and/or improvement. A growing corpus of PsyCap research exists, but only one study could be located that used PsyCap in any health condition (diabetes), and it was conducted in Iran and not published in English (Baghban Baghestan, Sheibani, & Javedani Masrur, 2017). The components of PsyCap fit well with the ultimate goal of improved quality of life and well-being for individuals with disabilities, and research needs to commence assessing the potentially beneficial nature of PsyCap.

Individuals with PD likely require additional supports to function optimally and to fully participate in life, and one of the most useful ways to provide this support is a strengths-based approach that focuses on promoting positive traits (Shogren, 2013). The effects of positive psychology on individuals with disabilities has become increasingly supported in the rehabilitation counseling community, and the individual core constructs of PsyCap, in particular, are frequently discussed as protective factors (Wehmeyer, 2013). Because PsyCap can be both developed and improved, it is hypothesized that, if

PsyCap is found to have a mediating effect between PD and participation, participation improvement may be possible through targeted interventions based on the PsyCap model.

### **Theoretical Framework**

This study is girded on the theoretical underpinnings of disability theory, which purports that disability cannot be understood by assessing any one factor but is only adequately described through a multi-faceted, biopsychosocial approach. In other words, understanding disability is well removed from strictly a pathological issue and, to fully appreciate how chronic illness and disability (CID) impacts the individual, every aspect of his or her life must be considered and addressed. Current disability theory is largely based on the research of Beatrice Wright and Tamara Dembo, which expanded on Kurt Lewin's field theory. Field theory emphasized behavior as a function of the person, environment, and the myriad interactions between the person and the environment (Noreau & Boschen, 2010). As a result of their pioneering work, the accepted disability dogma was thrust into a new era of removing the focus exclusively on the individual and beginning to assess all of the areas that may impact an individual's participation and QOL.

### **Purpose of the Study**

The purpose of this study is to develop and evaluate a model of participation for individuals with PD based on the ICF framework, and specifically, to explore the relationship between functioning with PD and participation with particular focus on the role of personal factors (represented with the components of the PsyCap model) as mediators in the relationship. To date, there is no well-validated, comprehensive model of community participation for people with PD, nor any empirical research on the role of

PsyCap in improving outcomes in individuals with CID. The ICF is an overarching framework that can capture the biological, functional, personal, and environmental factors of PD.

This study will review the rehabilitation literature to determine and incorporate the most salient predictors of participation for people with PD. Factors included in the study will be evaluated for their contribution to the model. More effective rehabilitation interventions can be provided to people with PD by systematically studying factors known to impact participation. Dunn and Elliott (2008) proposed that such theory-driven research is crucial to the development of evidence-based interventions in rehabilitation. Moreover, with the increased focus on evidence-based practice in rehabilitation counseling, intervention strategies are mandated to be founded on empirical research (Chan et al., 2009b; Rubin, Chan, & Thomas, 2003). Interventions derived from rigorous empirical research significantly improve rehabilitation outcomes (Kosciulek, 2010). This study will generate knowledge about the contribution of personality factors on participation and inform future research toward the development of potentially beneficial rehabilitation interventions.

### **Research Questions**

1. In terms of the ICF framework, what is the relationship between functioning and participation for individuals with PD?
2. Does PsyCap mediate the relationship between functioning and participation?

## **CHAPTER TWO**

### **Literature Review**

Extant literature largely fails to address how the functional effects of PD impact overall participation in life activities. As described below, the impact of PD on participation is significant. Rather than having a singular focus on one's chronic illness or disability, rehabilitation and related fields are focused on providing holistic interventions for individuals with disabilities to ultimately improve participation in meaningful life domains by assessing both personal and environmental factors (Chan, Gelman, et al., 2009; Heineman, 2010; Wright, 1983). Research is needed to thoroughly assess the relationships between personal and environmental factors and PD. Considering the incomplete explanations regarding the relationship between personal and environmental factors and disease-related characteristics in individuals with PD, this study provides an important initial investigation into uncharted territory.

#### **Parkinson's Disease**

Parkinson's disease (PD) is a chronic, degenerative, neurological condition that affects nearly 1 million individuals in the United States and more than 10 million worldwide (Parkinson's Disease Foundation [PDF], 2017), making PD the most prevalent neurodegenerative disorder after Alzheimer's disease (Dorsey et al., 2007; Jancovic, 2012). The prevalence of PD in the US has increased significantly as life expectancy has increased (Goldman & Tanner, 2015) and, with the relative growth in the size of the aging population, the number of individuals with PD is expected to double by 2030 (Dorsey et al., 2007). PD was first described over two centuries ago by English physician James Parkinson, and although significant progress has been made in understanding the



etiology and treatment, conceptualization of the disease continues to evolve (Kalia & Lang, 2015). Moreover, despite numerous advances in PD treatment, a cure remains elusive.

Parkinson's disease motor symptomatology is the result of a loss of dopaminergic neurons in the substantia nigra pars compacta (SNpc), which causes reduced dopamine release in the caudate nucleus and putamen (the striatum; Clark, Reddy, Zheng, Betensky & Simon, 2011). The etiology of Parkinson's disease is a combination of unknown genetic and environmental factors, which lead to a common pathogenic cascade of molecular events (Miller & Federoff, 2005; Simunovic et al., 2009). The pathological hallmark of PD is the  $\alpha$  (alpha)-synuclein containing Lewy body, an "eosinophilic, proteinaceous cytoplasmic inclusion seen in surviving neurons" (Walsh, Lynch, & Fahn, 2011, p. 77). Although PD is a single disease, several PD subtypes have traditionally been recognized. Among the earliest classifications of PD are two categories: (a) tremor-dominant (earlier onset and accounts for roughly 75% of all PD cases) and (b) postural instability and gait difficulty PD (PIGD; difficulty with balance, shuffling of gate, and frequent falls with a more rapid disease progression; Jancovic et al., 1990). A more recent systematic review of the literature not only confirmed the existence of tremor dominant and PIGD PD, but two additional subtypes were also identified: (a) young onset (YOPD; from 21-55 years of age) with slow progression and (b) old age at onset with rapid disease progression (van Rooden et al., 2010). PD is a heterogeneous disorder with variable identifying characteristics, but categorizing individuals into appropriate subtypes may aid in both understanding and treatment decisions.

**Etiology.** Over the past decade, the view of the etiology of PD has progressed significantly from the belief that the illness is simply genetic in nature to the now widely accepted view that both genetic and environmental factors contribute to the onset of PD (Schapira, 2009; Schapira & Tolosa, 2010). Despite this, the single most important factor contributing to the onset of PD is the aging process (Schapira & Jenner, 2011). Although certainty exists regarding the role of age, little is known about the precise mechanism for this relationship (Obeso et al., 2010). There are a host of identified environmental influences on the occurrence of PD. These include: industrialization, rural environment, well water, bacterial and viral infection, organic solvents, carbon monoxide, and carbon disulfide (Corrigan, Murray, Wyatt, & Shore, 1998). More recently, literature has begun to point to pesticide exposure as a contributing influence, but confounding results make identifying the specific pesticide elusive (Richardson et al., 2009). Factors that may contribute to a decrease risk of PD are important to consider to help determine etiology. Some activities clearly decrease the risk of PD (e.g., cigarette smoking, caffeine intake), while decided uncertainty exists about others (e.g., exercise, anti-inflammatories, calcium antagonists, antilipidemics; Ascherio et al., 2001; Warner & Schapira, 2003). The risk for developing PD is multi-factorial, but the relationship between the various factors is just beginning to be understood.

**Onset and prevalence.** Although the exact etiology is still largely not understood, the number of individuals affected is significant and continues to grow. Parkinson's disease is the most prevalent neurodegenerative movement disorder in adults (Borland et al., 2008) and the second most common neurodegenerative disorder, behind only Alzheimer's disease (Jankovic, 2012). PD affects more than one million people in

the US (Parkinson's Disease Foundation [PDF], 2017). Parkinson's disease affects approximately 0.3% of people in the developing world and approximately 2-3% of individuals over the age of 65 years (Cantuti-Castelvetri et al., 2007; Dexter & Jenner, 2013). It is typically diagnosed late in life and can negatively affect a number of life domains. The prevalence of PD in the United States (US) is roughly 1 million, with worldwide rates ranging from 7 to 10 million (PDF, 2017). Nearly 60,000 new cases of PD are reported annually in the US alone (National Institutes of Health - Senior Health [NIH], 2016). The incidence rate of PD is increasing significantly as life expectancy has increased and as the 77 million members of the American Baby Boom Generation continue to approach and achieve retirement age (Goldman & Tanner, 2015). Because the number of individuals with PD is expected to double by 2030 (Dorsey et al., 2007), the current disease-related costs in the United States of \$14 to \$23 billion are projected to increase to \$50 billion by 2040 (Kowal, Dall, Chakrabarti, Storm, & Jain, 2013). One of the explanations given for the dramatic rise in both PD prevalence and projected costs is the relative growth of the aging population. According to the National Parkinson Foundation (NPF; 2017), the mean age of onset of PD is 62, with increasing prevalence as the population ages.

Early-onset Parkinson's disease (EOPD), however, affects individuals between 21 and 55 years (Quinn, Critchley, & Marsden, 1987; Schrag & Schott, 2006). In comparison to typically diagnosed or late-onset PD (LOPD), EOPD has slower disease progression, lower rate of dementia (Schrag, Ben-Shlomo, Brown, Marsden, & Quinn, 1998) and less frequent gait disturbances (Wickremaratchi, Ben-Shlomo, & Morris, 2009). However, research suggests that rates of depression are higher in EOPD than in

LOPD (Kasten et al. 2012). Individuals diagnosed with EOPD represent about 10% of all PD diagnoses.

**Clinical features of PD.** PD is a progressive neurological disorder characterized by motor and non-motor symptoms. The motor symptoms include tremor, rigidity, akinesia or bradykinesia, postural instability, fixed posture, and freezing (Jankovic 2008). The cardinal motor features of PD are typically responsible for the patient seeking medical care, but by the time patients become symptomatic, the majority (60%) of dopaminergic neural function has already been lost, and the actual onset of PD generally predates the motor manifestation by approximately 4.5 years (Moeller & Eidelberg, 1997). PD is classified as a movement disorder, and, historically, the most commonly described manifestations have been motor in nature. However, during the 21<sup>st</sup> century, non-motor symptoms in people with PD are increasingly the focus of care in neurology clinics (Sauerbier & Chaudhuri, 2015). Non-motor symptoms of PD are a significant cause of disability in people with PD and may involve almost any aspect of the nervous system (e.g., autonomic, peripheral) including cortical and brainstem involvement (Stacy, 2011). The severity of motor and non-motor symptoms can significantly disrupt individual functioning, activity level, and health-related quality of life (HrQOL; Duncan et al, 2014; Jahanshahi & Marsden, 2000; Kadastik-Eerme, Rosenthal, Paju, Muldmaa, & Taba, 2015; Karlsen, Larsen, Tandberg, & Maeland, 1999; Karlsen, Tandberg, Arslan, & Larsen, 2000; Martinez-Martin, 1998; Muller, Assmus, Herlofson, Larsen, & Tysnes, 2013; O'Sullivan, 2007).

**Non-motor features.** Historically, PD has been conceptualized according to associated motor symptoms, but there is increasing consideration of the numerous non-

motor symptoms. Non-motor symptoms are PD symptoms that are not primarily related to movement and motor function. Non-motor symptoms include autonomic dysfunction (orthostatic hypotension, sweating dysfunction, sphincter dysfunction, erectile dysfunction), cognitive and neurobehavioral abnormalities (dementia, affective disorders, obsessive-compulsive and impulsive behavior), and sleep disorders and sensory abnormalities (Jankovic, 2008). Parkinson's disease patients experience an average of 8 to 13 non-motor symptoms even at early stages of the disease (Chaudhuri et al., 2006). Non-motor symptoms are considered a key determinant of both the individual with PD's and his or her caregiver's overall quality of life and social functioning. Due to a lack of treatment options, non-motor symptoms may present the most significant challenges to clinicians (Stern, Lang, & Poewe, 2012).

Many of the non-motor effects of PD present after diagnosis and are frequently associated with medication side-effects; however, there are a number of non-motor features that frequently present well before the onset of the motor dysfunction and diagnosis. Among the premotor or prodromal symptoms that appear, often up to 10 to 15 years before the motor manifestations, are impaired olfaction (e.g., hyposmia), constipation, depression, excessive daytime sleepiness, and rapid eye movement sleep behavior disorder (RBD; Kalia & Lang, 2015). These non-motor features are frequently attributed to other causes, but following the presentation of motor symptoms, they ultimately contribute to the PD diagnosis. Other non-motor effects of PD can include psychosis (60%; Riedel et al., 2010), urogenital dysfunction (38%-71%; Ransmayr et al., 2008), anxiety (40%; Dell'Angello et al., 2001), orthostatic hypotension (10%-20%; Stacy, 2011), vision and sensory decline, dementia (30%; Biggins et al., 1992), impaired

executive functioning, depression (17%-22%; Reijnders, Ehrt, Weber, Aarsland, & Leentjens, 2008), impulsivity (17.5%; Antonini et al., 2011), and pain (Alder, 2005; Barbas, 2006; Stacy, 2011). Among the common non-motor symptoms, pain, sleep disturbances, and anxiety are reported as the most bothersome and mentioned ahead of the motor symptoms (Politis et al., 2010); depression is the most common mood disturbance occurring in roughly 50% of individuals with PD (Dooneief et al., 1992).

**Diagnosis.** Although a host of symptoms are associated with PD, differential diagnosis remains challenging. Parkinson's disease can be clinically defined based on the presence of bradykinesia along with at least one other cardinal motor features (e.g., resting tremor, rigidity, impaired postural reflexes; Hughes, Daniel, Kilford, & Lees, 1992). Generally, the diagnosis of PD depends on the moderate-to-severe neuronal loss in the SNpc and no evidence of other diseases that produce PD-like symptoms (Gelb, Oliver, & Gillman, 1999). Additionally, the symptoms of PD are typically asymmetric at onset, and frequently there is a positive response to levodopa therapy (Magdalinou & Morris, 2017). Currently, there is no one technique or assessment that provides a primary diagnosis of PD, and due to symptom commonality, frequent misdiagnosis of similar conditions (e.g., essential tremor, atypical parkinsonism, secondary parkinsonism) may occur. Misdiagnosis of PD can occur for several reasons including the fact that the cardinal features of PD (e.g., bradykinesia, rigidity, gait disturbance) may be present as a result of normal aging or from comorbid conditions (e.g., diabetes, cancer; Arvanitakis et al., 2004; Inzelberg & Jancovic, 2007). Although the gold standard for diagnosing PD remains the neuropathological assessment, there are no generally accepted diagnostic criteria for PD (Dickson et al., 2009). The diagnosis of PD is based on a detailed record

of a patient's medical history along with a combination of thorough physical and neurological assessments (Hughes et al., 2002).

**Gender and ethnicity.** Evidence suggests the prevalence of Parkinson's disease is higher in the male population (Cantuti-Castelvetri et al., 2007) with males being 1.5 times more likely to be diagnosed with PD. The specific reason for the disparity in PD between men and women is unclear but the increased likelihood of men working with toxic chemicals and the protective effects of estrogen in women are believed to contribute to the gender differences (Goldman & Tanner, 2015). Historically, there has been limited evidence regarding the prevalence of PD in ethnic minority groups. Based on limited but current research, it appears that PD impacts diverse racial and ethnic groups worldwide, and one-fifth of patients with PD in the United States are from ethnic minority groups (Schneider, Bhatia, & Hardy, 2009). Among these groups, PD prevalence is highest in individuals from Hispanic origin, followed by non-Hispanic Caucasians, Asians, and African Americans (Van Den Eeden et al., 2003). Further investigations including incidence estimates and etiologic studies in multiethnic populations are warranted to further clarify the relationship between PD and ethnicity.

**Progression.** Disease progression in PD is the result of progressive nigrostriatal denervation and neurodegeneration in multiple brain areas and the peripheral autonomic nervous system (Sulzer & Surmeier, 2013). Although the progression of PD is largely heterogeneous, research indicates that bradykinesia, rigidity, and activities of daily living deteriorate more quickly in the early stages of the disease (Maetzler, Liepelt, & Berg, 2009); whereas, cognitive impairments, speech difficulties, sleep problems and gait difficulties develop throughout the progression of the disease (Maetzler et al., 2009). In

the later stages of the disease, orthostatic dysfunction, visual hallucinations, and variability in heart rate develop (Maetzler et al., 2009). The life expectancy of patients with PD has been reported to be lower than that of the general population (Hobson, Meara, & Ishihara-Paul, 2010), but more recent literature suggests that mortality rates among individuals with PD are similar to the general population (Williams-Gray et al., 2013). Specifically, in patients who do not develop dementia, life expectancy is similar to the overall population (Hobson et al., 2010). In other words, patients with dementia and with a younger onset of PD appear to have shorter life expectancies than other patients with PD (Hobson et al., 2010).

**Medical management of Parkinson's disease.** Due to the cardinal motor features of bradykinesia, tremor, and rigidity particularly in early PD, pharmacologic therapies are necessary to reduce symptom burden. Additionally, physical therapy has been shown to improve mobility, posture, and balance in individuals with PD (Fox et al., 2011). Non-motor symptoms may be present early in the disease course but are not as burdensome as in later stages of PD. Pharmacologic interventions for PD are intended to replace the lack of dopamine subsequent to the degeneration of the nigrostriatal pathway (Damier & Al-Hashel, 2017). Although currently available treatment options offer substantial benefits to the patient, as PD advances, problems arise associated with the side-effects of the drugs. The available pharmacologic treatments for PD are specifically geared toward reducing the motor symptoms; other commonly used agents are available to treat the non-motor features. In addition to drug treatments and physical therapy (PT), several surgical options (e.g., deep brain stimulation [DBS]) are available to ease the symptoms of PD.



**Psychosocial functioning.** Despite the array of available and largely beneficial therapeutic interventions, individuals with PD, as a result of the related physical and psychological morbidity, continue to be faced with challenges related to daily functioning. Psychosocial difficulties can result in significant challenges for individuals with PD. Although PD is characterized by the common motor symptoms, it is also frequently associated with psychiatric and cognitive symptoms including depression, anxiety, and decreased executive functioning (Alder, 2005; Barbas, 2006). Depression and anxiety disorders occur in a significant proportion of individuals with PD and are positively correlated with motor symptoms, motor complications, gait difficulties, freezing episodes, on-off fluctuations, cognitive impairment, disability, worsening quality of life, and poor self-perceived health status (Dissanayaka et al., 2010; Pontone et al., 2009; Yamanishi et al., 2013). In the early stages of PD, depression and anxiety may reduce working capacity more than the motor features, while in the later stages, cognitive issues and fatigue become more impactful (Martikainen, Luukkaala, & Marttila, 2006). As a result of disease progression and severity of both motor and non-motor symptoms, activities of daily living, socialization, productivity, employment, and health-related quality of life for individuals with PD can be dramatically affected (Hartley et al., 2014; Lawrence, Gasson, Kane, Bucks, & Loftus, 2014).

### **Participation and Parkinson's Disease**

Participation generally decreases as a consequence of aging, but having a chronic neurological disorder may significantly impact both the timing of changes in and the amount of participation (Thordardottir, Nilsson, Iwarsson, & Haak, 2014). Although participation in activities deemed personally meaningful is critical to overall health and

well-being (Chan, Cordoso, et al., 2009; Chan, Chan, et al., 2013; Kielhofner, 2008; Wilcocks, 2006), a paucity of literature exists examining the effects of PD on participation. Employment, which is a component of participation, has been the focus of several of these studies. (Armstrong et al., 2014; Banks & Lawrence, 2006; Gustafsson, Nordstrom, Strahle, & Nordstrom, 2015; Jasinska-Myga et al., 2012; Johnson et al., 2011; Keränen et al., 2003; Korchounov, & Bogomazov, 2006; Martikainen, Luukkaala, & Marttila, 2006; McDaniels, *forthcoming*; Murphy, Tubridy, Kevelighan, & O’Riordan, 2013; Schrag & Banks, 2006; Schrag, Hovris, Morley, Quinn, & Jahanshahi, 2003). These studies show that PD clearly has a negative impact on participation in employment (e.g., capacity to work, both motor and non-motor effects, fatigue, stiffness, depression).

Of the PD studies that have broadly addressed participation, most defined participation as the ability to participate in physical activity (e.g., walking, exercise; Duncan & Earhart, 2011; Ellis et al., 2011; Hammarlund, Andersson, Andersson, Nilsson, & Hagell, 2014; Foster, Golden, Duncan, & Earhart, 2013; Lamont, Morris, Woollacott, & Brauer, 2012; Nilsson, Iwarsson, Thordardottir, & Haak, 2015; O’Brien, C., Clemson, & Canning, 2016; Pretzer-Aboff, Galik, & Resnick, 2009; Quinn, Busse, Khalil, Richardson, Rosser, & Morris, 2010; Raggi et al., 2011; Ravenek, & Schneider, 2009; Thordardottir et al., 2014; Vlagsma et al., 2017). The commonly identified factors affecting physical activity have included both motor and non-motor features of PD.

Although there have been a number of PD studies investigating quality of life (QOL) and health-related quality of life (HrQOL), none included general participation as a predictor variable. Only one study (van Uem et al., 2016) assessed PD in terms of the ICF, but it was focused on assessing HrQOL and demonstrated that non-motor symptoms

were more associated with decreased HrQOL. Aside from medical management, HrQOL has been the most widely studied construct among individuals with PD. Several hundred articles appear in the literature and, rather than attempting to include them all, I chose to include the four published reviews (Den Oudsten, Van Heck, De Vries, 2007; Dowding, Shenton, & Salek, 2006; Soh et al., 2013; van Uem et al., 2016). Commonalities across all reviewed studies demonstrate that HrQOL in PD is negatively correlated with self-care limitations, mobility limitations, depression, anxiety, lack of disease education, and disease duration.

There are few empirical studies assessing the impact that PD has on participation using the ICF framework. The existing evidence supports that the progression of PD and the increase of both motor and non-motor symptoms negatively affect overall physical activity and other generic measures of participation. No studies were found that assessed the effects of PD on participation as defined by the ICF (described below), which provides the impetus for the current study.

### **International Classification of Functioning, Disability, and Health**

Understanding and explaining with a common nomenclature the ubiquitous effects Parkinson's disease, like other CIDs, is critical for thorough rehabilitation planning among multiple providers. As a classification system, the International Classification of Functioning, Disability, and Health (ICF; World Health Organization [WHO], 2001) was established in an attempt to provide a comprehensive system for conceptualization health in a holistic manner. Moreover, the ICF can be used to "provide a unified and standard language and framework for the description of health and health-related states" (WHO, 2001, p. 3). For several decades, rehabilitation and related

professions have had an overarching focus on the study of disability and its effects on various life domains (Peterson & Elliot, 2008). As such, providers in the multidisciplinary profession of rehabilitation counseling advocate for the improvement of living conditions for individuals with disabilities (Frank, Rosenthal & Caplan, 2009; Riggan & Maki, 2004). In attempts to satisfactorily conceptualize disability, several models have been proposed throughout the last few decades. Although the intentions of the various models were reasonable, each model's assumptions about disability, which may unfavorably affect the views and beliefs about individuals with chronic illness and disability (CID), arguably resulted in more questions than answers. The ICF presents a different way of conceptualizing CID than did previous models by classifying health and functioning rather than singularly focusing on disability. The following is a discussion of the antecedents of the ICF, its components and their interrelationships, and participation among individuals with disabilities.

### **Development of the ICF**

**Medical model.** One of the oldest and, for decades, the most widely accepted model of disability was the medical model, which carries the prestige associated with the medical community. The focus of the medical model was on the diagnosis of the disease or disorder with the goal of symptom remission and cure (Wright, 1980). Accordingly, the medical model aims to identify the cause (i.e., pathology) of the disease or disability and then prescribes the appropriate treatment (Reed et al., 2008). Because the medical model is diagnosis driven with a focus on pathology, individuals may be dehumanized due to disability being considered an objective, personal condition (Smart & Smart, 2006). One of the hallmarks of the medical model is the assertion that the disability is an

impairment and lies within the individual. As a result of the belief that the disability was intrinsic to the person, interventions are focused on trying to “fix” the individual, and anything outside the person (e.g., social structure, psychological factors) is viewed as inconsequential (Chan, Gelman, et al., 2009). As a result of this view, the person responsible for the “problem” should be totally responsible for the solution, which relieves society of any responsibility (Kiesler, 1999).

The underlying focus of the medical model was “normalcy” as determined by society, and, when an individual strays from the “norm,” the focus becomes helping them return to “normal” (Peterson, 2018). The medical model has been criticized for being highly paternalistic and hierarchical, with care for this return to “normal” being determined for the individual by professionals (e.g., Chan, Gelman, et al., 2009), and for ignoring contextual issues (Pledger, 2003; Smart & Smart, 2006). As such, individuals with disabilities are often reduced to the role of passive and compliant patients. And, as a result of the medical model’s focus on disease within the individual, “... many individuals with disabilities may see no value in trying to integrate into a society that automatically discounts and pathologizes them” (Smart & Smart, 2006). Recent literature suggests that diagnosis and pathology alone not only discount the individual’s functioning within his/her environment but also overlooks the role of society in regard to overall functioning (Peterson & Elliott, 2008).

**Social model.** Subsequent to the person-focused medical model of disability emerged the more extrinsically-focused social model, which was the first enablement model of disability (Pledger, 2003). A paradigm shift took place in rehabilitation medicine resulting in a departure from the medical model of disability toward a social

model, which considered the role of the environment in overall functioning (Smart & Smart, 2006; G.N. Wright, 1980). In contrast to the medical model, the social model attributes disability to the complex social structure that governs the interaction between person and environment. Disability is not a personal attribute; it is a social construct, and more accurately, it is a “sophisticated form of social oppression” (Backbench, Chatterji, Badley, & Üstün, 1999, p. 1173). The premise is that a person’s environment can either positively or negatively impact disability, based on whether the environment is accommodating or hostile (Livneh & Male, 1995; Tate & Pledger, 2003). In this model, stigma and prejudice are reduced, as individuals with disabilities are no longer viewed as being at fault for their own disabilities (Chan, Gelman, et al., 2009; Livneh & Male, 1995). This model is, therefore, an improvement to the medical model but not without its limitations: This model completely disregards the biological functions or impairments and makes determining who qualifies as an individual with a disability challenging (Chan, Gelman, et al., 2009; Livneh & Male, 1995; Pledger, 2003; Tate & Pledger, 2003).

**International Classification of Impairments, Disabilities, and Handicaps.** The International Classification of Impairments, Disabilities, and Handicaps (ICIDH; WHO, 1980) is the immediate predecessor to the ICF. Formal work on the ICIDH began in 1972, when the workgroup began collaborating on developing a method for classifying the consequences of disability and disease (de Kleijn-de Vrankrijker, 2003). The final model was published by the WHO in 1980. The goal of the ICIDH was to establish common nomenclature in the classification of disability incorporating a version of the social model (Bickenbach et al., 1999). Among the frequently noted flaws of the ICIDH

were (a) the use of language that was consistent with a disablement model (e.g., impairment, disability, handicap), (b) the characterization of disability as a linear process leading from impairment to handicap, and (c) failing to recognize the role of environment in functioning (Cieza & Stucki, 2008; de Kleijn-de Vrankrijker, 2003).

The ICIDH was developed as a complement to the International Statistical Classification of Diseases and Related Health Problems (ICD), which covers causes and underlying health conditions while the ICIDH addresses the associated consequences (Peterson & Rosenthal, 2005a). The ICIDH did provide a description of the concept of disability even though it has been criticized for the overly negative language (Chan, Gelman, et al., 2009). Accordingly, impairment is based on the manifestations of the dysfunctions in the body's structures or functions. Impairment is not determined by the presence of a disorder or disease, but instead is based on a deviation from what is considered normal standards of functioning (WHO, 2001). The degree to which an impairment results in disability is based on individual personal factors. Disability is defined as any impairments, activity limitations, and participation restrictions in the environment, 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). Handicap refers to the disadvantage created by a disability that affects the fulfilment of a normal life role (Chan, Gelman, et al., 2009). The ICIDH failed to be approved by the World Health Assembly, and its successor, the ICF, was subsequently established (Cieza & Stucki, 2005). Figure 2.1 is a graphical representation of the ICIDH model.

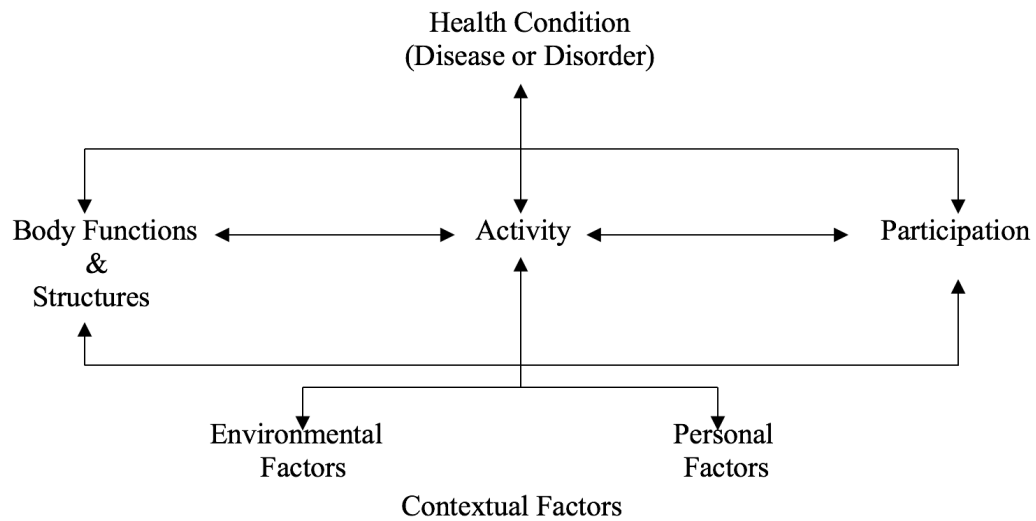


*Figure 2.1.* “International Classification of Impairments, Disabilities, and Handicaps: A Manual of Classification Relating to the Consequences of Disease,” 1980. Geneva: WHO. Copyright 1980 by WHO. Reprinted with permission

### **ICF Framework**

Building on the ICIDH, The WHO ratified the ICF in 2001. The ICF operationalizes disability across the domains of (a) body functions and structures, (b) activities, (c) participation, (d) personal factors, and (e) environmental factors (WHO, 2001). The ICF framework was ratified to (a) develop a scientific structure to study the effects of disability, (b) develop a language to improve communication about disability, (c) facilitate collaborative research, and (d) create code schemes for disability (WHO, 2001). Figure 2.2 conceptualizes the ICF and the various factor relationships.

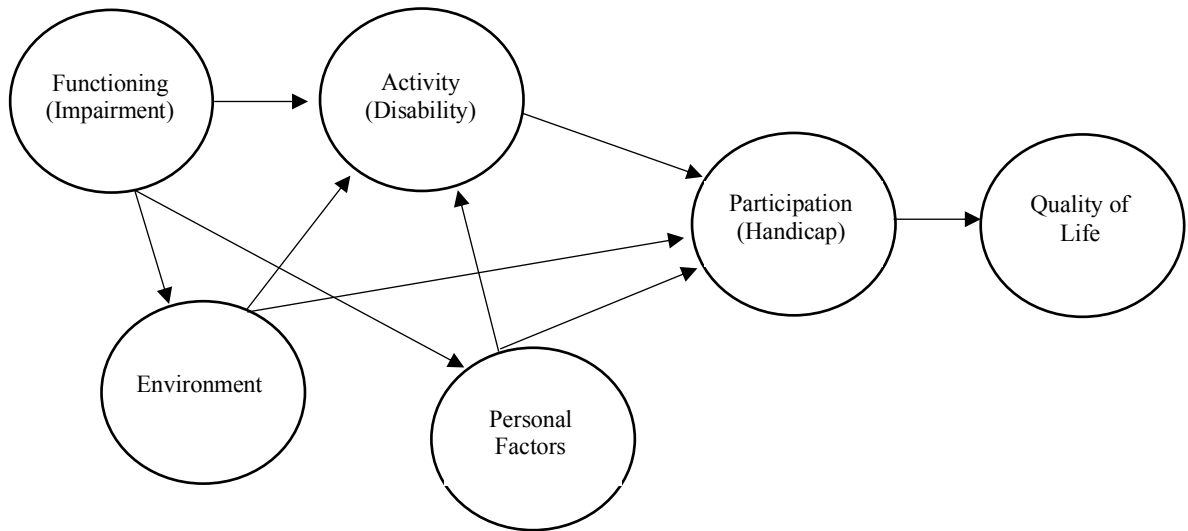




*Figure 2.2.* “International Classification of Functioning, Disability and Health,” 2001, Geneva: WHO. Copyright 2001 by WHO. Reprinted with permission.

The ICF framework advances disability theory by incorporating elements of previous models of disability while also accounting for contextual (i.e., personal, environmental) factors (Chan, Cordoso, et al., 2009). The ICF model is consistent with the rehabilitation counseling and psychology philosophy by emphasizing the environmental (E) and personal (P) factors, and the significance of the P X E interaction on the full integration of individuals with disabilities into the community. Chan, Cordoso, et al. advocated for the ICF as the best framework to study participation outcomes of people with chronic illness and disability. Figure 2.2 shows an adapted model of the ICF framework by Chan, Cordoso, et al. This adaptation details the relationship between functioning, activities, personal factors, and environmental factors and their ultimate impact on participation and quality of life. The ICF framework is considered an enablement model of disability, marking a shift from focus on medical impairments to

features within the person or environment that facilitate well-being, employment, or participation (Chan, Cordoso, et al., 2009).



*Figure 2.3.* Health-related and contextual factors of the ICF. Adapted from “The World Health Organization ICF Model as a Conceptual Framework of Disability,” by F. Chan, J.S. Gelman, N. Ditchman, J.-H. Kim, and C.-Y. in “Understanding Psychosocial Adjustment to Chronic Illness and Disability: A Handbook for Evidence-Based Practitioners in Rehabilitation,” by F. Chan, 2009, NY: Springer. Copyright 2009 by Springer Publishing. Reprinted with permission.

**Function, impairment, and disability.** Beginning with a basic understanding of the nomenclature of the ICF is necessary for conceptual clarity. Functioning consists of all body functions, activities, and participation, and it refers to the components of well-being. Both functioning and disability are conceptualized by the dynamic interaction between health conditions and contextual factors (e.g., impairment, disability, handicap). In contrast to the positive focus of functioning, disability refers to the negative aspects of the dynamics between health conditions (e.g., impairment) and contextual factors (i.e., environment and personal factors).

**Body functions and structures.** The body functions and structures component of the ICF consists of two parts: (a) body functions is the psychological and physiological function of specific body systems (e.g., hearing, sight, speech, memory) and (b) body structures, which relates to the anatomical structures of the body (e.g., organs, limbs, brain, spinal cord; WHO, 2001). Even though the two classifications are classified separately, they are parallel with each other, based on the same body system taxonomy. For example, memory problems lie within body functions, and the corollary of memory is the brain, which lies within body structures. 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 assessing and reporting impairment are the same for both 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 not a stand-alone construct, it is intended to be complemented by the other components in Domain I (e.g., activities and participation component).

**Activities and participation.** The constructs of activity and participation represent the consequences of alterations in body functions and structures into changes in functioning at both the individual and societal levels. Activity is defined as the execution of a task or action by an individual (e.g., sitting, running, eating, or driving), whereas participation is involvement in a life situation or the societal perspective of functioning (WHO, 2001). Despite important conceptual differences, there is limited evidence to completely differentiate between activity and participation (Nordenfelt, 2003). The ICF

proposes different ways to conceptualize the relationship between activities and participation. The user can consider each category as either activity or participation, which results in two mutually exclusive lists. Alternatively, one can code activities and participation as one construct or as an overlapping list, which is how it is often done in the U.S. (Reed et al., 2005; Threats & Worrall, 2004).

The activity and participation domains are specifically operationalized through two qualifiers: capacity and performance. Capacity “describes an individual’s ability to execute a task or action” or “the highest probable level of functioning that a person may reach in a given domain at a given moment” (WHO, 2001, p. 15). Alternatively, performance describes “what a person does in his or her current environment” or “involvement in a life situation” (WHO, 2001, p. 15). A simple way to conceptualize the difference between capacity and performance is: capacity is what a person can do, and performance is what a person actually does. This distinction serves to allow for interventions designed to reduce or eliminate barriers and maximize facilitators within a given context (Peterson, 2011).

In order to improve the conceptualization of activity and participation, Scherer, Sax, and Glueckauf. (2005) suggest that participation can be viewed as the individual’s involvement in life situations and roles, which may include parenting, interpersonal relationships, academic pursuits, employment, recreation, worship, political expression, and volunteering. They further opine that participation should be considered separate from basic functional capabilities (i.e., activity). Moreover, Fougeryollas and colleagues (1998) posit that it is the interaction between the person and the environment that ultimately determines participation. They defined activities as the functional abilities of

an individual apart from environmental or societal influences, whereas participation represents outcomes in a broader social context.

Operationally defining participation is not a straight forward task and considerable debate exists about appropriate methods. One consideration is to focus on the distinction between objective and subjective indicators of community participation (Dijkers, 2010). Objective performance measures focus on quantifying community activities (e.g., number of relationships, amount of participation in community activities), whereas subjective measures of participation focus on traits (e.g., autonomy, self-efficacy, self-worth; Dijkers, 2010), which is an interesting concept to investigate with a construct like PsyCap. One criticism of objective measures is that participation is dynamic and fluid. and objective measures might not reflect fluctuations in participation (Dijkers, 2010). However, there are no norm-referenced measures of subjective perceptions of participation (Dijkers, 2010). In fact, since the introduction of the ICF, researchers have encountered difficulty in operationally defining the various constructs and particularly the measure of participation (Heinemann, 2005).

### **Contextual Factors**

Contextual factors “represent the complete background of an individual’s life and living” (WHO, 2001, p. 16). Included within the contextual factors are the domains of personal factors and environmental factors. These contextual factors may present as either barriers or facilitators of overall functioning (Peterson, 2011). This domain of the ICF is based on the initial work of Kurt Lewin (1935, 1936) and subsequent work of Dembo, Leviton, and Wright (1975) and B.A. Wright (1980, 1983), who demonstrated the importance of both personal and environmental factors on overall outcomes.

**Personal factors.** Personal factors are those personal characteristics that can impact an individual's performance in body functions, activities, and participation (i.e., health and functioning; 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 (Peterson & Rosenthal, 2005b). Although personal factors are a consideration within the contextual factors, there is no specified component of the ICF regarding how personal factors may be barriers or facilitators to activities and participation because of the challenges of a universal definition. Nevertheless, personal factors are contextually considered within the overall model because of the potential role in restricting full participation in society for non-health related reasons (Peterson, 2016). An investigation of personal factors is likely to be a future focus of the application of the ICF to individuals with various disabilities (Duggan, Albright, & LaQuerica, 2008).

**Environmental factors.** Environmental factors are defined as “the physical, social, and attitudinal environment in which people live and conduct their lives,” which facilitate or hinder an individual's functioning and disability at the body functions and structures levels and the activities and participation levels (WHO, 2001, p. 171). There are five chapters of the environmental construct: (a) products and technology, (b) natural environment, (c) support and relationships, (d) attitudes, and (e) services and systems (WHO, 2001). Each of these chapters, depending on their presence or absence, affects the individual either positively or negatively. Environmental factors are designed to focus at both the individual and societal levels. The individual level has the most immediate

environmental influence, for instance, one's home, workplace, or school (Peterson, 2011). Therefore, one is influenced by personal interactions with others as well as the physical and material features of the environment. The societal level addresses both formal and informal social structures, services, and overarching approaches or systems in the community or society, which may "hinder an individual's performance because either it creates barriers (e.g. inaccessible buildings) or it does not provide facilitators (e.g. unavailability of assistive devices)" (WHO, 2001, p. 17).

### **Positive Psychological Capital**

Considering the growing focus on the impact of positive outlook on CID, assessing how Positive Psychological Capital (PsyCap) may improve participation outcomes among individuals with PD is needed. PsyCap is an increasingly recognized higher-order construct that was developed from the advances in positive psychology, positive organizational scholarship (POS), positive organizational behavior (POB), and resource theory. The following sections will provide an historical overview of the development of PsyCap, a detailed description of the first-order positive psychological resources that make up PsyCap, and available research supporting the implementation of PsyCap.

### **Positive Psychology**

Although the formal field of positive psychology is relatively new, it was first mentioned in the professional literature by Maslow (1954), who stated that psychology:

has been far more successful on the negative than on the positive side. It has revealed to us much about man's shortcomings, his illness, his sins, but little about his potentialities, his virtues, his achievable aspirations, or his full psychological height. It is as if psychology has voluntarily restricted itself to only half its rightful jurisdiction, the darker, meaner half. (p. 354)

Toward the turn of the 21<sup>st</sup> century, Dr. Martin Seligman, president of the American Psychological Association, opined that the field of psychology concentrates on repairing dysfunction from a disease-model perspective and neglects to focus on the positive qualities that contribute to a fulfilled life (Seligman & Csikszentmihalyi, 2000). More specifically, Seligman and Csikszentmihalyi stated that positive psychological “treatment is not just fixing what is broken; it is nurturing what is best” (p. 7). Positive psychology can be conceptualized as “the scientific study of what makes life worth living” and actualizing one’s full potential (Lopez & Snyder, 2009, p. XXIII). Seligman & Csikszentmihalyi characterize positive psychology as focusing on the three pillars: (a) valued subjective experience, (b) positive individual traits, and (c) civic values and the institutions that support them. Several years later, Hart and Sasso (2011), following a thorough content analysis of the elements of the various definitions of positive psychology, identified six common themes: (a) character strengths, personality traits; (b) fulfillment, quality of life; (c) actualization of potential; (d) a life worth living; (e) thriving and flourishing; and (f) adaptive functioning or behavior.

Clearly, positive psychology was a divergence from the accepted practice of focusing on healing the deficiencies in individuals and, alternatively, beginning to focus on positive attributes and ways to foster them. An important facet within positive psychology is the exploration of the relationships among various positive constructs and the associated positive outcomes. The scientific basis of positive psychology sets a precedent that has served as the prerequisite for positivity in the workplace in the form of PsyCap (Luthans, Youssef, & Avolio, 2007). In his book *Authentic Happiness*, Seligman (2004) originally asked the question of whether there is psychological capital, and if so,



what is it, and how do we get it. Seligman even goes so far as to suggest an answer; “...when we are engaged (absorbed in flow), perhaps we are investing, building psychological capital for our future” (p. 116). Positive psychology ignited a paradigm shift away from focusing on the negative aspects of an individual and, instead, became more positively valanced.

### **Positive Organizational Scholarship**

The positive psychology movement and its applicability in the workplace in terms of positive organizational scholarship (POS) and positive organizational behavior (POB) provided the impetus for the development of the core construct of PsyCap (Luthans, Youssef, & Avolio, 2007). In fact, the positive approach emanating from the field of psychology was extended to the workplace by focusing on both the value of positivity in individuals (micro-oriented; Luthans, 2002a, 2002b; Luthans, Youssef, & Avolio, 2007; Nelson & Cooper, 2007) and in organizations and communities (macro-oriented; Cameron & Caza, 2004; Cameron, Dutton, & Quinn, 2003). POS is a “movement in organizational science that focuses on the dynamics leading to exceptional individual and organizational performance such as developing human strength, producing resilience and restoration, and fostering vitality” (Cameron & Caza, 2004, p. 731). Additionally, POS is an emerging area of disciplined study that views standard organizational behavioral issues through the lens of positive psychology and is an overarching concept integrating multiple positive scientific perspectives, including positive traits, states, processes, and dynamics (Luthans & Youssef-Morgan, 2017).

Although the focus of POS is on positive phenomena, it does not ignore the negative world that it characterizes as driven by greed, manipulation, and distrust; it

simply chooses to focus on the other side of the equation (Caza & Cameron, 2008). With a clear affirmative bias, POS seeks to understand what the best of human conditions is and how to most effectively increase the focus on these conditions to the benefit of all participants touched by the organization. The best examples of flourishing, vitality, and strength are often found when surrounded by challenges, setbacks, and demands, rather than singularly blissful circumstances (Ryff & Singer, 2003). Accordingly, POS is focused on the interaction of both positive and negative conditions. Balancing the interaction between positive and negative conditions, therefore, is the essence of POS.

### **Positive Organizational Behavior**

Derived from the positive psychology and POS research, positive organizational behavior (POB) was developed as a way of improving workplace performance by focusing on individual strengths and psychological capacities (Luthans, 2002b). POB is defined as “the study and application of positively oriented human resource strengths and psychological capacities that can be measured, developed, and effectively managed for performance improvement in today’s workplace” (Luthans, 2002b, p. 59). For a human resource strength to be included in POB, it must be positively valenced and consistent with positive psychology, theory- and research-based, measurable, and state-like and open to development (Luthans & Youssef-Morgan, 2017). The critical feature of POB, and subsequent PsyCap, constructs is that they are state-like, which means that they are open to development or improvement through the use of brief training programs and highly-focused “micro-interventions” (Luthans, Luthans, & Avey, 2014; Luthans, Avey, Avolio, Norman, & Combs, 2006; Luthans, Avey, Avolio, & Peterson, 2010). The state-like human strengths (e.g., hope, resilience, optimism, gratitude) are what differentiates

POB from positive psychology and POS, which are both typically focused on trait-like characteristics (e.g., conscientiousness, extroversion, neuroticism, agreeableness).

Similar to the disease perspective in clinical psychology that fails to allow clinicians to fully appreciate the broad dynamic of optimal functioning, organization theories, which are negatively skewed, result in ineffective and unethical leaders, dysfunctional attitudes and behaviors, and counter-productive organizational structures (Cameron & Spreitzer, 2012). The relationship between focusing on positivity and ultimate well-being extends well beyond the individual level toward an understanding of how the organization's interactions positively affect employee health and well-being (Heaphy & Dutton, 2008). Through the exploration to identify the psychological capacities best suited for POB, Luthans and colleagues (2007) concluded that four capacities fully met the criteria: hope, (self)-efficacy, resilience, and optimism (HERO), which became the first-order constructs of PsyCap.

### **Positive Psychological Capital**

In an attempt to directly identify and ultimately quantify positive psychological resources, the higher-order construct of PsyCap was introduced to represent individuals' positive psychological state of development (Luthans, Youssef, & Avolio, 2007). The concept of psychological capital is a divergence from other, more common types of capital: human capital (what one knows in terms of knowledge, skills, abilities and experience), social capital (whom one knows, including networks and relationships), and financial capital (what one has in terms of financial resources) (Avey, Luthans, & Jensen, 2009; Luthans et al., 2004). In terms of positive development, PsyCap is viewed as who one is and what one can become (Luthans et al., 2006).

PsyCap is the amalgamation of the four psychological constructs that were determined to best fit the inclusion criteria for POB (i.e., hope, (self)-efficacy, resilience, and optimism [HERO]; Luthans et al., 2004; Luthans, Youssef-Morgan, & Avolio, 2015). The composite construct of PsyCap is defined as,

...an individual's positive psychological state of development and is characterized by: (1) having confidence (self-efficacy) to take on and put in the necessary effort to succeed at challenging tasks; (2) making a positive attribution (optimism) about succeeding now and in the future; (3) persevering toward goals and, when necessary, redirecting paths to goals (hope); and (4) when beset by problems and adversity, sustaining and bouncing back and even beyond (resilience) to attain success. (Luthans et al., 2007, p. 3)

Put simply, PsyCap is a framework for understanding the psychological resources that people use to effectively surmount obstacles in their lives (Krasikova, Lester, & Harms, 2015). Evident from the definition and as a result of research by Luthans and his team, PsyCap is a higher order positive construct made up of the previously identified and commonly accepted four first-order constructs (i.e., HERO).

This concept of synergy, a higher-order factor being composed of distinct components, is not novel; it is found in other theories, including: (a) Hobfoll's (2002) idea of "resource caravans" where similar psychological characteristics do not exist in isolation but, when together, they aggregate and interact synergistically; (b) transformational leadership is composed of charisma, individual consideration, intellectual stimulation, and inspirational motivation (Avolio, Bass, & Jung, 1999); (c) core self-evaluation is composed of self-esteem, generalized self-efficacy, locus of control, and emotional stability (Judge & Bono, 2001); and (d) empowerment is composed of meaning, competence, self-determination, and impact (Spreitzer, 1995). To work as a higher-order construct, there has to be a common theme tying the individual

constructs together, and in the case of PsyCap, the link between the individual components is that they all contribute “to a motivational propensity to accomplish tasks and goals” (Luthans, Avolio, Avey, & Norman, 2007, p. 548).

The four first-order constructs (i.e., hope, efficacy, resilience, optimism) have been demonstrated to be conceptually and psychometrically distinct; however, they share evidence of convergent validity and when combined, give rise to an underlying psychological resource for an individual to perform at consistently higher levels than is possible with any of the individual components (Luthans, Norman, Avolio, & Avey 2008). In other words, PsyCap may be referred to as a multidimensional construct (Law, Wong, & Mobley, 1998). There is, indeed, empirical evidence to support the multidimensionality of PsyCap. Through the application of competing confirmatory factor analytic model comparisons, high correlations (0.6 to 0.7) demonstrate the convergent validity, and PsyCap was best modeled as a second-order factor (Luthans, Avolio, et al., 2007). In comparison with the four constructs modeled separately, the model with PsyCap as a second-order factor fit the data the best (Luthans, Avolio, et al., 2007) A discussion of each of these constructs follows.

**Hope.** The construct of hope is pervasive throughout the positive psychology literature but is often misunderstood. In fact, many may confuse hope with wishful thinking (Lopez, 2013) or simply a positive attitude. According to Rick Snyder, a renowned researcher on hope in positive psychology, hope can be defined as “a positive motivational state that is based on an interactively derived sense of successful (1) agency (goal-directed energy) and (2) pathways (planning to meet goals)” (Snyder, Irving, & Anderson, 1991, p. 287). When considering hope, it is important to note that hope is an

individual's perceived belief that he/she can produce goals, pathways, and agency (Snyder, Lehman, Kluck, & Monsson, 2006), which together are the defining characteristics of hope (Snyder, Cheavens, & Michael, 1999). Hope is an essential cognitive feature in the motivation process because a sense of agency motivates people to pursue goals, take control of their lives, confront challenges, and overcome obstacles to success (Bandura, 1986; Snyder, 2000; Snyder, Shorey, Cheavens, Pulvers, Adams, & Wiklund, 2002). Moreover, Luthans and Youssef (2004) assert that hope includes "the quality of goals being set and the mechanisms through which increasingly challenging goals are selected, approached, accomplished, and changed if necessary in light of additional evidence and new realities of the situation" (p. 230).

With regard to goals, individuals cognitively assess both agency and pathways that are critical in achieving their goals. Hope not only provides the "will" to succeed but also the ability to identify, clarify, and pursue the "way" to success (Luthans & Jensen, 2002). This idea is supported by Snyder (2002) who suggests that goals without the necessary means to accomplish them are futile. Additionally, there is a temporal component to goal setting; "we typically think how we can link our present to our imagined futures" (Snyder, 2002, p. 251). In the pursuit of goals, individuals establish pathways or functional paths that allow for the movement from point A to point B (Snyder, 1994a, 1994b, 2000). Individuals with high hope who are pursuing a specific goal are typically able to confidently generate at least one reasonable path but frequently maintain alternative routes accounting for potential barriers (Snyder, Harris, et al., 1991). In contrast, individuals with low hope have difficulty generating reasonable paths and are unlikely to develop alternative contingency routes (Snyder, 2002).

Although pathways refer to the functional route for attaining goals, agency is the motivational component, the mental energy, that propels one toward his/her goals and keeps them focused on the identified pathway (Snyder, 1994b; 2000; 2002). In their seminal work, Snyder, Harris, and colleagues (1991) posited that both agency and pathways were critical to sustaining movement toward one's goals and that neither agency nor pathways alone is sufficient to adequately define hope (Snyder, 1995; Snyder, Cheavens, & Sympson, 1997). Agency provides the impetus for people to pursue goals and persevere toward ultimate achievement, which may suggest that agency is more responsible for goal attainment than the specific pathways (Feldman, Rand, & Kahle-Wroblewski, 2009).

Consistent with the inclusion criteria set forth in POB and subsequently in PsyCap, hope has been determined to be a state-like characteristic (Locke & Latham, 2002). Longitudinal (Avey, Luthans, Smith, & Palmer, 2010; Peterson, Luthans, Avolio, Walumbwa, & Zhang, 2011) and experimental studies (Dello, Russo, & Stoykova, 2015; Demerouti, van Eeuwijk, Snelder, & Wild, 2011; Ertosun, Erdil, Deniz, & Lutfihak, 2015) support the position that hope is fluid and can be both developed and improved through specific interventions. Additionally, there are several positive psychology interventions that have demonstrated effectiveness for increasing positivity, alleviating negativity, and improving overall well-being and that can likely be adapted for use in PsyCap (Sin & Lyubomirsky, 2009).

**Self-Efficacy.** Self-efficacy or the perception that people have regarding their capability to complete given tasks is theoretically similar to hope, which is the belief that goals will be achieved through motivation and the associated paths, but the two are

conceptually distinct (Davidson, Feldman, & Margalit, 2012; Luthans, Youssef, & Avolio, 2007; Snyder, Harris, et al., 1991). The development and understanding of self-efficacy as a construct can be traced back to the work of Bandura's (1977, 1986) and his Social Cognitive Theory (SCT), which emerged from his earlier work in behaviorism. SCT asserts that functioning is the result of interactions between personal, behavioral, and environmental factors. Individuals have substantial influence over their functional outcomes and their environment via forethought, self-reflection, and self-regulating processes: all essential in SCT (Bandura, 1986, 1989, 1997). According to Bandura (1986), what individuals believe about their capabilities is a better predictor of their behavior than the results from previous performances.

One's belief in his/her capabilities (i.e., self-efficacy) is an important factor in determining how knowledge and skills are both acquired and used. For example, in the educational setting, students develop beliefs about their academic capabilities that inform how they utilize information (Pajares, 1996). As such, a student's academic performance reflects what he/she believes about past and future accomplishments and may help to explain how two students with similar perceived capabilities can perform dramatically differently academically. Research supports the notion that beliefs (i.e., self-efficacy) have a mediating effect on overall engagement and may result in the use of cognitive strategies, which may potentially improve performance (Pintrich, 1999).

The constructs of self-efficacy and confidence are frequently considered to be synonymous, but they are clearly distinct. Bandura (1997) made a clear distinction between the two by proffering that confidence is a term used to describe a strong but ambiguous belief, but self-efficacy is a "belief in one's agentic capabilities, that one can



produce given levels of attainment” (p. 382). In PsyCap, however, efficacy and confidence are considered synonymous, and efficacy is best defined as “one’s conviction (or confidence) about his or her abilities to mobilize the motivation, cognitive resources, and courses of action needed to successfully execute a specific task within a given context (Stajkovic & Luthans, 1998, p. 66). Regardless which construct is used, the operative consideration is one’s belief system and its ultimate linkage to the construct. Luthans, Youssef, and Avolio (2007) discerned five characteristics that are critical to distinguish individuals with high self-efficacy from those without:

(1) They set high goals for themselves and self-select into difficult tasks. (2) They welcome and thrive on challenge. (3) They are highly self-motivated. (4) They invest the necessary effort to accomplish their goals. (5) When faced with obstacles, they persevere. (p. 38)

Individuals with these characteristics are undoubtedly self-motivated to plan and perform effectively with limited external influence. People who demonstrate high PsyCap efficacy frequently prefer challenging tasks and goals and are relatively unaffected by self-doubt, negative feedback, social criticism, or obstacles, which would, indeed, cause distress for an individual with low efficacy (Bandura & Locke, 2003). Bandura (2008) stated that one of the most significant roles of self-efficacy is manifested in an individual’s ability to manage both stress and success. Accordingly, Bandura (1997) illuminates four routes that may be used to develop and improve an individual’s confidence or self-efficacy: (a) mastery experiences, (B) vicarious learning, (c) social persuasion, and (d) emotional or psychological arousal. In order for these factors to actually improve PsyCap efficacy, one must select (i.e., cognitively process) and act upon the factors through forethought, observation, self-regulation, and self-reflection (Luthans, Youssef, & Avolio, 2007).

**Resilience.** Resilience is defined as “the capacity to rebound or bounce back from adversity, conflict, failure, and even positive events, progress, and increased responsibility” (Luthans, 2002a, p. 702). From a PsyCap perspective, the definition has expanded to include not simply returning to one’s previous set-point but going beyond this equilibrium state (Avolio & Luthans, 2006; Youssef & Luthans, 2005). In other words, resilience is when an individual remains well, recovers well, and thrives despite adversity (Hardy, Concato, & Gill, 2004). According to Lamers, Westerhof, Bohlmeijer, ten Klooster, & Keyes (2011), there are two distinct components of resilience: (a) significant adversity and (b) positive adaptation. Additional research suggests four individual characteristics of resilience: (a) the capacity to make realistic plans and execute actions to achieve those plans, (b) having a positive view of self (i.e., self-efficacy), (c) appropriate communication and problem-solving abilities, and (d) ability to positively manage strong feelings (Luthans, Youssef, & Avolio, 2007). Evidence from the disability literature is clear that there is a correlation between resilience and positive outcomes.

Resilience is the one first-order construct of PsyCap that is conceptually different from the other three in two ways: (a) as opposed to the proactive nature of hope, efficacy, and optimism, resilience is a reactive response to a setback; and (b) resilience relies on external resources (i.e., contextual) when internal resources are lacking, whereas hope and efficacy rely on internal mechanisms (i.e., psychological; Avey, Luthans, & Youssef, 2010). Moreover, resilience “engages creative and flexible adaptive mechanisms, guided by ethical values and strong belief systems, toward the achievement of personally and organizationally meaningful goals (Luthans & Youssef, 2007, p. 334). This may explain

the reasoning behind the US Army's Resilience Training curriculum, which aims to foster optimism, faith, problem-solving, self-efficacy, flexibility, sense of meaning, and spirituality in soldiers destined for combat operations (Moran & Nemecek, 2013).

Frequently, resilience has been purported to be a characteristic of only extraordinary individuals, but Masten (2001) notes: "Resilience does not come from rare and special qualities but from the everyday magic of ordinary, normative resources in the minds, brains, and bodies of children..." (p. 238).

Resilience may be associated with either positive or negative events, and positive psychology has several factors that have been posited to either facilitate or impede the development of resilience (Luthans, Youssef-Morgan, & Avolio, 2015). Accordingly, these factors are recognized as assets, risk factors (Masten, 2001; Masten, Cutuli, Herbers, & Reed, 2009), and values (Coutu, 2002; Richardson, 2002). Among the identified assets are cognitive abilities, temperament, positive self-perceptions, faith, emotional stability, and sense of humor (Masten, 2001). Risk factors include alcohol and drug abuse (Sandau-Beckler, Devall, & de la Rosa, 2002), stress or burnout (Smith & Carlton, 2001), and poor health and unemployment (Collins, 2001). Ultimately, resilience has been described as the most important positive resource by equipping individuals to adapt to change and maintain flexibility in order to meet new demands when faced with adversity (Avey et al., 2009).

**Optimism.** Broadly, optimism is described as "positive expectations about future events" (Sharpe, Martin, & Roth, 2011, p. 946). The construct of optimism is clearly rooted in the positive psychology movement and the work of Martin Seligman. Seligman (1998) described optimism as an explanatory construct that attributes positive events and

outcomes to personal, permanent, and pervasive causes but interprets negative outcomes as external, temporary, and situation-specific; alternatively, pessimism is the opposite. Additionally, Carver, Scheier, Miller, and Fulford (2009) propose that optimism is a general positive outlook that results in positive overall outcomes. From a state-like perspective, optimism is a positive future expectation, and “change in an optimistic direction is possible” through targeted interventions (Carver & Scheier, 2002, p. 240). The idea that optimism can be developed is consistent with the concept of “learned optimism” (Seligman, 2006). Consequently, the positive state-like construct of optimism has garnered sufficient support to be included in the higher-order PsyCap construct (Luthans & Youssef, 2007). Optimists maintain an overall positive outlook regardless of their external circumstances, which typically results in positive outcomes.

As a result of the work by Seligman, optimism may be more closely associated with positive psychology than any of the other constructs. Optimism is commonly used vernacular, but Seligman’s view of optimism is based on attribution theory, which is the basis for an individual’s explanation of good and bad outcomes and consists of two distinct dimensions: permanence and pervasiveness. Attribution theory deals with how people perceive information to arrive at causal explanations for events (Fisk & Taylor, 1991). For optimists, bad outcomes are only temporary, but pessimists assume bad outcomes are permanent. With regard to positive life events, optimists make permanent attributions and pessimists make a temporary attribution. (Seligman, 2004).

Pervasiveness, on the other hand, deals more with generalizations with regard to specific events. Optimists focus only on a specific outcome for negative events, whereas pessimists take a single event and make it personal (Luthans, Luthans, & Luthans, 2004).

Optimism levels are instrumental in magnifying positive events and act as a buffer for negative events (Luthans, Youssef, Sweetman, & Harms, 2013). Therefore, optimism is more important to satisfaction and overall well-being than objective circumstances. Moreover, the positive psychology literature has demonstrated that objective circumstances are responsible for only about 10% of one's happiness, but optimistic predispositions account for roughly 50% of well-being (Lykken & Tellegen, 1996; Lyubimirsky, 2007). This leaves about 40% open to development.

### **Literature Supporting PsyCap**

Evidence regarding positive PsyCap outcomes is critical in determining whether it is worthy of further investigations. Although positivity has been demonstrated to result in positive outcomes, PsyCap, a higher order construct, requires evidence-based answers on the specific outcomes. Luthans, Youssef, and Avolio (2007) proposed that the synergistic outcome of the four combined resources yields greater potential than the impacts from any of them separately. In two separate meta-analyses of PsyCap literature, study conclusions support that the second-order construct of PsyCap is strongly associated with desirable employee attitude, behavior, and performance outcomes and may help to decrease undesirable attitudinal and behavior outcomes (Avey, Reichard, Luthans, & Mhatre, 2011; Jeong & Baek, 2017). Additional studies provide evidence for the relationships between PsyCap and job satisfaction (Avey et al., 2011; Larson & Luthans, 2006; Youssef & Luthans, 2007), organizational citizenship behavior (Avey, Luthans, & Youssef, 2010; Walumbwa, Peterson, Avolio, & Hartnell, 2011), organizational commitment (Youssef & Luthans, 2007), and performance (Avey et al., 2011; Luthans, Norman, et al., 2008; Peterson, Luthans, et al., 2011; Walumbwa et al., 2011; Zamahani,

Ghorbani, & Rezaei, 2011). Clearly, the literature supports the relationship between the higher-order construct of PsyCap and multiple employment-related variables.

### **Work-Related Performance**

Performance has been the most researched outcome among all variables related to PsyCap (Avey et al., 2011). Luthans (2002b) emphasized that to be considered a higher-order positive psychological construct, the combination of resources should synergistically work to improve performance. These four psychological resources of PsyCap have been heralded for creating positive organizational climate and a positive work performance (Avey et al., 2011; Luthans, Avolio, et al., 2007; Luthans, Norman, et al., 2008). Mounting evidence supporting the association between PsyCap and performance has been seen in the business literature. For example, Zamahani and colleagues (2011) examined the relationship between PsyCap and job performance using a sample of 200 employees of a large Iranian telecommunications firm. Results demonstrated a statistically significant positive correlation between employee PsyCap and job performance ( $r = .48, p < .001$ ). Similarly, from a sample of 422 Chinese factory employees, Luthans and colleagues (2005) reported a positive correlation between worker's PsyCap and their supervisor-rated performance ( $r = .26, p < .01$ ). Similar results were reported among a sample of 456 employees from two Chinese copper refining factories (Luthans, Avey, Smith, & Li, 2008). Additionally, a statistically significant positive correlation between PsyCap and supervisor-rated performance was reported ( $r = .25, p < .01$ ).

Evidence also exists that PsyCap is positively correlated with more subjective performance measures such as manager ratings and intra-firm referrals (Avey, Luthans,

Smith, & Palmer, 2010). In fact, results indicate that the overall magnitude of the relationship between PsyCap and performance is not significantly different than other self, subjective, and objective performance measures. Additionally, evidence supports that positive PsyCap ratings among employees contributes to effectiveness and flourishing in organizations (Luthans & Youssef, 2007). Lastly, Peterson and Zhang (2011) assessed top management team's collective PsyCap, and the results suggest that the higher the collective PsyCap, the better their business unit performed. According to Luthans and colleagues (2010), the additive components of PsyCap "can be expected to be related to higher performance based on their reinforcing greater extra effort from individuals, promoting the generation of multiple solutions to problems, ...and positive results to setbacks" (p. 48). Overall, Avey et al.'s (2011) meta-analysis consisting of 51 independent samples and more than 12,000 employees supports PsyCap as a predictor of self-rated, supervisor-rated, and objective performance.

### **Employee Attitudes**

Work attitudes can be conceptualized as an individual's evaluation of his/her job and their overall commitment to the organization (Verquer, Beehr, & Wagner, 2003); however, job satisfaction and organizational commitment may be seen as proxies for employee attitudes (Kappagoda, Othman, Zainul, & Alwis, 2014). Strong positive correlations have been reported between PsyCap and both job satisfaction and organizational commitment, and PsyCap is negatively correlated with undesirable attitudes (e.g., cynicism, turnover intentions, work stress, anxiety) and undesirable behavior (e.g., deviance; Avey et al., 2011; Luthans, Norman, et al., 2008; Youssef & Luthans, 2007). Moreover, those individuals with high levels of PsyCap were involved in

facilitating positive organizational change, and those with lower levels of PsyCap demonstrated more resistance to change (Avey, Wernsing, & Luthans, 2008). There exist a couple of reasons why those higher in PsyCap experience lower levels of undesirable attitudes and behaviors. First, PsyCap's agentic thinking is essentially motivating and may have a positive effect on internalization and determination, which is in stark contrast to the giving-up and despair associated with cynicism (Avey, Luthans, & Youssef, 2010). Second, higher levels of PsyCap has been associated with more positive emotions as a by-product of one's perceived ability to succeed (Snyder, Harris, et al., 1991). Given that cynicism can be detrimental to organizational initiatives, the development of employee PsyCap has potential as a human resource management strategy to counteract these attitudes and promote positive change in organizations (Avey et al., 2008).

One possible explanation for the positive effect of PsyCap on employee attitudes may be that those with higher levels of PsyCap expect positive things to occur (optimism) and believe that they are responsible for creating their own successes (efficacy, hope) while being less effected by obstacles (resilience; Avey et al., 2011). Taken together, the available evidence strongly supports the contention that PsyCap is positively correlated with positive employee attitudes, behaviors, and performance and negatively correlated with undesirable attitudes and behaviors. The evidence on PsyCap is consistent with the preponderance of support for the effects of positivity on multiple life domains, which is contrary to the conventional belief that success is what leads to positivity (Lyubomirsky, King, & Diener, 2005).



## CHAPTER THREE

### Methodology

This chapter addresses the various components of the methodology as it relates to my dissertation proposal. Included will be my proposed research questions, research design, procedures, measurement instruments, and statistical analysis.

#### Research Questions

The overarching goal of this study is to more thoroughly understand the factors associated with community participation for individuals with PD, with particular attention being paid to factors amenable to interventions (i.e., personal factors). More specifically, the study will investigate the relationship between the personal factor PsyCap as a mediator between health functioning and participation among people with PD.

**Research Question 1.** Do the constructs defined in the ICF framework predict participation for people with PD?

**Research Question 2.** Does PsyCap mediate the relationship between functioning and participation among people with PD?

#### Research Design

In this study, I used the ICF model to investigate how well the distinct domains predict participation in individuals with PD and whether and to what extent PsyCap mediates the relationship between functioning with PD and participation. A quantitative, correlational research design employing multiple regression and hierarchical regression analysis was used to examine the relationships between the variables of interest received from surveys.

## **Participants**

After University of Kentucky IRB approval, a purposive sample of individuals with PD was obtained from peer-led PD support groups in a mid-western state. Potential participants were invited to participate during the support groups. These groups met bi-monthly, and a total of 114 usable surveys were collected. There were several reasons for choosing the proposed strategy: (a) by choosing to deliver the survey questionnaires in-person at the support groups, and forego mailing the surveys, I was able to receive completed surveys much quicker; (b) the individuals who attend these support groups tend to be willing to participate in research efforts that may benefit them in the future; (c) I had professional contacts in these areas who were willing to assist in the recruitment of participants; and (d) the heterogeneity of these groups offered a variety of viewpoints based on physical functioning, time since diagnosis, age, employment issues, and varying life circumstances that increased the robustness of the data received.

## **Instrumentation**

The survey questionnaire included five measures: (a) demographic information, (b) the World Health Organization Disability Assessment Schedule version 2.0 (WHODAS 2.0; Üstun, Kostanjsek, Chatterji, & Rehm, 2010) to measure function and activities, (c) the Impact on Participation and Autonomy scale (IPA; Cardol, de Haan, van den Bos, & de Groot, 1999) to measure participation, (d) the Personal Resource Questionnaire (PRQ2000; Weinert, 1987, 2003) to measure environmental factors, and (e) the Psychological Capital Questionnaire (PCQ-24; Luthans, Avolio, Avey, & Norman, 2007) to measure personal factors. These instruments are further described below.

**Demographics.** General demographic and PD characteristics information were collected along with PD characteristics that were used to evaluate their impact on participation. Demographic characteristics included: gender, age, race/ethnicity, educational attainment, marital status, and household income. Two temporal questions were asked: age at first signs of PD and age at formal diagnosis of PD. Descriptive statistics for participants' characteristics were presented with means and standard deviations for continuous data (e.g., age, age at first signs of PD, age at diagnosis) and counts and proportions for categorical data (e.g., gender, race, relationship status, education, household income).

**WHODAS 2.0.** Activity-related skills and body function was measured by using the World Health Organization Disability Assessment Schedule 2.0 (WHODAS-2.0; Üstun et al., 2010). The WHODAS-2, originally developed by Üstun et al. (2010), was designed as a self-report measure of an individual's level of functioning in six major life domains: cognition (e.g., understanding and communicating with others), mobility (e.g., getting around), self-care (e.g., dressing, feeding), getting along with others (e.g., dealing with strangers, getting along with friends and family), life activities (i.e., Activities of Daily Living or ADLs), and participation (e.g., difficulty experienced taking part in typical community activities, dealing with barriers and hindrances). The WHODAS 2.0 is the only instrument of function and disability specifically designed through an understanding of the ICF framework (Üstun et al., 2010). According to the WHO (Üstun et al., 2010), the WHODAS 2.0 is “a practical, generic assessment instrument that can measure health and disability at the population level or in clinical practice” (p. 4).

The WHODAS 2.0 was chosen because it is widely considered the most thorough and detailed assessment of the individual ICF domains and allows for analysis of both composite domain scores and overall functioning scores (Üstün et al, 2010). Responses to the 36 questions are based on a 5-point Likert-type scale (i.e., 1 = none, 2 = mild, 3 = moderate, 4 = severe, and 5 = extreme or cannot do), and each item begins with the phrase “In the past 30 days, how much difficulty did you have in:” followed by specific questions (e.g., “starting and maintaining a conversation?”).

The psychometric properties (i.e., reliability and validity) of the WHODAS 2.0 have been assessed internationally in 4 different groups: general population, people with physical problems, people with mental and emotional problems, and people with problems related to alcohol and drug use (WHO, 2001). The intraclass correlation coefficient (ICC) values for the test-retest reliability results of the WHODAS 2.0 during initial and follow-up administrations (within 7 days) were as follows: at item level (ICC=0.69-0.89), at domain level (ICC=0.93-0.96), and at overall level (ICC=0.98). Cronbach alphas were calculated for internal consistency, and results by domain were as follows: Domain 1 (Cognitive) 0.59- 0.70; Domain 2 (Mobility) 0.74 0.79; Domain 3 (Self-care) 0.47-0.73; Domain 4 (Getting along) 0.52-0.76; Domain 5 (Daily life activities) 0.88-0.94; and Domain 6 (Participation) 0.54-0.74. The internal consistency of the WHODAS 2.0 has been reported to be 0.98 (Üstün et al., 2010), and an internal consistency reliability estimate (Cronbach’s alpha) of 0.96 was found in this study.

Face validity was examined by asking experts whether the WHODAS 2.0 content measures disability as defined by the domains of ICF, and 64% of experts agreed that it did. Several health status and functioning instruments were administered simultaneously

with the WHODAS 2.0 to assess concurrent validity. These instruments included the London Handicap Scale (LHS), the Medical Outcomes Study's 36-Item Health Survey (SF-36), SF-12, the Functional Independence Measure (FIM), the WHO Quality of Life (WHOQOL-100), and the WHO Quality of Life Brief Scale (WHOQOL-BREF). The correlation coefficients were determined to be between .45 and .65 (WHO, 2010).

Confirmatory factor analysis was performed to test the association between the individual item factor structure and the various domains along with any cross over among dimensions. As a result, the independent structure of each domain was supported and results were similar across testing sites (coefficients ranged from 0.82-0.98 across domains). In the responsiveness study, the WHODAS 2.0 demonstrated at least as much sensitivity to change across time as similar measures of social functioning, and the results remained consistent regardless of varying demographic factors, which indicates cross cultural applicability (Üstün et al., 2010).

Face, concurrent, and construct validity were all evaluated for the WHODAS 2.0. As previously reported, the research team asked a group of experts to review the instrument, and 64% agreed that the content of the instrument measures disability according to the ICF framework. Additionally, results from the two waves of testing produced scores that were expected based on characteristics (e.g., the treatment groups scored significantly higher than the general population indicating disability). Relationships between participant group characteristics and instrument scores were all in the expected directions (Üstün et al., 2010). These two results were taken as evidence of face validity or that the instrument measures what purports to measure. In terms of construct validity, Üstün et al. proposed that this measure is consistent with the

underlying concepts of health and functioning. Evidence of the ability to differentiate samples of people with and without health problems was presented to support construct validity (Üstün et al., 2010).

**Impact on Participation and Autonomy.** Cardol et al. (1999) developed the IPA as a comprehensive measure of community participation. The IPA contains 32 items and 5 subscales including: (a) autonomy indoors (7 items; e.g., “my chances of getting around in my house where I want to are”); (b) family role (7 items; e.g., “my chances of contributing to looking after my home the way I want to are”); (c) autonomy outdoors (5 items; e.g., “my chances of visiting relatives and friends when I want to are”); (d) social life and relationships (7 items; e.g., “my chances of talking to people close to me on equal terms are”); and (e) work and education (6 items; e.g., “my chances of getting or keeping a paid or voluntary job that I would like to do are”). Items are rated on a 5-point Likert-type scale (0 = very good to 4 = very poor). Considering that the scoring of the IPA is reversed from the other instruments (i.e., lower indicates more participation), interpretations of coefficients and the subsequent direction of relationships between constructs should be made accordingly. Internal reliability coefficient estimates (Cronbach’s alpha) range from .83 to .91 (Cardol et al., 1999), and Cronbach’s  $\alpha$  of 0.90 was found in this study. The English version of the IPA was validated by Sibley, Kersten, Ward, White, Mehta, & George (2006).

**The Personal Resource Questionnaire.** The PRQ2000 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 (Dilorio, Faherty, & Manteuffel, 1992a, 1992b, 1994). The PRQ2000 instrument uses 15 positively worded questions (e.g., “There is someone I feel close to who makes me feel secure”) answered with a seven-point Likert scale ranging from 1=Strongly Disagree to 7=Strongly Agree. The items are summed for a total Social Support score (15-105) with higher numbers indicating a higher level of perceived social support in the domains of self-worth, social integration, intimacy, nurturance, and assistance.

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. Reliability estimates for the instrument indicate an internal consistency of Cronbach’s  $\alpha = 0.87-0.93$ . Although social support is not the same as mental health predictors, correlation with mental health indicators for this instrument is good, with Cronbach  $\alpha$  scores ranging from  $\alpha = 0.89-0.95$  (Weinert, 2003). A Cronbach’s  $\alpha$  of .93 was reported in a sample of people with epilepsy (Bishop, Berven, Hermann, & Chan, 2002), and the Cronbach’s  $\alpha$  of 0.94 was found in this study

**Psychological Capital Questionnaire.** The adapted PCQ was developed by Luthans, Youssef, & Avolio (2007) and will be used in this study to measure the personal factor PsyCap. Although the PCQ has demonstrated sufficient validity and reliability, it is specific to a work domain and, therefore, the specific verbiage had to be adapted to a

health domain. Care was taken to keep the original questions as unaltered as possible. This 24-item, self-report questionnaire consists of a 6-point Likert scale (1 = strongly disagree to 6 = strongly agree) and has 6-item subscales designed to measure each of the four psychological constructs of PsyCap (i.e., hope, efficacy, optimism, and resilience). The PCQ is derived from widely-recognized standardized measures for each of the individual psychological constructs and has sound psychometric properties. The foundation for the development of PsyCap is: (a) the Hope Scale (Snyder et al., 1996); (b) the Role Breadth Self-Efficacy (RBSE; Parker, 1998); (c) the Life Orientation Test (Scheier & Carver, 1985); and (d) the Resiliency Scale (Wagnild & Young, 1993). As noted by Luthans, Avolio, et al. (2007), each of these individual measures meets the state-like selection criterion for measuring PsyCap. For example, the selected hope scale was specifically designed to measure “state hope” (Snyder et al., 1996). The Scheier and Carver (1985) scale, although linked to dispositional optimism (or life orientation), has also been associated with and capable of measuring state-like optimism (Shifren & Hooker, 1995). The scales selected to measure resiliency and efficacy are commonly associated with state-like measurement; however, the Parker (1998) efficacy scale diverges with Bandura’s (1997) suggested measurement of specific task magnitude and strength.

According to Luthans, Avolio, et al. (2007), the reliability estimate for total PsyCap was calculated from four sample populations, and the Cronbach’s  $\alpha$  for each component were as follows: hope (0.74, 0.75, 0.80, 0.76), efficacy (0.75, 0.84, 0.85, 0.75), resilience (0.71, 0.71, 0.66, 0.72), optimism (0.74, 0.75, 0.76, 0.79), and overall PsyCap (0.88, 0.89, 0.89, 0.89). Internal consistency reliability for optimism and



resilience were found to be consistently lower than self-efficacy and hope domains (Dawkins, Martin, Scott, & Sanderson, 2013). However, Luthans believed that this difference is because of the reverse-scored items in resilience and optimism scales that can reduce scale reliability (Schmitt & Stults, 1985). The Cronbach's  $\alpha$  results for each of the PsyCap components of the adapted PCQ in the current study are as follows: hope (0.87), efficacy (0.89), resilience (0.60), and optimism (0.55). For the overall PCQ in the current study, Cronbach's  $\alpha$  was calculated to be 0.90.

Each of the four first-order factors have demonstrated discriminant validity in previous studies (Bryant & Cvenegros, 2004; Carifio & Rhodes, 2002; Magaletta & Oliver, 1999; Youssef & Luthans, 2007). PsyCap ratings have been shown to be unrelated to age or education and are not related to the personality dimensions of agreeableness or openness (Luthans, Avolio, et al., 2007). Among the constructs that PsyCap did have positive correlations with are: core-self evaluations (CSE; 0.60), extraversion (0.36), and conscientiousness (0.39; Luthans, Avolio, et al.). Additionally, in the studies with PsyCap, the regression model without the PsyCap composite was found to be significant ( $R^2 = 0.13, p < 0.001$ ); however, the change in  $R^2$  was also significant ( $\Delta R^2 = 0.04, p < 0.001$ ) (Luthans, Youssef, & Avolio, 2007; Luthans, Avolio et al.). This indicated that PsyCap predicted unique variance in job satisfaction which was beyond the two personality traits and core self-evaluations. PsyCap was confirmed to be the greater contributor in predicting affective organizational commitment as the beta weight for PsyCap was largest in the regression model (Luthans, Avolio, et al.).

The study by Luthans, Avolio, et al. (2007) found that PsyCap had a stronger relationship to job satisfaction ( $p < 0.01$ ) than did conscientiousness and extraversion;

however, not as much as Core Self-Evaluations (CSE) and affective organizational commitment had with PsyCap ( $p < 0.001$ ). Studies have reported that the impact of PsyCap is greater in US-based samples than those outside of the US (Avey, Wernsing, & Mhatre, 2011). Additionally, PsyCap's impact varied based on the sample context (e.g., service industry versus manufacturing industry; Luthans, Avolio, et al.). However, it is empirically validated that PsyCap consistently predicted attitudinal and behavioral variances in both varying demographic characteristics and personality traits (Luthans, Avolio, et al.). Additionally, both the self-ratings and ratings by supervisors have shown to be similar with PsyCap, thus indicating an absence of source bias with the instrument (Avey, Reichard, Luthans, & Mhatre, 2011).

### **Procedures**

The Statistical Package for Social Sciences (SPSS) 24.0 for MAC was used to manage raw data and perform all necessary data analysis. Data were analyzed using descriptive statistics, preliminary screening procedures, multiple regression, and hierarchical regression analysis. Descriptive statistics for demographic information included mean and standard deviation for continuous variables and frequency and proportions for categorical variables. Additionally, descriptive statistics for normality, central tendency, and dispersion were computed. The data were assessed to determine whether there was evidence of missing data, outliers, and multicollinearity. Moreover, regression assumptions of linearity, normality, and homoscedasticity were evaluated.

### **Sample Size**

Determining the needed sample size was based on analysis of the number of predictor variables included in the regression analysis, while assuming a medium effect

size (e.g., 0.30) between the predictor variables and the outcome variable (Wampold, Kivlighan, & Heppner, 2008). An *a priori* power analysis using G\*Power 3.1 was performed for the total  $R^2$  value for a multiple regression analysis based on a power of 0.80 at an alpha level of 0.05 to obtain a medium effect size. The necessary sample size was determined to be 62. The 9 independent variables (IVs) include five demographic characteristics (age, gender, race, income, and marital status); one measure of personal factors (PsyCap); one dimension of activity (WHODAS 2.0); and one dimension of environment (social support [PRQ2000]).

### **Statistical Analysis**

**Hierarchical Regression Analysis.** The presumed relationships between the specified constructs of the ICF was evaluated using hierarchical regression analysis (HRA; Cohen, Cohen, West, & Aiken, 2003), which is considered an acceptable technique, particularly when research is conducted in an applied setting (Hoyt, Imel, & Chan, 2008; Hoyt, Leierer, & Millington, 2006). Specifically, HRA was used to investigate the hypothesized relationships between the ICF constructs, PsyCap in particular, and participation. This procedure is useful when multiple predictor variables are evaluated with regard to their predictive capability on one dependent variable. In HRA, the change in  $R^2$  ( $\Delta R^2$ ) represents the variance accounted for by the dependent variables, whereas  $sr^2$  is representative of the shared variance of all of the dependent variables (Hoyt et al., 2008).

In HRA, a predetermined order of independent variables (IVs) are entered into the regression model as sets, based on a predetermined order that is based on hypothesized relationships informed by past research. Given the hierarchical order of entry, HRA

allows researchers to examine incremental variance accounted for by a subsequent set of predictor variables by controlling for the effects of the previously entered predictor set. HRA is also beneficial when there is more than one IV measuring a construct (Hoyt et al., 2008). For this study, the order of entry into the model was based on a theoretical understanding of the ICF framework and the hypothesized contribution of each variable to the measure of the dependent variable participation.

In step 1, the demographic variables (age, gender, income, education, and marital status) were entered as covariates. The variables of race and relationship status were transformed into dichotomous categorical variables to allow for regression analysis.

In step 2, functioning and disease-related variables were entered, which included age at diagnosis, time since diagnosis, and activity (WHODAS 2.0). In this step, the effects of functioning on participation were determined after controlling for demographic factors. The selection personal factors for entry in step 2 was based on the ICF framework and proposed domain relationships where functioning precedes personal factors, environmental factors, and participation (Chan, Gelman, et al., 2009).

In step 3, environmental factors (social support; PRQ2000) were entered, and the effect of environmental factors on participation was determined after controlling for demographics and personal factors. The same theoretical reasoning used in steps 2 and 3, was applied toward choosing environmental factors in step 4. After completing the previously described steps, the unique variance in participation explained by the IVs can be identified.

In step 4, personal factors (e.g., PsyCap and its components) were entered, and the effect of personal factors on participation were determined after controlling for the

demographic characteristics. The theoretical reasoning for this step was based on the same proposed domain relationships, which posits that personal factors precede participation (Chan, Gelman, et al., 2009)

**Mediation Analysis.** Multiple regression analysis was utilized to evaluate mediator hypotheses examining the effect of personal factors on the relationship between health functioning and participation in individuals with PD. In fact, multiple regression is considered by many to be the optimal analysis to evaluate the mediator relationship (Aiken & West, 1991; Baron & Kenny, 1986; Frazier, Tix, & Barron, 2004). Mediation analysis is a crucial part of theory testing and 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 in 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 correlates with the DV. Mediation analysis allows for a better understanding for the mechanisms of change and to explain how an independent variable and dependent variable are related. In this study, mediation analysis was used to examine the role of personal factors (PsyCap) as mediators between health functioning and participation in individuals with PD.

## **CHAPTER FOUR**

### **Results**

The purpose of this study is to develop and evaluate a model of participation for individuals with PD based on the ICF framework with a specific focus on the relationship between functioning with PD and participation and the mediating role personal factors (i.e., PsyCap) in the relationship. Hierarchical regression analysis was performed to evaluate the relationships between the demographic variables and components of the ICF model to determine both their individual and collective influence on participation in individuals with PD. Additionally, mediation analysis utilizing multiple regression analysis was performed to evaluate the potential mediating effect of personal factors (i.e., PsyCap) on the relationship between functioning and participation.

#### **Regression Assumptions**

Data for all predictor and criterion variables were screened for accuracy, data entry errors, multivariate outliers, and normality using SPSS 24.0. Multicollinearity was assessed using the variance inflation factors (VIF) and tolerance. None of the VIF values exceeded 5.0 (Rogerson, 2001) with values ranging from 1.11 to 1.93, and none of the tolerance values were less than .10, ranging from .52 to .90, which together indicate absence of multicollinearity. Additionally, the variables were independent based on a Durbin-Watson of 1.91, which lies between the recommended values of 1 and 2. These findings indicate that no multicollinearity exists within the dataset and that deleting or adding variables was not indicated and would not result in a large change in the coefficients. However, the VIF values for participant age and age at diagnosis were similar and close to the cutoff of 5 (4.90 and 4.64) respectively, and the decision was

made to remove one of them from the model. A post hoc analysis revealed that the  $R^2$  values for age and age at diagnosis were the same (.67), indicating the same amount of variance was accounted by each in the model, and the SE for both variables was also the same (.44), suggesting that the decision was an arbitrary one, and the variable age at diagnosis was eliminated. Outliers for the remaining nine variables were assessed with a  $p < .05$  using the Mahalanobis distance squared index. The Mahalanobis distance was then compared to a chi-square distribution to determine significant outliers. No extreme outliers were identified in the sample; therefore, all 114 completed surveys were included in the final analysis. There was homoscedasticity as assessed by visual inspection of a plot of studentized residuals versus unstandardized predicted values, linearity as assessed by partial regression plots and a plot of studentized residuals against the predicted values, and normality as assessed by the Q-Q plot.

### **Participants**

The sample for this study consisted of adults with a self-reported diagnosis of PD. Although this was a purposive sample of individuals who attended PD support groups, the characteristic differences between the locations of the various groups allowed for the inclusion of participants with a variety of experiences in terms of contextual factors (i.e., environmental differences, personal differences). A total of 114 surveys were completed and all were included in the analysis.

### **Sample Characteristics**

Descriptive statistics for the sample ( $n = 114$ ) are presented in Table 4.1. The sample was comprised of 77 (67.5%) males and 37 (32.5%) females. The participants ranged in age from 36 to 88 ( $M = 68.82$ ,  $SD = 8.30$ ). The age when the first noticeable

symptoms of PD began ranged from 31 to 83 ( $M = 61.19$ ,  $SD = 9.13$ ), and the age at PD diagnosis ranged from 31 to 82 ( $M = 63.32$ ,  $SD = 8.66$ ). The sample was predominantly Caucasian (96.5%), followed by African American (2.6%), and Native American (0.9%). Most of the sample reported being married (80.7%), followed by divorced (7.9%), widowed (7.0%), single (3.5%), and cohabitating (0.9%). The majority of participants (77.2%) reported having attended some level of college, with 15.8% having taken some college courses, 7.9% earning an associate's degree, 24.6% earning a bachelor's degree, and 28.9% completing graduate degrees. Of those who did not attend college, 14% completed high school or earned a GED, 7.0% went to technical or trade school, and 0.9% did not complete high school. For annual household income, 25.4% earned between \$25,001 and \$50,000, 21.1% earned both \$50,001 to \$75,000 and more than \$100,000, 19.3% reported \$75,001 to \$100,000, and 10.5% earned less than \$25,000.

Table 4.1

*Participant Demographic Characteristics*

Variable	<i>n</i> (%)	<i>Mean (SD)</i>
Age		68.82 (8.30)
Age at first signs of PD		61.19 (9.13)
Age at diagnosis of PD		63.32 (8.66)
Gender		
Male	77 (67.5)	
Female	37 (32.5)	
Race/ethnicity		
Caucasian	110 (96.5)	
African American	3 (2.6)	
Native American	1 (0.9)	
Relationship status		
Single	4 (3.5)	



Married	92 (80.7)
Divorced	9 (7.9)
Widowed	8 (7.0)
Cohabiting	1 (0.9)
Education	
Less than high school	1 (0.9)
High school/GED	16 (14.0)
Some college	18 (15.8)
Technical/Trade	8 (7.0)
2-year college degree	9 (7.9)
4-year college degree	28 (24.6)
Graduate degree	33 (28.9)
Household income	
Less than \$25,000	12 (10.5)
\$25,001-\$50,000	29 (25.4)
\$50,001-\$75,000	24 (21.1)
\$75,001-\$100,000	22 (19.3)
More than \$100,000	24 (21.1)

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### Correlational Analysis

Pearson's Product-Moment ( $r$ ) and Spearman Rank ( $r_s$ ) correlations were computed to assess the relationships between the criterion variable (i.e., participation) and the predictor variables and are presented in Table 4.2. The effect sizes ranged from small ( $r = .06$ ) to large ( $r = .86$ ). Participation (i.e. IPA) had a positive and moderate linear correlation with race ( $r_s = .30, n = 114, p < .01$ ); had a negative and small-to-moderate linear correlation with both income ( $r = -.21, n = 111, p < .05$ ) and environmental factors (PRQ;  $r = -.36, n = 111, p < .001$ ); and had a negative and strong linear correlation with personal factors (PCQ;  $r = -.56, n = 114, p < .001$ ). Gender had a

negative and small-to-moderate linear correlation with income ( $r_s = -.21, n = 111, p < .05$ ) and education ( $r_s = -.19, n = 113, p < .05$ ); a positive and small-to-moderate linear correlation with age ( $r = .19, n = 114, p < .05$ ); and a positive and moderate linear correlation with relationship status ( $r_s = .33, n = 114, p < .001$ ). Age had a negative and moderate linear correlation with functioning (WHODAS 2.0;  $r = -.26, n = 111, p < .001$ ) and a positive and small linear correlation with relationship status ( $r = .06, n = 114, p < .001$ ). Relationship status had a negative and moderate linear correlation with income ( $r = -.40, n = 111, p < .001$ ). Race had a negative and small linear correlation with functioning (WHODAS 2.0;  $r = -.19, n = 111, p < .05$ ). Income had a negative and moderate linear correlation with education ( $r = -.28, n = 111, p < .001$ ). Functioning (WHODAS 2.0) had a positive and moderate linear correlation with environmental factors (PRQ;  $r = .36, n = 111, p < .001$ ) and a positive and strong linear correlation with personal factors (PCQ;  $r = .61, n = 111, p < .001$ ).

When each of the four components of the PsyCap construct were examined, hope was the strongest predictor in magnitude for both participation ( $r = -.62, n = 111, p < .001$ ) and functioning ( $r = .57, n = 111, p < .001$ ). All four first-order variables (i.e., hope, efficacy, resilience, optimism) individually were significant predictors of participation and functioning.

Table 4.2  
*Correlations for Variables Used in Hierarchical Regression Analysis*

Var iable	1	2	3	4	5	6	7	8	9	10	11
1. Participation (IPA)	1										
2. Gender	-.09	1									
3. Age	.11	.19*	1								
4. Relationship status	.11	.35**	.25**	1							
5. Race	.29**	-.11	-.03	-.05	1						
6. Income	-.21*	-.21*	-.11	-.29**	-.17	1					
7. Education	-.08	-.19*	.06	.08	-.15	-.28**	1				
8. Age at Diagnosis	-.02	.16	.86**	.21*	-.04	-.22*	.01	1			
9. Functioning (WHODAS-2.0)	-.78**	.01	-.26**	-.09	-.19*	.15	.08	-.08	1		
10. Environment factors (PRQ2000)	-.36**	-.02	-.09	-.14	-.05	.19*	.08	-.02	.36**	1	
11. Personal factors (PCQ-24)	-.56**	-.01	-.13	-.06	-.13	.12	.05	-.05	.61**	.52**	1

*Note.* \*  $p < .05$ , \*\*  $p < .01$

## Hierarchical Regression Analysis

A forward hierarchical multiple regression (HRA), based on *a priori* specifications, was run to determine if the stepwise addition of functioning (i.e., WHODAS 2.0), followed by environmental factors (i.e., PRQ), and lastly personal factors (i.e., PCQ) improved the prediction of participation (i.e., IPA) over the demographic factors entered in step 1. HRA was used to quantify the total variance accounted for by the addition of each of the sets of ICF factors of participation for individuals with PD. The results include  $R^2$ , the change in  $R^2$  ( $\Delta R^2$ ), the unstandardized regression coefficients ( $B$ ), and the standardized coefficients ( $\beta$ ) for all predictor variables for each model. See Table 4.3 for full details on each regression model.

The first step (i.e., Model 1) of the HRA assessed the effect of demographic characteristics (gender, age, relationship status, race, income, and education) on participation for individuals with PD. The demographic characteristics accounted for a small but significant amount of variance in participation [ $R = .391$ ,  $R^2 = .153$ , adjusted  $R^2 = .104$ ,  $F(6,103) = 3.101$ ,  $p < .05$ ], and results indicate that only race is significantly associated with participation [ $\beta = .259$ ,  $t(114) = 2.763$ ,  $p < .05$ ]. These results indicate that non-Caucasians have .259- point decrease in participation score compared with Caucasians.

The second step (Model 2) consisted of the addition of the functioning variable (i.e., WHODAS 2.0) into the model while controlling for demographic characteristics. According to the WHO (2001), when any domain of the WHODAS 2.0 has a 25% or more non-response rate, it should not be included in the simple scoring analysis; therefore, the domain of Work and Education was dropped from the final analysis due to

a 35% non-response rate. The addition of the functioning variable accounted for a significant amount of variance in participation [ $R = .808$ ,  $R^2 = .652$ , adjusted  $R^2 = .629$ ,  $F(7,102) = 27.350$ ,  $p < .001$ ]. The effect of the addition of the functioning variable is further evidenced by the significant ( $p < .05$ )  $\Delta R^2 (.499)$  from Model 1 to Model 2. In Model 2,  $\beta$  for the race variable was reduced from .259 to .120 race was no longer significantly associated with participation. Additionally, the standard error of the estimate ( $\sigma_{est}$ ) is much lower in Model 2 than in Model 1 (.443 vs .689), which indicates Model 2, with the addition of functioning, better predicts participation. The results indicate that on average, when controlling for demographic characteristics, a 1-point decrease in functioning is associated with a .757-point lower participation score in individuals with PD.

The addition of environmental factors (i.e., PRQ) in Model 3, while controlling for demographic characteristics and functioning, suggested that environmental factors did not account for a statistically significant amount of variance in participation [ $R = .813$ ,  $R^2 = .661$ , adjusted  $R^2 = .634$ ,  $F(1,101) = 2.19$ ,  $p = .142$ ]. There was only a .009 increase in  $R^2$  and a .003 decrease in  $\sigma_{est}$  from Model 2 to Model 3, which indicates small, insignificant improvements with the addition of environmental factors. Model 3 accounted for 66.1% of the variance in participation. The  $\beta$  for the race variable increased from .120 to .125 resulting in the association of race being significant in Model 3.

The full model, Model 4, consisted of the addition of the personal factors variable (PCQ) while controlling for demographic variables, functioning (i.e., WHODAS 2.0), and environmental factors (i.e., PRQ) and this variable failed to meet statistical significance [ $R = .813$ ,  $R^2 = .004$ , adjusted  $R^2 = .637$ ,  $F(1,100) = 1.19$ ,  $p = .28$ ]. Although

there was a slight increase in  $R^2$  from Model 3 to Model 4 (.661 vs. .667), and a slight decrease in the  $\sigma_{\text{est}}$  was observed (.440 vs. .439), the results were not significant. Only race and functioning were found to be significant predictors of participation albeit in opposite directions.

Table 4.3

*Hierarchical Regression Analysis for Predictors of Participation*

Variable	Participation							
	Model 1		Model 2		Model 3		Model 4	
	B	$\beta$	B	$\beta$	B	$\beta$	B	$\beta$
Constant	.886		4.247		4.544		4.663	
Gender	-.272	-.175	-.154	-.099	-.141	-.091	-.144	-.092
Age	.011	.123	-.007	-.076	-.006	-.074	-.006	-.071
Relationship Status	.176	.097	.050	.028	.006	.003	-.014	.007
Race	1.033	.259*	.466	.120	.483	.125*	.517	.133*
Income	-.082	-.149	-.056	-.102	-.053	-.097	-.053	-.097
Education	-.020	-.052	.003	.007	.006	.016	.006	.014
Functioning (WHODAS-2.0)			-.625	-.757**	-.596	-.722**	-.552	-.668**
Environment Factors (PRQ2000)					-.005	-.103	-.003	-.066
Personal Factors (PCQ-24)							-.104	-.105
$R^2$	.153		.652		.661		.667	
$\Delta R^2$	.153		.499		.009		.006	
$\Delta F$	3.101*		146.561**		2.551		1.682	

Note. \*  $p < .05$ , \*\*  $p < .01$

## Mediation Analysis

A mediator is a variable that explains the relationship between a predictor and outcome variable(s) (Baron & Kenny, 1986; James & Brett, 1984). In the current study, personal factors (i.e., PsyCap) were hypothesized to mediate the relationship between functioning and participation in individuals with PD. Literature presents various methods of assessing mediation (e.g., structural equation modeling, Sobel test), but in samples of less than 200, multiple regression is the preferred method (Holmbeck, 1997). To validate the regression results, a bootstrapping test will be conducted, which will test for indirect effect and has good statistical properties (Hoyt et al., 2008). The mediation analysis adhered to the assumptions set forth by Baron and Kenny and Frazier, Tix, and Baron (2004), which include:

1. The independent variable (functioning) predicts the dependent variable (participation).
2. The independent variable (functioning) predicts the mediating variable (PsyCap).
3. The independent variable (functioning) and the mediating variable (PsyCap) together predict the dependent variable (participation)

The analysis followed the steps of (a) regressing the criterion variable on the predictor variable to demonstrate a significant relationship between the two, (b) regressing the mediator variable on the predictor to show that the predictor is related to the mediator, (c) regressing the outcome variable on the mediator to show that the outcome variable is related to the mediator, and (d) regressing the outcome variable on the predictor variable controlling for the mediator variable to assess the change in the relationship between predictor and outcome variable.



Figure 4.1 illustrates the standardized regression coefficients for the paths between functioning (WHODAS 2.0) and participation ( $c$ ), functioning and PsyCap ( $a$ ), PsyCap and participation ( $b$ ), and functioning and participation controlling for PsyCap ( $c'$ ). The regression analysis was used to investigate the hypothesis that PsyCap mediates the effect of functioning on participation in individuals with PD. Results indicated that functioning is a significant predictor of participation ( $c$ ),  $b = -.646$ ,  $t(112) = 170.66$ ,  $p < .01$ , and the model is significant,  $F(1,112) = 66.88$ ,  $R^2 = .604$ ,  $p < .01$ . Results also indicated that PsyCap was a significant predictor of participation ( $b$ ),  $b = -.553$ ,  $t(112) = -7.08$ ,  $p < .01$ , and the model was significant,  $F(1,112) = 50.15$ ,  $R^2 = .309$ ,  $p < .01$ . The results of the analysis demonstrate a significant effect of functioning on participation ( $c$ ),  $b = -.646$ ,  $t(112) = -13.06$ ,  $p < .01$ , with a significant model,  $F(1,112) = 170.66$ ,  $R^2 = .604$ ,  $p < .01$ . Lastly, as a result of the significant effect of functioning on participation when controlling for PsyCap ( $c'$ ),  $b = -.581$ ,  $t(111) = -9.37$ ,  $p < .01$ , with a significant overall model,  $F(1,111) = 88.37$ ,  $R^2 = .614$ ,  $p < .01$ , PsyCap was determined to not have a mediating effect between functioning and participation. To confirm this result, the indirect effect was tested using a bootstrap estimation approach with 1000 samples (Shrout & Bolger, 2002). The results indicated that the completely standardized indirect coefficient was not significant,  $b = .065$ ,  $SE = .0617$ , 95%  $CI = -.213, .029$ , with 0 falling within the CI, which confirms no significant effect of the mediator PsyCap. Table 4.1 illustrates summaries for each model.

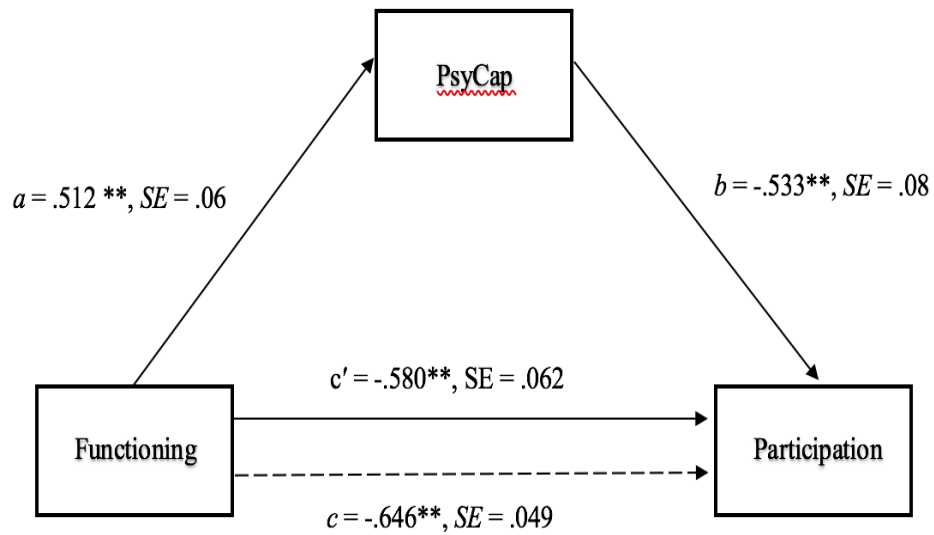


Figure 4.1. Path coefficients for regression mediation analysis on participation ( $n = 114$ ).  
 Note. Dotted line illustrates the effect of functioning on participation without PsyCap as a mediator.  $a$ ,  $b$ ,  $c$ , and  $c'$  are standardized regression coefficients.  
 $*p < .05$ ,  $**p < .01$

Table 4.4

*Multiple Regression Analysis Model Summaries*

Model Path	$R$	$R^2$	$SE$	$F$	$p$
$a$	.612	.374	.578	66.879	< .001
$b$	.556	.309	.603	50.146	< .001
$c$	.777	.604	.457	170.66	< .001
$c'$	.784	.614	.205	88.374	< .001

## CHAPTER FIVE

### **Discussion**

Participation is generally considered one of the most important rehabilitation outcomes for individuals with chronic illness and disability (CID; Chan, Gelman, et al., 2009; Heinemann, 2010). The reduction of the consequences associated with CID and an improvement in participation are important aims not only in rehabilitation but also in health policy (Parenboom & Chorus, 2003). Following years of relying on the disablement model and attributing responsibility for disability to the individual, a paradigm shift has occurred that has changed the focus from a disability- and limitation-focused model to one that focuses on optimizing abilities and participation. A number of factors appear to influence the degree to which an individual with PD engages in the community (i.e., participation), and the ICF model conceptualizes the myriad interactions effecting such outcomes.

A consensus on an accepted definition of participation is lacking, but one commonly cited conceptualization consists of an individual's involvement in a variety of life roles (e.g., vocational, social, family; Fougere et al., 1998; Scherer et al., 2005). However, participation as an outcome measure is not well understood. The ICF provides a conceptual framework that organizes information about health-related conditions, functioning, and contextual factors that contribute to participation. The increased focus on participation as a rehabilitation outcome is reasonable considering its relationship with two other widely accepted outcome measures - subjective well-being and quality of life (Bishop, 2005; Cantor & Sanderson, 1999).

The focus on participation is particularly important for individuals with chronic, progressive conditions like PD. Despite the availability of numerous pharmacologic and medical interventions, PD generally results in a wide range of restrictions that affect participation and, over time, negatively impact QOL (Shulman et al., 2008). Identifying the factors affecting outcomes for people with PD is critically important if interventions to improve participation are to be realized. Increased participation has been demonstrated to be associated with relevant rehabilitation outcomes including both improved employment outcomes and QOL and is largely protective against detrimental outcomes including functional limitations and depression (Chang & Coster, 2014). As a result of the low rates of community participation among individual with PD and the limited research examining the factors related to participation, the purpose of this study was to evaluate participation using the WHO ICF framework as a model for participation and to assess the potential mediating effects of PsyCap on overall participation among individuals with PD.

### **Summary of Findings**

Following the data screening procedures to ensure the assumptions for multiple regression were met, both hierarchical regression analysis and multiple regression were performed to address the research questions. All of the instruments used in the analysis to measure the predictor and outcome measures were assessed for reliability, and the internal consistency reliability estimates ranged from .90 to .96.

### **Correlational Analysis**

Pearson's Product-Moment ( $r$ ) and Spearman Rank ( $r_s$ ) correlations were computed to examine the relationships between participation and the nine predictor

variables among a sample of individuals with PD. The nine predictor variables included: (a) demographic characteristics (e.g., gender [1 = male, 2 = female], age, relationship status [1 = married, 2 = not married], race/ethnicity [1 = Caucasian, 2 = not Caucasian], income, educational attainment), overall functioning (i.e., WHODAS 2.0 [1 = better functioning, 5 = poorer functioning]), environmental factors (i.e., PRQ2000; social support), and personal factors (i.e., PsyCap). A statistically significant positive moderate linear correlation ( $r = .30, p < .001$ ) was calculated for the relationship between the predictor variable “race” and the outcome variable of participation, which, based on the reverse scoring of the IPA instrument, indicates that non-Caucasians participate less than Caucasians. Conversely, statistically significant moderate-to-strong negative correlations were calculated for environmental factors (i.e., PRQ2000;  $r = -.36, p < .001$ ), personal factors (PsyCap;  $r = -.56, p < .001$ ), and functioning (WHODAS 2.0;  $r = -.78, p < .001$ ). Again, due to the reverse scoring of the participation instrument (IPA), a negative correlation actually indicates a positive relationship. Therefore, higher levels of participation were associated with higher rates of functioning, and higher scores on the environmental factors and PsyCap measures. The results of the correlation analysis indicated that only functioning and PsyCap were significantly correlated with participation.

### **Hierarchical Regression Analysis**

Forward hierarchical multiple regression analysis was performed to test the relative influence of the nine predictor variables on participation for individuals with PD. Respondents’ demographics, a variable that consisted of gender, age, relationship status, race/ethnicity, income, and educational attainment were entered into the first block. The

participants' level of functioning score, as assessed by the WHODAS 2.0, was entered into the second block. The respondents' reported environmental factors score, as assessed by the PRQ2000, was entered into the third block. Finally, the respondent's personal factors or PsyCap score, as assessed by the PCQ-24, was entered into the fourth block.

In Model 1, the overall group of demographic characteristics accounted for a significant amount (15.3%) of the variance in participation scores. Among the various demographic variables, only race was a significant predictor of participation. On average, being non-Caucasian is associated with a .259-point increase in participation score, which indicates less overall participation.

In Model 2, the functioning variable was entered and regression was performed controlling for demographic factors to assess the relative contribution of functioning to overall participation among individuals with PD. As a whole, Model 2 accounted for a significant amount (65.2%) of the variance in participation scores. Moreover, the amount of variance accounted for in the model increased ( $\Delta R^2 = .499$ ) significantly from Model 1 ( $R^2 = .153$ ) to Model 2 ( $R^2 = .652$ ) indicating that the addition of the functioning variable, while controlling for demographic characteristics, improved the ability to predict participation. These results are not unexpected given the significantly strong absolute correlation (.78) between functioning and participation. As a result of the functioning variable being such a strong predictor of participation, the significant relationship of the race variable seen in Model 1 was lost. This is indicative that changes in functioning with PD affect every individual in a proportional manner regardless of demographic differences.

Environmental factors as measured by the PRQ2000 were added to Model 3. The addition of environmental factors while controlling for both demographic and functioning variables resulted in a small, non-significant increase in the amount of variance accounted for by the model. We can conclude, due to the strong and significant correlation between functioning and participation and the high amount of variance accounted for by the functioning variable, that environmental factors failed to make any meaningful improvements in the predictive capacity of participation in Model 3.

In Model 4, personal factors or PsyCap scores were added, and the results were similar to Model 3. The addition of PsyCap to Model 4, while controlling for demographic characteristics, functioning, and environmental factors, resulted in small (.006), but insignificant changes in the amount of variance accounted for by this Model, which indicates, again, that because functioning is highly correlated with and a strong predictor of participation that no other blocks of variables contributed significantly to this relationship.

The results of this analysis investigating the predictive capacities of demographic characteristics, functioning, environmental factors, and personal factors on participation among individuals with PD revealed a distinct pattern supporting that decreased functioning alone accounts for significant decreases in participation even when considering the other variables. Regardless of the respondents' demographic characteristics, reported social support, and state-like characteristics making up PsyCap, their reported functional capabilities demonstrated a direct and strong positive relationship with community participation. On average, a 1-point decrease on the functioning scale is associated with a .76-point increase on the participation scale, which

indicates poorer participation. That PD, with the associated significant effects on a number of functioning areas, significantly predicts participation is not altogether surprising. No demographic or contextual factors examined in the model of best fit (Model 2) had any role in predicting participation in this sample of individuals with PD.

Overall, the results of the HRA are not overly surprising given the only small-to-moderate correlations between demographic variables and environmental factors and participation, which suggests that these predictors minimally explain participation. However, personal factors (PsyCap) were moderately-to strongly (-.56) correlated with participation, which suggests that PsyCap explains participation reasonably well and a significant predictive capacity of PsyCap was expected. These findings are, however, consistent with traditional clinical judgement indicating that as one's functioning with PD deteriorates, the amount of participation decreases accordingly. Additionally, because PD is a disease largely associated with advancing age, there are undoubtedly a host of comorbid conditions that also negatively affect functioning and, ultimately, participation, which were not included in the analysis of this study.

### **Mediation Analysis**

In the primary HRA, results indicate that only functioning was a significant predictor of participation among individuals with PD. To further examine this finding and to assess whether PsyCap mediates the relationship between functioning and participation, a mediation analysis using multiple regression was conducted. The analysis demonstrated that (a) functioning strongly predicts PsyCap (path *a*) – on average, every 1-point decrease in functioning is associated with a .512-point decrease in PsyCap; (b) PsyCap strongly predicts participation (path *b*) – a 1-point increase in PsyCap was



associated with a .533-point increase in participation; (c) functioning strongly predicts participation (path  $c$ ) – on average, a 1-point decrease in functioning is associated with a .646-point decrease in participation; and (d) functioning also strongly predicts participation when controlling for PsyCap (path  $c'$ ) – on average, a 1-point decrease in functioning is associated with a .580-point decrease in participation. Due to all of the aforementioned relationships being statistically significant ( $p < .01$ ), it can be concluded that PsyCap does not mediate the relationship between functioning and participation.

For a chosen mediator variable to demonstrate full mediation, the relationship between functioning and participation in path  $c'$  would have to be zero and not statistically significant. Even though there was a small reduction (0.9%) in the ability of functioning to predict participation when controlling for PsyCap, the result did not reach statistical significance indicating that PsyCap does not play a significant role in the relationship between functioning and participation. Both paths ( $c$  &  $c'$ ) maintained the statistically significant predictive capacity of functioning on participation, which also indicates no effect of the mediator variable. This result also points to the strong association between functioning and participation for individuals with PD, which provides further support for the role of interventions aimed at maintaining functioning as being paramount in the treatment for individuals with PD.

### **Clinical Implications**

Rehabilitation researchers have largely embraced participation as a salient outcome measure for individuals with disabilities. This is the first study to specifically assess community participation among people with PD using the ICF as a guiding framework. Parkinson's disease generally leads to limitations in activities of daily living

and negatively affects QOL (Morris, Martin, & Schenkman, 2010; Shulman et al., 2008) As activities become more challenging, individuals with PD may curtail participation in any number of domains (e.g., work, social, leisure). Findings from this study have a number of clinical implications for the field of rehabilitation and individuals with PD.

### **ICF Model**

The ICF model is a comprehensive biopsychosocial model that can allow professionals to more thoroughly understand the myriad interactions that affect outcomes for individuals with CID. Although growing literature exists regarding the prominence of participation as the optimal goal of rehabilitation (Heinemann, 2010), questions persist about the most effective means of conceptualizing and measuring not only participation among adults with CID but the other constructs of the ICF model (Chan, Gelman, et al., 2009). The ICF model is an effective and widely used framework to conceptualize CID and to assess the myriad factors contributing to positive rehabilitation outcomes.

Results of this study support the use of the ICF model as an effective assessment tool for measuring participation among individuals with PD. Although not all of the components of the ICF were determined to significantly predict participation, functioning was largely responsible for the variance in participation among the sample. The WHODAS 2.0 is comprehensive, well-validated, and reliable measure capable assessing numerous constructs (e.g., personal factors, environmental factors, activity), but it was used in this study as a proxy for functioning. And, although functioning was demonstrated to significantly predict participation in people with PD, due to the high correlations between WHODAS 2.0 and the other instruments, the results may be somewhat skewed. However, the results do support the outcomes of previous

investigations (e.g., Bishop et al., 2013; Yorkston et al., 2012) that functional decline is associated with lower levels of community participation.

Although positive psychology, which PsyCap is both consistent with and derived from, may improve mental health and outlook among individuals with CID, it appears in this study not to negate the resultant functional challenges associated with PD and its progression. Therefore, medical rehabilitation interventions that address function must remain, and undoubtedly are, the primary focus of minimizing the negative effects of PD. Interventions and appropriate resources such as exercise, physical therapy, occupational therapy, access to necessary assistive technology, counseling, and connections with local PD support groups are all instrumental dealing with the physical and emotional aspects of disease progression. Having access to and actually engaging in these types of interventions may play an important role in maintaining optimal functioning and, therefore, community participation.

This investigation used only PD symptoms as a proxy for functioning; it neglected a host of other potential issues. Clearly, functioning was a strong predictor of participation, but there may be and likely are other issues that moderate that relationship. Because PD is a disease associated with older age, the chances of having comorbid conditions is considerably greater than for diseases that typically affect a younger population (e.g., multiple sclerosis). Therefore, the relationship between PD and participation may be overestimated; however, the functional challenges associated with PD are no less significant. Health promotion and health screening for secondary conditions should be a critical component to routine care. Maintaining health and engaging in health promoting activities is critical to the management of CID (Lynch &

Chiu, 2009). Having a thorough understanding of the comorbid conditions that accompany individuals with PD and effect functioning is an important endeavor for gaining an accurate picture of life with PD.

### **PsyCap**

PsyCap is a framework for understanding the psychological resources that people use to effectively surmount obstacles in their lives (Krasikova, Lester, & Harms, 2015). Psychological Capital is a higher-order construct representing the combination of four state-like personality characteristics (i.e., hope, efficacy, resilience, optimism), which is associated with achieving successful outcomes in the workplace. PsyCap conceptually fits within the personal factors domain of the ICF but due to the lack of precision in classifying personal factors, challenges persist and remain a cause of uncertainty when employing the ICF model to CID (Duggan, Albright, & LaQuerica, 2008; Hurst, 2003; Smedema, 2014).

Although the results of this study did not identify PsyCap as a significant predictor of participation, nor as a mediator in the relationship between functioning and participation, this study represents the first evaluation of the role PsyCap in a relatively small sample of people with PD, and correlational analyses confirm that continued investigation of these relationships is warranted.

Considering the significant relationship between functioning and participation among individuals with PD, developing clinical interventions, many of which currently exist, aimed at maintaining or slowing the deterioration of functioning is critically important. Empirically validated rehabilitation interventions play a critical role in the ability of individuals with PD to maintain the ability to fully participate in activities they

deem to be personally important. Accordingly, despite the challenges faced by individuals with disabilities, personal assets or characteristics can assist people in overcoming the obstacles and thrive with their disability (Dunn & Elliott, 2008). This study attempted to provide support for the benefits positive PsyCap in assessing participation among individuals with PD and, although the findings did not support the association, it did provide the impetus for additional research into ways to delay functional decline and, ultimately, participation in people with PD.

### **Implications for Future Research**

The results of this study provide support for the use of the ICF model as a framework to predict participation in adults with PD. Additionally, although PsyCap did not mediate the relationship between functioning and participation, it remains a construct of interest in assisting individuals with PD improve outcomes. An important consideration to note is that this study, like most of the available research, is descriptive, correlational, and cross-sectional, which precludes implying causality between functioning and participation. Therefore, to ascertain causal relationships, randomized controlled studies and longitudinal studies should be considered in the future.

The ICF framework is widely considered the most comprehensive model of disability and continues to garner empirical support; however, most studies are conceptual in nature. Notable overlaps, ambiguities, and measurement challenges exist both within and between the ICF constructs, which present substantial limitations preventing a more thorough and precise evaluation of the entire framework. Longitudinal randomized controlled studies should be conducted to further establish appropriate operationalization and validation of the ICF constructs.

Literature indicates that PsyCap can be developed and improved in employees through a variety of interventions (Dello Russo & Stoykova, 2015; Ertosun et al., 2015; Harty, Gustafsson, Bjorkdahl, & Moller, 2016; Luthans et al., 2014). Research needs to be conducted assessing the capability of these interventions to be effective for individuals with CID. The applicability of PsyCap to the world of CID is conceptually evident, but in order to understand the exact relationship, rigorous research needs to ensue.

The mediating effect of PsyCap on the relationship between functioning and participation among individuals with PD was a central target of this study and although no mediation was discovered, future research implications around PsyCap abound. This study illustrated that functioning significantly predicts participation in people with PD, a conclusion that has been reached in many other investigations across a wide range of disabilities. As such, being able to maintain or slow the decrease of functioning appears to be of necessity for individuals with PD to realize improved outcomes. Ensuring, for example, that individuals with PD engage in a consistent exercise regimen is important.

The PD literature recommends that people with PD engage in various types of physical activity from physical therapy to individual and group exercise classes. Exercise has been linked to increased mobility, improved mood, specifically symptoms of depression and anxiety, and has been negatively correlated with the progression of PD (Parkinson's Outcome Report [POR], 2014; NPF, 2014). Although exercise was added to the POR investigative protocol, few participants with PD adhered to the exercise regimen. Limited research is available that assesses the factors that influence exercise engagement of individuals with PD. Similarly, little research has been done assessing the determinants of exercise adherence in chronic illness as a whole.

Problematically, limited research is available evaluating the role of personal factors in predicting adherence to treatment recommendations (e.g., medication, diet, appointments), but the results from one meta-analysis indicate that the personal characteristics of self-efficacy, hope, and optimism are positively correlated with adherence to healthcare advice (DiMatteo, 2004). Moreover, there is a common theme tying the individual constructs of PsyCap together: they all contribute “to a motivational propensity to accomplish tasks and goals” (Luthans, Avolio, et al., 2007, p. 548). Because the current study established the positive predictive capacity of functioning on participation and exercise is positively correlated with functioning in people with PD, it stands to reason that identifying factors that improve one’s exercise habits would be a worthy endeavor. Particularly if those factors are amenable to change (i.e., PsyCap).

### **Limitations**

There are a number of limitations that need to be considered when interpreting the results. First, a cross-sectional purposive sample was used in this study. Participants were recruited from PD peer-led support groups in a Midwestern state. As a result, participants were almost exclusively Caucasian, well-educated, and male. Although the reported ratio of men-to-women is roughly 1.5:1, the ratio in this study was considerably higher (2:1). The use of a convenience sample of those who attend support groups undoubtedly resulted in bias because those who decide to go to support groups are more highly functioning and, therefore, more likely participate more in the community. These limitations limit the generalizability of the findings to all individuals with PD. A larger sample from a more diverse, random pool would have likely resulted in a more generalizable sample.

Second, the study relied exclusively on self-report measures obtained through surveys. Self-report data are vulnerable to error and “affective bias, poor insight, and recent life events” (Atkinson, Zibin, & Chuang, 1997, p. 99). Individual perception and appraisal of community participation is subject to many factors and may result in socially desirable responses. Additionally, the length of the survey (111 questions) may have negatively affected the quality of the responses (Frede, 2010).

Third, no variables other than PsyCap were included in the personal factors construct. As evidenced by the number of available measures that include personal factors, there are certainly other personal attributes that contribute to predicting outcomes in the ICF model. To have a more thorough understanding of the interactions between the constructs of the ICF model a more complete set of secondary variables representing the personal factors domain is needed.

Fourth, the variables assigned to the ICF constructs activity and participation were not specifically differentiated and, therefore, were treated as a single, combined construct. Since the development of the ICF, researchers have noted the difficulty in operationally defining the constructs and particularly in developing a measure of participation. Although there is considerable research discussing the challenges with appropriately differentiating activities and participation, because these two constructs overlap considerably and the WHODAS 2.0 includes both, the decision was made to choose only a separate instrument for the outcome variable – participation. Therefore, the inclusion and exclusion of instruments in this study may not adequately capture and measure all aspects under each of the constructs.



Fifth, the research design is a descriptive correlational study that uses cross-sectional data and, as a result, the directionality of the effects of causality among variables cannot be determined. The study did not actively manipulate variables; therefore, the relationships between predictor and outcome variables cannot be deemed causal.

Sixth, as a result of the PCQ-24 instrument being validated and having reliability demonstrated in a workplace setting only, adaptations were necessary. With the consent of the developer, wording was changed to more appropriately conform to individuals with CID. Although the reliability of the instrument was evaluated in this study, and the Cronbach alpha was comparable to those previously reported, the results must be taken with caution.

Although the identified limitations affect the overall conclusions and subsequent implications of this study, the results provide an initial investigation into the factors affecting participation among individuals with PD and indicate the need for further examination of the role of PsyCap in PD.

### **Conclusion**

This study was novel because it was the only study that has used the ICF model and PsyCap to specifically assess participation among individuals with PD. Overall, the study demonstrated that the ICF framework provide a useful model for predicting participation among individuals with PD. Specifically, functioning, as assessed by the WHODAS 2.0, was the strongest and only significant predictor of participation based on the hierarchical regression analysis. Additionally, PsyCap was determined to not mediate the relationship between functioning and participation. However, as a result of the

medium-to-strong correlation between PsyCap and participation, there remain reasonable optimism of identifying a role for PsyCap in individuals with PD. Additionally, PsyCap was also moderately-to-strongly correlated with both functioning and environmental factors. These significant correlations indicate that PsyCap may play a role in all factors associated with participation found in the ICF model.

As a result of the high correlational and predictive capacity of functioning on community participation for individuals with PD, investigating interventions aimed at maintaining functional capacity and the potential role of PsyCap has emerged as a research opportunity. Considering the ability to develop and improve PsyCap and the reported role of a positive attitude in CID, investigations into how PsyCap impacts individuals with PD may be fruitful.

As participation has emerged as an important outcome goal for rehabilitation efforts for individuals with PD, a shift in the way that rehabilitation interventions are planned and carried out may be warranted. The present investigation provides rehabilitation researchers with initial evidence to support the use of the ICF for predicting participation for individuals with PD and the impact of personal, environmental, and functional factors in achieving positive outcomes.

## Appendix A

### Institutional Review Board (IRB) Approval Letter



Initial Review

Approval Ends:  
4/16/2019

IRB Number:  
44405

TO: Bradley McDaniels,  
Early Childhood, Spec Ed, Reha  
PI phone #: 8592859329  
  
PI email: bradley.mcdaniels@uky.edu

FROM: Chairperson/Vice Chairperson  
Non Medical Institutional Review Board (IRB)

SUBJECT: Approval of Protocol

DATE: 4/17/2018

On 4/17/2018, the Non Medical Institutional Review Board approved your protocol entitled:

The effect of Parkinson's disease on participation: Investigating the role of Positive Psychological Capital.

Approval is effective from 4/17/2018 until 4/16/2019 and extends to any consent/assent form, cover letter, and/or phone script. If applicable, the IRB approved consent/assent document(s) to be used when enrolling subjects can be found in the "All Attachments" menu item of your E-IRB application. [Note, subjects can only be enrolled using consent/assent forms which have a valid "IRB Approval" stamp unless special waiver has been obtained from the IRB.] Prior to the end of this period, you will be sent a Continuation Review Report Form which must be completed and submitted to the Office of Research Integrity so that the protocol can be reviewed and approved for the next period.

In implementing the research activities, you are responsible for complying with IRB decisions, conditions and requirements. The research procedures should be implemented as approved in the IRB protocol. It is the principal investigator's responsibility to ensure any changes planned for the research are submitted for review and approval by the IRB prior to implementation. Protocol changes made without prior IRB approval to eliminate apparent hazards to the subject(s) should be reported in writing immediately to the IRB. Furthermore, discontinuing a study or completion of a study is considered a change in the protocol's status and therefore the IRB should be promptly notified in writing.

For information describing investigator responsibilities after obtaining IRB approval, download and read the document "PI Guidance to Responsibilities, Qualifications, Records and Documentation of Human Subjects Research" available in the online [Office of Research Integrity's IRB Survival Handbook](#). Additional information regarding IRB review, federal regulations, and institutional policies may be found through [ORT's web site](#). If you have questions, need additional information, or would like a paper copy of the above mentioned document, contact the Office of Research Integrity at 859-257-9428.

## Appendix B

### Letter of Invitation and Informed Consent for Parkinson's Disease Survey Participants

Dear Sir or Madam:

You are invited to take part in a research project aimed at addressing issues related to participation for individuals with Parkinson's disease (PD). The project is titled: *Parkinson's disease and participation: The role of Positive Psychological Capital*. We hope to receive completed surveys from about 300 people, so your answers are important to us. Of course, you have a choice about whether or not to complete the survey, but if you do choose to, you are free to skip any questions or discontinue at any time.

The survey should only take about 30 minutes to complete. By doing this study, we hope to learn about the impact of PD on community participation and assess the factors related to participation in desired life activities. You are receiving this invitation because you are an adult affiliated with a Kentucky Parkinson's Disease Support Group. Although you will not get personal benefit from taking part in this research study, we will use the information to better understand the needs of people with PD and to develop responsive programs, services, and information for persons living with PD. It is important to note that there are no more than minimal risks associated with participation in this study.

The person in charge of this study is Bradley McDaniels of the University of Kentucky Rehabilitation Counseling Program. Malachy Bishop, PhD., professor in the University of Kentucky Department of Early Childhood, Special Education, and

Rehabilitation Counseling will serve as an advisor. There may be other people on the research team assisting at different times during the study. Your response to this survey is anonymous, which means no names will appear or be used in research documents or be used in presentations or publications. The research team will not know that any information you provided came from you, nor even whether you participated in the study.

If you have questions about the study, please feel free to ask; my contact information is given below. If you have complaints, suggestions, or questions about your rights as a research volunteer, contact the staff in the University of Kentucky Office of Research Integrity at 859-257-9428 or toll-free at 1-866-400-9428.

If you would like to take part in this research, you are asked to complete a survey.

Thank you in advance for your assistance with this important project.

Sincerely,

Bradley McDaniels, MS, CRC  
Rehabilitation Counseling Program, Department of Early Childhood, Special Education,  
and Rehabilitation Counseling  
University of Kentucky  
Phone: (859) 285-9329  
Email: Bradley.mcdaniels@uky.edu

NOTE: By completing and returning the survey to the investigator, you are giving your consent to participation in this research project. If you do not wish to participate, simply do not complete the survey.

Appendix C

Instrument

**1. What is your gender?**

Male \_\_\_\_ Female \_\_\_\_

**2. What is your age in years?**

\_\_\_\_\_

**3. What is your current relationship status? (Check one)**

Single \_\_\_\_

Married \_\_\_\_

Divorced \_\_\_\_

Widowed \_\_\_\_

Living with significant other \_\_\_\_

**4. What is your primary racial or ethnic group?**

Caucasian \_\_\_\_

African American \_\_\_\_

Latino/Hispanic \_\_\_\_

Asian American or Pacific Islander \_\_\_\_

Native American \_\_\_\_

Other \_\_\_\_\_

**5. Which best describes your annual household income in 2017 (i.e., how much all members of your household earn in one year)?**

- Less than \$25,000 \_\_\_\_
- \$25,001 - \$50,000 \_\_\_\_
- \$50,001 - \$75,000 \_\_\_\_
- \$75,001 - \$100,000 \_\_\_\_
- Greater than \$100,000 \_\_\_\_

**6. Which best describes your formal education?**

- Didn't complete high school \_\_\_\_
- High school graduate or GED \_\_\_\_
- Some college \_\_\_\_
- Technical or trade school \_\_\_\_
- 2-year (Associates) degree \_\_\_\_
- 4-year (Bachelor's) degree \_\_\_\_
- Master's degree or higher \_\_\_\_

**7. At what age did you first begin experiencing signs of Parkinson's disease?**

\_\_\_\_\_

**8. At what age were you formally diagnosed with Parkinson's disease?**

\_\_\_\_\_

For the next few sets of questions, think back over the past 30 days to answer each item. For each question, answer how much difficulty you had with each. For each statement, please choose only ONE response.

**9. In the last 30 days...**

**Understanding and Communication**

Concentrating on doing something for ten minutes?	<b>None</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Extreme or cannot do</b>
Remembering to do important things?	<b>None</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Extreme or cannot do</b>
Analyzing and finding solutions to problems in day-to-day life?	<b>None</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Extreme or cannot do</b>
Learning a new task, for example, learning how to get to a new place?	<b>None</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Extreme or cannot do</b>



Generally understanding what people say?	<b>None</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Extreme or cannot do</b>
Starting and maintaining a conversation?	<b>None</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Extreme or cannot do</b>

**10. In the last 30 days...**

**Getting Around**

Standing for long periods of time such as 30 minutes?	<b>None</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Extreme or cannot do</b>
Standing up from sitting down?	<b>None</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Extreme or cannot do</b>
Moving around inside your home?	<b>None</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Extreme or cannot do</b>

Getting out of your home?	<b>None</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Extreme or cannot do</b>
Walking a long distance such as a mile?	<b>None</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Extreme or cannot do</b>

**11. In the last 30 days...**

**Self-Care**

Washing your whole body?	<b>None</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Extreme or cannot do</b>
Getting dressed?	<b>None</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Extreme or cannot do</b>

Eating?	<b>None</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Extreme or cannot do</b>
Staying by yourself for a few days?	<b>None</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Extreme or cannot do</b>

**12. In the last 30 days...**

**Getting Along with People**

Dealing with people you do not know?	<b>None</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Extreme or cannot do</b>
Maintaining a friendship?	<b>None</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Extreme or cannot do</b>
Getting along with people who are close to you?	<b>None</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Extreme or cannot do</b>

Making new friends?	<b>None</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Extreme or cannot do</b>
Sexual activities?	<b>None</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Extreme or cannot do</b>

**13. In the last 30 days...**

**Life Activities**

Taking care of your household responsibilities?	<b>None</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Extreme or cannot do</b>
Doing most important household tasks well?	<b>None</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Extreme or cannot do</b>

Getting all the housework done that you needed to do?	<b>None</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Extreme or cannot do</b>
Getting your housework done as quickly as you needed?	<b>None</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Extreme or cannot do</b>

**14. In the last 30 days...**

**Participation in Society**

How much of a problem did you have in joining in community activities (for example, festivities, religious, or other activities) in the same way as everyone else can?	<b>None</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Extreme or cannot do</b>
How much of a problem did you have because of the	<b>None</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Extreme or cannot do</b>

barriers or hinderances in the world around you?					
How much of a problem did you have living with dignity because of the attitudes and actions of others?	<b>None</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Extreme or cannot do</b>
How much time did you spend on your health condition or its consequences?	<b>None</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Extreme or cannot do</b>
How much have you been emotionally affected by your health condition?	<b>None</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Extreme or cannot do</b>
How much has your health been a drain on the financial resources of you and your family	<b>None</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Extreme or cannot do</b>
How much of a problem did your family have because of your health problems?	<b>None</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Extreme or cannot do</b>

How much of a problem did you have in doing things by yourself for relaxation or pleasure?	<b>None</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Extreme or cannot do</b>
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**This section is particularly concerned with how your Parkinson’s disease affects your ability to do things when you want and how you want to (Autonomy). Please select only ONE response to each question based on your own perceptions.**

**15.**

**Autonomy Indoors**

My chances of getting around my house <i>where</i> I want to are...	<b>Very Good</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	<b>Very Poor</b>
My chances of getting around my house <i>when</i> I want to are...	<b>Very Good</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	<b>Very Poor</b>
My chances of getting washed and dressed the <i>way</i> I wish are...	<b>Very Good</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	<b>Very Poor</b>

My chances of getting washed and dressed <i>when</i> I wish are...	<b>Very Good</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	<b>Very Poor</b>
My chances of getting up and going to bed <i>when</i> I want to are...	<b>Very Good</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	<b>Very Poor</b>
My chances of going to the toilet <i>when</i> I wish and need to are...	<b>Very Good</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	<b>Very Poor</b>
My chances of eating and drinking <i>when</i> I want to are...	<b>Very Good</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	<b>Very Poor</b>

16.

### Family Role

My chances of contributing to looking after my home <i>the way</i> I want to are...	<b>Very Good</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	<b>Very Poor</b>
My chances of getting light tasks done around the house (e.g., making tea or coffee), either by myself or by others,	<b>Very Good</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	<b>Very Poor</b>



<i>the way</i> I want them done are...					
My chances of getting heavy tasks done around the house (e.g., cleaning), either by myself or by others, <i>the way</i> I want them done are...	<b>Very Good</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	<b>Very Poor</b>
My chances of getting housework done, either by myself or by others, <i>when</i> I want them done are...	<b>Very Good</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	<b>Very Poor</b>
My chances of getting minor repairs and maintenance work done in my house and garden, either by myself or by others, <i>the way</i> I want them done are...	<b>Very Good</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	<b>Very Poor</b>
My chances of fulfilling my role at home as I would like are...	<b>Very Good</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	<b>Very Poor</b>
My chances of choosing how I spend my own money are...	<b>Very Good</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	<b>Very Poor</b>

17.

**Autonomy Outdoors**

My chances of visiting relatives and friends <i>when</i> I want to are...	<b>Very Good</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	<b>Very Poor</b>
My chances of going on the sort of trips and holidays I want to are...	<b>Very Good</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	<b>Very Poor</b>
My chances of using leisure time <i>the way</i> I want to are...	<b>Very Good</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	<b>Very Poor</b>
My chances of seeing people as often as I want are...	<b>Very Good</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	<b>Very Poor</b>
My chances of living life the way I want to are...	<b>Very Good</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	<b>Very Poor</b>

18.

**Social Life and Relationships**

My chances of talking to people close to me on equal terms are...	<b>Very Good</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	<b>Very Poor</b>
The quality of my relationships with people who are close to me is...	<b>Very Good</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	<b>Very Poor</b>
The respect I receive from people who are close to me is...	<b>Very Good</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	<b>Very Poor</b>
My relationships with acquaintances are...	<b>Very Good</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	<b>Very Poor</b>
The respect I receive from acquaintances is...	<b>Very Good</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	<b>Very Poor</b>
My chances of having an intimate relationship are...	<b>Very Good</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	<b>Very Poor</b>
My chances of helping or supporting people in any way are...	<b>Very Good</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	<b>Very Poor</b>

The following questions relate to employment and education; if any questions are not applicable to you in your current situation, please leave blank. Otherwise, please choose the ONE best answer.

19.

**Work and Education**

My chances of getting or keeping a paid or voluntary job that I would like to do are...	<b>Very Good</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	<b>Very Poor</b>
My chances of doing my paid or voluntary work <i>the way</i> I want to are...	<b>Very Good</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	<b>Very Poor</b>
My contacts with other people at my paid or volunteer work are...	<b>Very Good</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	<b>Very Poor</b>
My chances of achieving or keeping the position that I <i>want</i> in my paid or voluntary work are...	<b>Very Good</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	<b>Very Poor</b>

My chances of getting different paid or voluntary work are...	<b>Very Good</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	<b>Very Poor</b>
My chances of getting the education or training I <i>want</i> are...	<b>Very Good</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	<b>Very Poor</b>

Below are some statements that some people agree and others disagree. Please read each statement and select the ONE response most appropriate for you.

20.

There is someone I feel close to who makes me feel secure	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Neutral</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>
I belong to a group in which I feel important	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Neutral</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>
People let me know that I do well at my work	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Neutral</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>

(e.g., job, homemaking)							
I have enough contact with the person who makes me feel special	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Neutral</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>
I spend time with others who have the same interests that I do	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Neutral</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>
Others let me know that they enjoy working with me (e.g., job, committees, projects)	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Neutral</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>
There are people who are available if I need help over	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Neutral</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>

an extended period of time							
Among my group of friends, we do favors for each other	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Neutral</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>
I have the opportunity to encourage others to develop their interests and skills	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Neutral</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>
I have relatives or friends who will help me out even if I can't pay them back	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Neutral</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>
When I am upset, there is someone I can	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Neutral</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>

be with who lets me be myself							
I know that others appreciate me as a person	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Neutral</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>
There is someone who loves and cares about me	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Neutral</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>
I have people to share social events and fun activities with	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Neutral</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>
I have a sense of being needed by another person	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Neutral</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>



For this last set of questions, please read each statement, and select the **ONE** response that you believe most appropriately represents your perceptions today.

21.

I feel confident analyzing a long-term problem to find a solution	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>
I feel confident representing myself with others	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>
I feel confident contributing to discussions with others	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>
I feel confident setting targets/goals for my health	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>
I feel confident contacting people other than my close family and friends to discuss problems	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>

I feel confident presenting information in a group of friends	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>
If I find myself in a jam at home, I could think of many ways to get out of it	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>
At the present time, I am energetically pursuing my health goals	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>
There are lots of ways around any problem	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>
Right now, I see myself as being pretty successful in life	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>
I can think of many ways to reach my current health goals	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>

At this time, I am meeting the health goals that I have set for myself	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>
When I have a health setback, I have trouble recovering from it and moving on	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>
I usually manage health difficulties one way or another	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>
I can be "on my own," so to speak, with regard to my health if I have to	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>
I usually take stressful things in life in stride	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>
I can get through difficult health situations because	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>

I've experienced difficulty before						
I feel like I can handle many things at a time at home	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>
When things are uncertain for me, I usually expect the best	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>
If something can go wrong for me health-wise, it will	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>
I always look at the bright side of things regarding my health	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>
I'm optimistic about what will happen to me in the future as it pertains to my health	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>
With my health, things never work	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>

out the way I want them to						
I approach my health as if "every cloud has a silver lining."	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Somewhat Disagree</b>	<b>Somewhat Agree</b>	<b>Agree</b>	<b>Strongly Agree</b>

**Thank you for your participation in this survey. I hope that the responses will result in additional information and potential interventions to the challenges associated with Parkinson's disease. Please email your responses back to me at:**

**[Bradley.mcdaniels@uky.edu](mailto:Bradley.mcdaniels@uky.edu)**

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## Vita

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### **EDUCATION**

2015 MS, Rehabilitation Counseling  
University of Kentucky

1992 BS, Biology and Chemistry  
Eastern Kentucky University

### **CERTIFICATION**

2015-Present Certified Rehabilitation Counselor (CRC)  
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### **PROFESSIONAL EXPERIENCE**

2014-Present Graduate Research Assistant  
University of Kentucky  
Dr. Malachy Bishop

Fall 2017 - Present Counselor  
Crossroads Counseling, Georgetown, KY.

Spring 2015 Internship in Job Placement.  
Employment Solutions, Lexington, KY. 600 hours

Fall 2014 Practicum in Job Placement.  
Employment Solutions, Lexington, KY. 200 hours

2013-2014 Direct Support Worker  
Private family for a young man with Autism

## **AWARDS**

- 2017 Human Development Institute, University of Kentucky, Conference  
Travel Scholarship Award
- 2015 Institute for Community Inclusion, ExploreVR Open Data Competition  
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## **PUBLICATIONS IN REFEREED JOURNALS**

Bishop, M., Chiu, C-Y., **McDaniels, B.**, Kim, B-J., & Tiro, L. (in press). A population-based investigation of healthcare needs and preferences in American adults with MS. *International Journal of MS Care*.

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vocational rehabilitation in rural, frontier, and territory communities. In D.A.

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**McDaniels, B.**, & Fleming, A. (2016). *Sexual Education for Clients with Intellectual Disabilities: What is the Role of the Transition Rehabilitation Counselor?* NCRE Spring Conference, Newport Beach, CA.

Fleming, A., Bishop, M., Tiro, L., & **McDaniels, B.** (2016). *Critical readings for training in rehabilitation counseling: A modified Delphi study.* NCRE Spring Conference, Newport Beach, CA.

Bishop, M., Rumrill, P.D., Chiu, C-Y., **McDaniels, B.**, & Kim, B-J. *Optimizing multiple sclerosis health care: Health care priorities of Americans with multiple sclerosis.* Paper presented at Annual Meeting of the Consortium of Multiple Sclerosis Centers. National Harbor, MD, June 3, 2016.

Bishop, M., Frain, M., Tansey, T., Rumrill, P., & **McDaniels, B.** *Health care priorities and preferences of Americans with multiple sclerosis.* Annual Meeting of the International Society of Social Sciences and Behavioral Research. Boca Raton, FL, November 13, 2016.

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