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### Promoting Hope and Resilience in Parkinson's Disease

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## Promoting Hope and Resilience in Parkinson's Disease

by

Emily R. Brunner, B.A.

MSW Clinical Research Paper

Presented to the Faculty of the  
School of Social Work  
St. Catherine University and the University of St. Thomas  
St. Paul, Minnesota  
In Partial fulfillment of the Requirements for the Degree of

Master of Social Work

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The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis nor a dissertation.

**Abstract**

The purpose of this project was to explore how or if social workers promote hope and resiliency in individuals' with Parkinson's disease. Using a qualitative design, eight licensed social workers throughout the United States, with between two to thirty years of experience working with individuals suffering from Parkinson's disease. The participants reflected on their experiences and observations of hope and resiliency in individuals with Parkinson's disease. The researcher analyzed data by looking for themes and commonalties between the participant responses during the interviews. The interviews were transcribed and linked to previous related literature. The findings indicated that all of the participants did discuss hope and resilience with their clients. However, the participants address hope and resilience in variety of ways. The participants discussed how positivity, education, depression, and unrealistic hope could influence individuals, families and the community. The findings of the study demonstrated a need for future research in promoting hope and resilience in other chronic conditions

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As many as one million people are currently living with Parkinson's disease. In the United State, 60,000 individuals are diagnosed each year (<http://www.pdf.org>). Parkinson's disease is a neurodegenerative disease that influences an individual's motor, emotional, and mental functioning. Men are more likely to develop Parkinson's disease and as individuals age the probability of being diagnosed with the disease increases (<http://www.pdf.org>). Tanner and Aston (2000) (as cited in Simmons and Tarsy 2006) discussed that Parkinson's disease affects approximately 1 million people in United States. Individuals such as Michael J. Fox and Muhammad Ali have experienced Parkinson's disease (Simmons & Tarsy, 2006). There is not a cure for Parkinson's disease and it does not matter what the socioeconomic status, profession or religion is of an individual (maybe change the format of this sentence to "there has been no identifiable relationship between...and the onset of the disease). Parkinson's disease can affect anyone. Older individuals are more likely to develop the disease. Unfortunately, there are no direct causes for Parkinson's disease nor is there a cure for this debilitating disease. There are remedies meant only to mitigate symptoms of the disease and not the progression.

### **Understanding the Symptoms**

Parkinson's disease is a chronic degenerative neurological condition. This condition affects a person's physical, emotional and mental functioning. Parkinson's disease occurs because of a nerve cell death that occurs in the substantia nigra, which is located in the center of the brain. The substantia nigra is responsible for regulating movements and coordination with the help from a neurotransmitter named dopamine. The

deterioration of the substantia nigra reduces dopamine, which results in the symptoms of Parkinson's disease (Teichberg, 2000).

The symptoms are often subtle and a diagnosis is often made after years of living with the disease. For example fine motor skills may have deteriorated slowly over time such as coordination and hand writing abilities (Simmons & Tarsy, 2006). Waite (2000) discusses five stages of Parkinson's disease that are categorized by the progress of symptoms. The five stages are called "Independent", "Supervision", "Minimal Assistance", "Moderate Assistance", and "Maximum Assistance" (Waite, 2000).

The first stage is considered to be the "Independent" stage. During this stage, individuals are able to function as they did before the diagnosis. However, locomotion such as fine motor skills and speech begin to become slow and rigid. Some individuals notice a difference in hand writing and a tremor may begin to develop (Simmons & Tarsy, 2006).

The second stage is called "Supervision", during in this stage an individual's cognitive abilities and muscle movement become slower. A few examples of this stage is when an individual needs reminders about routines or responsibilities but are able to take care of themselves physically such as grooming, dressing and hygiene (Waite, 2000).

The third stage is "Minimal Assistance" during this stage the individual may be unable to work full-time (Waite, 2000). During the third stage the individual begins to exhibit problems with balance, difficulty walking and trouble with concentrating. An individual may also have difficulty communicating and socializing with others.

Waite (2000) discusses that as the disease progresses into the "Moderate Assistance" stage, an individual can begin to experience difficulty with dressing

themselves, swallowing, and speaking (Waite, 2000). Twenty-four hour care might be needed when an individual enters the last two stages of Parkinson's disease because of the significant increase in disabilities the patient is experiencing. When an individual enters the "Maximum Assistance" stage, is often bedridden with severe rigidity (Waite, 2000).

As the disease progresses the individual can become more and more debilitated. Simmons and Tarsy (2006) discuss different treatments that could be used to aid in reduction of symptoms of Parkinson's disease. Simmons and Tarsy (2006) recommend a regular exercise during early stages of Parkinson's disease. Exercise can help with motor abilities and overall health of the patient. Simmons and Tarsy (2006) also discussed the impact exercise has on mental health. Individuals who have Parkinson's disease often experience depression, anxiety and difficulty with sleep. Some of the recommended exercises that assist with flexibility and stability are yoga and tai chi (Simmons & Tarsy, 2006). Medications are also used to assist with motor and non-motor symptoms of the disease. Medications with dopamine agonist are used to help with coordinated movements and tremors. However, medications interventions can have adverse side effects and are not always helpful. Individual's independence and disabilities may fluctuate because of different medications.

Waite (2000) discusses the phenomena of the "on-off" effect. The "on-off" effect is when the medication has an effect during the beginning of use but wears off and the symptoms quickly return (Waite, 2000). Confusion and the diagnosis of dementia can also occur as the patient progresses in later stages of the disease (Waite, 2000). The medication interventions can be beneficial to some individuals, especially if the



individuals adhere to doctor recommended medication regimens. Surgeries such as Subthalamic nucleus deep-brain stimulation can be beneficial to some individuals with Parkinson's disease (Simmons & Tarsy, 2006). Electrodes are implanted in the individual's brain and then pulse generator is placed in the chest. The goal of this procedure is to help reduce the "off" effect of medication (Simmons & Tarsy, 2006). Unfortunately, some medication and surgeries are unable to help with the physical symptoms of Parkinson's disease and can have even worse side effects such as hallucinations and paranoia (Simmons & Tarsy, 2006).

Erickson and Muramatsu (2004) address how medication can assist with symptoms of depression. According to Erickson and Muramatsu (2004), depression is often found in people with Parkinson's disease but is often mistaken for symptoms of the disease. The symptoms include difficulty-concentrating, loss of emotional affect, weight loss, and sleep disturbances (Erickson & Muramatsu, 2004). Erickson and Muramatsu (2004) discuss that depression and medication adherence can go hand and hand. If an individual has depression it is difficult for them to stay on the recommended medication regimen and by not taking the correct amount of medication, depression can occur. Therefore, it is important for patients and caregivers to be educated about medication and the high risks for depression.

### **Impact of Disease on Society**

As individuals continue to age, the likelihood of developing Parkinson's disease increases. Parkinson's disease has an intense impact on the individual in every aspect of their lives. In order to combat the symptoms of Parkinson's disease individual are instructed to use medical interventions such as medication. There are countless

medications used to reduce symptoms. The medications used to reduce symptoms can be extremely expensive for individuals. With the progression of the disease individuals might need considerable help or resources that are costly. Depending on the individual and their stage in the disease they might be unable to work. The individual's inability to work might put more pressure on their significant other or family members to help pay for the patient's care. In the United States, it is estimated that indirect and direct costs of treatments for Parkinson's disease are around 25 billion dollars per year (<http://www.pdf.org>). Some surgeries can cost up 100,000 dollars (<http://www.pdf.org>). The costs associated with medical interventions are expensive but completely necessary to help reduce some symptoms of diagnosed with Parkinson's disease.

Another cost stimulated by the diagnoses of Parkinson's disease is the profound effect the disease has on the family. Sprinzeles (2000) discusses how impairments can influence an individual's perception of themselves. Individuals with an impairments or disabilities tend to have a negative perception of themselves and have feelings of embarrassment or resentment (Sprinzeles, 2000). Spouses and children can also have these feelings towards the individual with limitations. Spouses and children may have to take on more responsibilities to help compensate for the individual with Parkinson's disease. Therefore, family members may have to give up activities and dreams of their future (Sprinzeles, 2000). Richardson and Barusch (2006) discuss how caregivers can often feel alienated and struggle with acceptance of a chronic disease. Sprinzeles (2000) explains that families with disabled men have higher reports of seeking counseling because of the significant impact the disabilities have on the family. Sprinzeles (2000) and Richardson and Barusch (2006) discuss how economic pressures are one of most

significant reasons for stress for families. Depending on the progression of the disease, an individual may have to leave their job causing the spouse to bear the entire financial burden. Caregivers of individuals with Parkinson's experience physical and emotional fatigue and can isolate themselves from peers (Sprinzeles, 2000). The financial and emotional costs of this disease are too much. Therefore, we must turn to different treatments to help both individual and families throughout the progression of the disease.

### **Treatment Responses to Parkinson's**

#### **Surgeries and Medications Interventions**

The Parkinson's Disease Foundation was able to provide information about different types of medication that are the most beneficial to reducing symptoms of Parkinson's disease. Some prescription medication categories are Levodopa therapy, Dopamine Agonists, Anticholinergics, MAO-B inhibitors, COMT inhibitors, and other over-the-counter medications (<http://www.pdf.org>). Research is still being done to investigate the effectiveness of over the counter medications such as vitamin E or vitamin C (<http://www.pdf.org>). Each medication intervention comes with advantages and disadvantages. With each medication there are different side effects and no one drug is able to cure Parkinson's disease. Some individuals do not benefit from pharmacological interventions and turn to surgeries.

Deep Brain Stimulation surgery is a procedure when electrodes are inserted in the brain, the correct location is found using MRI and neurophysiological mapping. An impulse generator is then placed in the individual chest near the collarbone (<http://www.pdf.org>). The generator is able to send electrical impulses to the brain. The individual receives a controller that helps control the impulses and turns the generator on

and off (<http://www.pdf.org>). Surgery is a great for reducing symptoms of the disease. However, an individual must qualify for the surgery. (<http://www.pdf.org>). Researchers are trying to find therapies that help improve the quality of life for individuals suffering from Parkinson's disease.

### **Social Services Interventions**

Individuals can receive a wide range of types of therapy such as surgeries, medications, physical therapy, and occupational therapy. Most of these therapies focus on the physical symptoms of the disease. However, a disease effects more than the body, it effects the mind and soul of the individual. Social services are able to address the emotional and psychological stresses that come from having a chronic disease like Parkinson's disease. Support groups and social supports are able to help caregivers maintain their health (Monahan & Hooker, 1997).

### **Aging in the United States**

According to Scharlach, Damron-Rodriguez, Robinson, and Feldman (2000), the proportion of older adults in the United States has tripled since the 1990s. In the year 2030, more than 20 percent of Americans will be 65 or older (Scharlach et al., 2000). The limitations older adults face significantly impacts several aspects of their own life as well as others around them. Depression and suicide are concerns that social workers need to be able to address. Older adults are dealing with many struggles such as financial burdens, loss of functioning, loss of significant others, and in some cases loss of residence. As a result of the current increase in life expectancy, more and more individuals are becoming dependent on social services as well as their families. The dependence of family members can strain the relationship, and cause the caregiver to

become depressed. The same problems are escalated when a chronic illness is present. The prevalence of being diagnosed with Parkinson's disease as older adults' age is important for social workers to address. All chronic illnesses challenge a person's quality of life.

### **Role of Social Work**

Berkman, Gerdener, Zodikoff, and Karootyan (2005) discussed the increase in the proportion of older adults in the United States and how it will influence many areas within our society. Berkman et al. (2005) argues that the increase of proportion of older adults will influence the society's healthcare systems and financial systems. Social workers can help in many ways, ranging from systemic efforts and advocacy to individual or family care with the change by understanding aging, families and healthcare systems. Social workers are able to help with family dynamics, caregiver burnout, and improving quality of life. By fostering hope, the social worker can increase supports to help the family and let the family know they are not alone in combating the disease. Social workers are able to provide education and increase awareness to help reduce the stigmas associated with Parkinson's disease.

The purpose of this research study is to address quality of life in individuals with Parkinson's disease. I will examine different methods social workers use to help promote hope and resilience in individuals with Parkinson's disease. I will do this by interviewing social work professionals who interact with individuals with Parkinson's disease throughout their social work practice. I hope to gain a great knowledge on how to promote hope in individuals with Parkinson's disease in order to increase the individuals overall quality of life.

### **Literature Review**

Individuals with Parkinson's still have dreams and aspirations. Unfortunately, the progression of the disease, threatens these dreams and aspirations of individuals with Parkinson's disease. Social workers must work to help foster dreams and future aspirations. A way to do this is by empowering individuals to be resilient and to have hope. Before a social worker can promote hope and resilience they must first understand the important role that they play. This review of the literature regarding symptoms, loneliness, caregivers, and quality of life helped demonstrate the need for the promotion of hope and resilience in individuals with Parkinson's disease.

Parkinson's is more than a medical condition; it effects and also alters lives because of changes in losses. Throughout the progression, some individuals who are diagnosed with Parkinson's disease are robbed of their dignity, autonomy and ultimately their identity. As individuals age, they have this vivid image of themselves and their life. A chronic illness can shatter dreams and cause feelings of frustration and hopelessness. In order for a social worker to be effective when working with individuals with Parkinson's disease they must first understand the symptoms of the disease.

### **Ambiguous Loss**

Boss (2006) describes two types of ambiguous loss. The first type of loss is when there is a physical absence with an emotional or psychological presence. The second type of ambiguous loss is when an individual is physically present, but has become emotionally or psychologically absent. Individuals who are physically present but emotionally absent are individuals' who often have mental or physical illnesses that take away memory or emotional expression (Boss, 2006). Individuals suffering from

Parkinson's disease are constantly losing aspects of their daily living capabilities, dignity and ultimately their identity. The progression of the disease is ambiguous and can occur slowly or very quickly. Tickle-Degenen and Lyons (2004) discuss the masking symptom that often occurs in Parkinson's disease. Tickle-Degenen and Lyons (2004) were able to demonstrate how the loss of emotional expression can influence an individual ability to understand an individual's with Parkinson's needs.

### **Perceptions of Outsiders**

Individuals with Parkinson's still have desires to connect, interact and be an involved within the community. However, individuals with physical disabilities find it difficult to interact with the general public because of their impairments due to the progression of the disease. Tickle-Degenen and Lyons (2004) investigated how the expressive mask symptom of Parkinson's disease can influence a practitioner's impression of the individual. The expressive mask of Parkinson's disease is considered to be a reduction bodily, facial and vocal spontaneity (Tickle-Degenen & Lyons, 2004). The masking symptom is cause by the reduction of dopamine that assists with coordinated and smooth movements or coordination. With the reduction in spontaneous and smooth muscle movement the face becomes rigid. Thus, causing the face to look more like a "mask". Verbal and non-verbal forms of communication help individuals understand and observe an individual's character. If an individual is unable to respond in a timely manner or in "socially acceptable way", there are misperceptions of an individual. Therefore, reduce the individual's quality of life (Tickle-Degenen & Lyons, 2004). The expression-masking symptom reduces the individuals with Parkinson's ability express themselves effectively. Tickle-Degenen and Lyons (2004) observed how masking

symptoms of Parkinson's could influence novice and expert practitioner's impressions of the individual's personality.

Six individuals with Parkinson's disease participated in Tickle-Degenen & Lyons (2004) expressive masking research study. Five of the participants were male and there was one female utilized in this study and their age ranged from 49-79 years old. Thirty novice practitioners and 50 expert practitioners were used for this study. Each Parkinson's patient was videotaped and categorized into three different masking groups. The three groups were low, intermediate and high expressive masking. After viewing the videotapes of the Parkinson's patients, the practitioners used the NEO-Five Factor inventory to rate their perceptions of the patient's personality. The patient then used the same inventory to rate their own perceptions of their personality.

The results of this study revealed that the more pronounced an individual's masking symptom, the more likely the practitioners would attribute less positive personality traits to the individual. The study was able to demonstrate that the practitioners were focused on the individual's expressivity of their voice, body and face. The novice practitioners were more likely to be inaccurate when passing judgments on an individual personality. Novice practitioners incorrectly perceived individual with more masking as neurotic (Tickle-Degnen & Lyons, 2004). The expert practitioners were able to be more sensitive to the masking symptom. However, the expert practitioners still incorrectly perceived an individual personality because of expressive cues. Tickle-Degnen and Lyons (2004) were able to explore misperceptions and individuals with Parkinson's disease can often be misinterpreted or misunderstood. Misunderstanding of individual with a progressive disease like Parkinson's disease can lead to ineffective



treatment. Therefore, it is important to be aware of how individuals perceive each other and if the interpretations are correct.

### **Perceptions of Patients**

Rokach, Lehcier-Kimel, and Safarov (2006) further explored social expectations of individuals and how appearance can greatly influence an individual's perception of another person. Rokach, Lehcier-Kimel, and Safarov (2006) explained the social expectations of individual's in North America. Appearance, activities and roles are valued, whereas, individuals who do not fit the "norm" or expectations are stigmatized. The "social norms" can be damaging to individuals who have profound physical disabilities. For example, Rokach et al. (2006) discussed how physical disabilities could negatively influence individuals' psychological perception of themselves. The stigmatization and negative psychological perception of oneself can foster feelings of loneliness (Rokach et al., 2006).

Rokach et al. (2006) discussed the significant effect physical disabilities have on an individual's quality of life. Rokach et al. (2006) examined loneliness in individuals who have physical disabilities. Individuals who were considered to have a physical disability were then placed in five different subgroups. The five groups included: multiple sclerosis, osteoporosis, Parkinson's disease, arthritis and "other" disabilities (Rokach et al., 2006). Each subgroup was then compared to individuals who did not have any physical disabilities. Rokach's et al. (2006) study was able to recruit two hundred and seventy people with physical disabilities and three hundred and nineteen people nondisabled individuals to participate in the study (Rokach et al., 2006). A 10-minute questionnaire with 30 questions was used to measure the participants experience with

loneliness. Five factors were revealed with themes of loneliness in the participants. The five factors were described as *Emotional distress*, *Social inadequacy and alienation*, *Growth and discovery*, *Interpersonal isolation* and *Self-isolation* (Rokach et al., 2006).

The overall results of this study demonstrated that individuals with physical disabilities scored higher in the areas of *Emotional distress*, *Social inadequacy and alienation* and *Self-isolation* than the nondisabled participants and lower on *Growth and discovery* (Rokach et al., 2006). The subscales showed that individuals with physical disabilities are more likely to experience feelings of inner turmoil, hopelessness, social detachment, and rejection (Rokach et al., 2006). Whereas, the nondisabled participants scored higher on *Growth and discovery* subscale. The *Growth and discovery* subscale demonstrates how an individual is likely to capture positive growth, inner strength and resourcefulness (Rokach et al., 2006). The results of this study were able to highlight the importance of understanding the intense feelings and experiences of individual's with physical disabilities with regard to loneliness and quality of life. Rokach et al. (2006) discussed the need for future research in providing emotional coping strategies for individuals with physical disabilities.

The experience of loneliness can occur in individuals with Parkinson's disease and coping strategies are important when faced with a chronic illness. To increase an individual's quality of life and increase coping strategies a social worker must understand how individuals with Parkinson's disease view themselves.

Schenkman, Cutson, Zhu and Whetten-Goldstein (2002) investigated the progression of Parkinson's disease and how the progression influenced the patient's perceptions of their experiences with the disease, health and mortality throughout the

course of three years. One hundred and nine patients were interviewed (Schenkman et al., 2002). The semi-structured method was used for the interviews. Seventy-eight men and 30 women with ages ranging from their late 50 to late 80s were the subjects for this study (Schenkman et al., 2002). The results demonstrated the importance of knowing how an individual's perception over time when facing a chronic illness. Schenkman et al. (2002) discussed three categories of responses, "Functional limitations, impairments, and social/emotional problems". Limitations were considered to be loss of independence, decrease in active daily living skills (dressing, eating, grooming), change in lifestyle, and coordination. The responses that would fall under the impairments category would be rigidity or stiffness, tremor memory loss, pain and fatigue. Emotional or social problem responses included items such as fear of the future, concerns about disease progression, embarrassment, stigma and concerns about being an economic burden.

The participants were more likely to discuss their functional limitations as burdensome than impairments in open ended questions. However, when asked specifically about impairments during structured questions, participants recognized tremors and rigidity as impairments (Schenkman et al., 2002). The discrepancy between the structured and open-ended questions was the discussion of impairment vs. limitation. Participants' focused on the one specific issue that was burdensome to them at that time. Schenkman et al. (2002) discussed the importance of understanding this difference between an "experts" concerns and the actual patients concern.

Another interesting finding from Schenkman et al. (2002) was the participant's perception of surviving for 10 years after their diagnosis. Nearly 17 individuals passed away before the study concluded even though they had a high percentage of living for 10

more years with diagnosis of Parkinson's disease (Schenkman et al., 2002). Many of the women participants were hesitant to answer the question about mortality. Some of the women were encouraged not to answer by their husbands (Schenkman et al., 2002). This is important to note and be aware of the influence others can have on patients.

Schenkman et al. (2002) also analyzed the differences in the participants' perception throughout the duration of the study. Schenkman et al. (2002) discussed year 3 of the study, many of the participants did not recognize other problems, limitations or impairments with Parkinson's disease. Schenkman et al. (2002) argued that this change in perception could be a result from adjusting or coping with the disease. Another perception that changed was the individual's perception of mortality by year 3.

Schenkman et al. (2002) found that those who did not answer the question about where they saw themselves in 10 years were more likely to die by the third year of the study when compared to the participants who answered the question. Schenkman et al. (2002), further discussed that the individuals who could not answer the question were less likely to be able to cope with Parkinson's disease. Schenkman et al. (2002) explored how an individual's perception would change throughout the progression of Parkinson's disease. This study was able to highlight the importance of knowing the needs or perceptions of individuals with Parkinson's disease or any chronic illness.

### **Caregivers**

Individuals with Parkinson's are experiencing numerous losses. As the patient is suffering, the individual's families and caregivers are also suffering. Stella, Banzato, Quagliato, Viana and Christofolletti (2009) discuss neuropsychiatric symptoms. Stella et al. (2009) investigated how neuropsychiatric symptoms can influence an individual with

Parkinson's disease quality of life and caregiver burden. During this study, Stella et al. (2009) utilized semi-structured interviews of 50 patients with Parkinson's disease who have been using medication as treatment for two years. The patients' caregivers were also included in the study. The participants were separated into three groups: individuals with major depression, individuals with dementia and individuals who were non-depressed and non-demented (NDND) (Stella et al., 2009). The caregivers of the patients were separated into the corresponding group in which their patients were matched. Stella et al. (2009) assessed the neuropsychiatric by using the Neuropsychiatric Inventory (NPI) which is able to measure behaviors such as "delusions, hallucinations, agitation/aggression, depression, anxiety, elation/euphoria, apathy, disinhibition, irritability, motor behaviors, sleep disturbances and appetite changes" (Stella et al., 2009). The NPI is able to measure behaviors four weeks before evaluation.

The results of the interviews and NPI measured the quality of life of caregivers. The study revealed that individuals who suffered from Parkinson's disease and dementia had more neuropsychiatric symptoms. Their caregivers also expressed greater burden when compared to the other two groups. The depressed group had more burden and neuropsychiatric symptoms than the NDND group. This study revealed the intense impact dementia and other neuropsychiatric symptoms could have on individuals and caregivers' burden. Stella et al. (2009) is able to demonstrate the importance of being aware of caregiver burden and an individual quality of life.

### **Determinants of Quality of life in Parkinson's disease**

Soh, Morris and McGinley (2011) conducted a systematic literature review that examines clinical factors and demographics that influence the quality of life in

individuals with Parkinson's disease. The demographic factors observed were age, sex and employment status and the clinical factors were severity/duration of disease and Parkinson's symptoms (Soh et al. 2011). Soh et al. (2011) reviewed 29 full-text reports that helped further explain health-related quality of life. Three categories were found: health status, utility of health, and wellbeing (Soh et al. 2011). Within this study there were three major contributors to overall decrease in health-related quality of life. Depression was considered to be one of the significant reductions in health-related quality of life. Disability and severity of disease was also found to negatively affect health-related quality of life. Motor symptoms were also observed to impact overall health-related quality of life (Soh et al. 2011). Soh et al. (2011) discussed that individuals with Parkinson's disease who are depressed, in progressed stages and have a significant level of disability are more likely to have reduced health-related quality of life. Within this study there were numerous limitations. The focus of health-related quality of life was put under three categorizes. However, the concept of quality of life is broad and many other aspects can influence the concept besides health (Soh et al, 2011). The review of information was limited because this study did a critical literature review of pervious research. Therefore, this study was limited by the previous studies individual research topics. For example, support and coping strategies were not addressed during this study (Soh et al. 2011).

### **Optimism and the Quality of life in Parkinson's disease**

Gruber-Baldini, Ye, Anderson and Shulman (2009) investigated if an individual's health-related locus of control, optimism and pessimism influences their quality of life. According to Gruber-Baldini et al. (2009), health-related locus of control is the extent to

which the individual believes that their health is controlled by external or internal factors. Individuals with internal locus of control believe that their actions and behaviors are responsible for their health or events (Gruber-Baldini et al., 2009). Whereas, individuals with external locus of control believe fate, chances or other with power influence events or their health (Gruber-Baldini et al., 2009). Individuals who have optimistic personality traits are more likely to anticipate outcomes to be positive. However, individuals who have a pessimistic personality trait are more likely to anticipate outcomes to be negative. Gruber-Baldini et al.'s (2009) study specifically addressed individuals with Parkinson's disease locus of control, optimism and pessimism and the concepts influence on the individuals' quality of life.

During the months of September and October in 2003, 99 patients with Parkinson's disease from University of Maryland Parkinson's and Movement disorders Center participated in the Gruber-Baldini et al. (2009) study. Optimism and pessimism was measured by the Life Orientation Test and locus of control was then assessed by the Multidimensional Health Locus of Control Scale. The results of this study revealed that individuals with better mental health quality of life were associated with greater optimism and less pessimism. Another interesting finding was that higher internal locus of control was associated with less disability but not quality of life (Gruber-Baldini et al., 2009). These results showed that other factors can influence an individual with Parkinson's life. This study revealed that the severity of the disease and disability or quality of life is influenced by the progression of the disease and symptoms. For example, some individuals may have severe disabilities but does not view themselves as severely disabled and therefore may have higher quality of life.

The main finding was that locus of control and optimism or pessimism played a large role in an individual's quality of life (Gruber-Baldini et al., 2009). Gruber-Baldini et al. (2009) believed that throughout the progression of Parkinson's disease, individuals' loss their independence and in turn their mental health quality of life might deteriorate. However, an interesting finding was that there was not an association with progression and severity with quality of life (Gruber-Baldini et al. 2009).

This lead Gruber-Baldini et al. (2009) to speculate that individuals who are more optimistic might report they are doing well and might be more proactive with care. These speculations needed to be further addressed in future research with Parkinson's disease. Gruber-Baldini et al. (2009) study revealed that individuals with higher optimism are associated with a better quality of life and decreased in disability. Therefore, interventions for promoting positivity and internal locus of control might be helpful when working with individuals with Parkinson's disease.

Robottom, Gruber-Baldini, Anderson, Reich, Fishman, Weiner and Shulman (2012) investigated the relationship between resiliency and Parkinson's disease. Resilience is an individuals' ability to adapt when faced with adversity (Robottom et al. 2012). Previous research found that resilience was associated with cognitive factors, social supports and connection with their environment, however, little research has been done on resilience in individuals with Parkinson's disease. (Robottom et al., 2012). Robottom et al. (2012) had 83 participants from University of Maryland Parkinson's Disease and Movement Disorder Center participate in the study from October 2006 to December 2006. The instruments used were University of Maryland Quality of Life and



Function study questionnaire, Unified Parkinson's Disease Rating Scale, Resiliency Scale, Life Orientation Test and Locus of Control Test (Robottom et al. 2012).

The findings of this study revealed that resiliency in Parkinson's disease is associated with less disability, better health-related quality of life, reduced non-motor symptoms such as depression, and fatigue. The personality trait of being optimistic also revealed to be associated with resilience in individuals with Parkinson's disease (Robottom et al., 2012). However, resiliency was not associated with disease severity. According to Robottom et al. (2012) higher resilience has been associated with less depression. Findings imply that resilience was also associated with more optimistic personality traits (Robottom et al., 2012). Discussion of the severity of the disease was also examined. Robottom et al. (2012) explained that resilience is independent from physical function in Parkinson's disease. Therefore, as the disease progresses, the individual might not lose their resilience.

Robottom et al. (2012) discussed future research and how resiliency can be fostered in individuals with Parkinson's disease. Robottom et al. (2012) discussed the promotion of involvement and social supports might influence an individual's resilience with facing a chronic illness like Parkinson's disease.

### **Promoting Hope**

"Hope is defined as belief in a future good. It is a positive belief with the expectation of fulfillment. It is believing that suffering can stop and that comfort is possible in the future" (Boss, 2006, p. 177). Boss (2006) discussed that hope is an ever-changing process. In order for an individual to have hope, they must reevaluate and discover attainable goals. Part of the reevaluating process is finding new meaning in a

person's life. In order for an individual to find *meaning*, they must be able to understand or make sense of their own situation (Boss, 2006). For example, an individual who is diagnosed with Parkinson's or a chronic disease can often wonder why they were given the diagnosis. Therefore, it is important for social workers to help the individual process, understand, and finding meaning in their diagnosis.

Bergin and Walsh (2005) addressed the role of hope in psychotherapy in older adults. In this study, Bergin and Walsh developed a practice model based on Frank's (1971) therapeutic factors in psychotherapy. Community based studies and psychotherapy of hope in older adults facing chronic illnesses were also used to help form this practice framework. Three types of hope were explored when working with older adults. Bergin and Walsh discussed that individuals who fall under this category are likely to have little experience with psychotherapy and have established trusting relationships. These individuals may have just had a diagnosis or sudden change in their lives. The approach used when working with these individuals is a two-step process: 'challenging unrealistic hopes' and 'reinstallation of realistic hope' (Bergin & Walsh, 2005). An example of unrealistic hope is when an individual has a stroke and expects to regain their full body functioning again. The unrealistic hope can affect the patient's inability to expect their limitations and permanent disability. The goal of the psychotherapist should promote realistic goals for therapy. Realistic goals help foster hope, if goals are unattainable then the individual it will be detrimental to the individual. An example of realistic hope is instilling that life can still be satisfying regardless of their new limitations. By helping a client adjust to their limitations and capitalize on the

client's strengths and skills the therapist can help them remain their quality of life (Bergin & Walsh, 2005).

The second type of hope work is "work of despair" (Bergin & Walsh, 2005). Within this type of work the clients might be linked to having mental health problems. This type of work revolves around realistic assessment of the client's life. The therapist is able to help the client to analyze dissatisfying and satisfying experiences within their life and how they can remain balanced (Bergin & Walsh, 2005). These clients once again must have realistic hope.

The third type of hope work is "surviving not thriving" (Bergin & Walsh, 2005). The clients who fall under this category of work usually have significant psychological trauma or persistent mental health problems (Bergin & Walsh, 2005). The therapist role is to help the client realize that the adult has met old age regardless of their past experiences. The therapist can discuss that the individual persevered and developed coping skills when others did not help them. The therapist may want to help the client with developing more functional coping strategies (Bergin & Walsh, 2005).

Bergin and Walsh (2005) discussed the importance of promoting realistic hope in older adults. Bergin and Walsh (2005) were able to demonstrate how psychotherapists can use hope work in older adults by different methods with clients at a variety levels. This study is able to shed light on how individuals with Parkinson's disease could benefit from hope work. Little research has been done on promoting hope in individuals who are diagnosed with Parkinson's disease.

### **Hope in Social Workers**

Koenig and Spano (2006) discuss the importance of professional hope when working with older adults. Koenig and Spano (2006) explore the need for social work professionals to address how they have hope when working with older adults. At times old age can be associated with negative experiences. However, Koenig and Spano (2006) believe that it is imperative for social work professionals to have hope in order to promote hope in older adults. According to Koenig and Spano (2006) hope is considered to be a multidimensional concept. An individual's ability to have hope is based on six components. The six components are: behavioral skills, spirituality, cognitive skills, environmental skills, time-orientation and confidence. Behavioral skills are considered to be coping skills when faced with life challenges. Spirituality assists with an individual's ability to have endurance when faced with difficulties. Cognitive skills are considered to be skills of motivation and goal development. Environmental support also contributes to hope. For example, if an individual has financial and family support throughout emotional difficulties. According to Koenig and Spano (2006) older adults focus on present concerns instead of the future. Therefore, an understanding of time-orientation in older adults is important for understanding hope. The last component is confidence or facing adversity with humor. These six components of hope are important to be aware of and how social workers stay hopeful when working with older adults.

### **Summary**

According to Boss (2006) hope is critical for an individual to achieve resiliency. Having a sense of meaning in one's life creates Hope. Berg and Walsh (2005) discussed the importance of realistic hope. If an individual has too much hope or unrealistic hope, it can be damaging to the healing process. The literature review was able to reveal how

Parkinson's disease is multifaceted and ambiguous. Social workers must also be aware of the ambiguity and loss associated with Parkinson's disease. The disease not only impacts the individuals but also has a rippling effect throughout the different micro, mezzo and macro systems. Therefore, social workers must be aware of how the disease impacts the clients and society at large. Hope and resilience are impacted by the individual's personality traits and environment in which they live. Individuals with Parkinson's disease face many obstacles. Social workers can find ways to promote reasonable hope in their clients who are suffering from chronic condition such as Parkinson's disease. In order for an individual to have hope, they must be able to rediscover their sense of hope and find new meaning in order to stay resilient (Boss, 2006). Therefore, the goal of this study will examine what methods social workers use to help promote hope and resilience in individuals with Parkinson's disease.

### **Conceptual Framework**

In this study, the researcher will be using the ecological framework (Forte, 2007) to direct this study. Individuals who are diagnosed with Parkinson's, experience numerous losses and increased disabilities. Richardson and Barusch (2006) discuss the high rates of depression in individuals with chronic illness. The individual's disease impacts their attitude and quality of life. In order for an individual to have hope or be resilient they must be able to finding meaning within their life (Boss, 2006). The social worker's role is to help promote and empower individuals to have hope when dealing with a chronic disease. By promoting hope and resiliency social workers are able to able to address individuals strengths. Strengths perceptive "emphasize the client's resources, abilities, support system, and motivations to meet challenges and overcome adversity. This approach does not ignore the existence of social problems, individual disease, or family dysfunction; it emphasizes the client's assets that are used to achieve and maintain individual and social well-being" (Barker, 2005, p. 420). In the current study, the researcher would like to investigate if social workers are able to use strength perspective as a method to promote hope and resilience in individuals with Parkinson's disease.

### **Ecological Framework**

Ecological Framework demonstrates the interrelatedness of individuals and their environment. Bronfenbrenner discusses *microsystems*, *mezzosystems* and *macrosystems* (Forte, 2007). The individual's attitude or personality features can influence the kind of reaction the individual has to particular environment (Forte, 2007). Parkinson's disease affects numerous systems throughout an individual's life. The Ecological Framework can

provide a wider lens that can help explore the multiple factors related to working with people with Parkinson's disease.

The *micro systems* is defined as “a term used by social workers to identify professional activities that are designed to help solve the problems faced primarily by individuals, families and small groups. Usually micro practice focuses on direct intervention on a case-by-case basis or in a clinical setting” (Barker, 2005 p. 272).

According to Barker (2005), within the micro level social workers work to provide direct intervention for the individual, families and small groups. The social worker can help the individual's voice be heard and understood by others. Social workers can assist individuals with education, socialization, and advocacy (Chapin & Opal-Cox, 2001).

Parkinson's disease can rob individuals of their capabilities. Therefore, social workers can capitalize on the strengths of the unique client and help advocate for the client's needs. Depending on the progression of the disease in a specific individual, the individual could be living in a variety of settings. For example, individuals could be in nursing homes, assisted living or still living in their homes. In order for hope and resilience to be promoted by social worker, the social worker needs to be aware of the certain situations in which the individual is living. By involving the client with their own care, the client can find their own voice and feel like they have control over their situation.

The *mezzo system* is defined as “social work practice primarily with families and small groups. Important activities at this level include facilitating *communication*, *mediation*, and *negotiation*; education; and bringing people together” (Barker, 2003 pg. 272). When working with families, social workers can empower the individuals with the

chronic disease and/or the caregiver. The disease causes sudden changes in individual with the disease; Parkinson's disease can significantly alter family dynamics. Sprinzeles (2000) and Richardson and Barusch (2006) discusses how family members of an individual with a chronic illness like Parkinson's disease often have a negative perception of individual and have feelings of embarrassment or resentment towards the individual. In many settings, social workers can meet with the family for care conferences to help the family understand the disease and the progression. In these care conferences family members can become disgruntled with each other. The role of the social worker is to mediate discussion about the care of the individual. By bringing the family together and negotiating care, the social worker will help the family feel more supported. Therefore, the family will be able to provide more care to the individual with Parkinson's disease. Feelings of support help promote feelings of hope and resilience. Social workers can also be used throughout the community and in small groups to help educate individuals about Parkinson's and the progression of the disease.

The *macro system* is defined as “*social work practice* aimed at bringing about improvements and changes in the general society. Such activities include some types of political action, community organization, public education campaigning and the administration of broad-based social services agencies or public welfare departments” (Barker, 2003, p. 257).

At the Macro level, social workers can advocate for older adults with policy issues. Parkinson's disease can be costly to the patient and family. The disease can be expensive with medications, doctor visits and surgeries. Social workers can help advocate with changing policies that can help provide more coverage for resources for patients. Some of



the resources could include medication, therapies, and surgeries. Social workers can also work to help reduce the stigma associated with having a chronic illness like Parkinson's disease. The symptoms of Parkinson's disease can cause an individual to feel embarrassed or ashamed (Sprinzeles, 2000). In order to combat these feelings, social workers can educate individuals within communities to help reduce stigmas that cause these negative feelings. Organizations like National Parkinson's Foundations are able to connect individuals and their families' to resources and other social support systems that can help normalize the experience of the disease.

The ecological framework guided this study in forming the questions used to interview social workers that work with individuals with Parkinson's disease. The questions developed for the qualitative semi-structured interviews in this study will seek to gain reflection of social workers' awareness of the hope and resilience in their clients with Parkinson's disease and how it informs their practice.

## **Methods**

### **Research Design**

The purpose of this study was to determine how social workers promote hope and resiliency in individuals with Parkinson's disease. This qualitative study relied on semi-structured interviews of social workers that have worked with individuals with Parkinson's disease in diverse settings. The interview process of this study allowed social workers from various settings such as hospitals and care management settings to reflect on their experiences and observations of hope and resiliency in individuals with Parkinson's disease.

### **Sample**

The primary participants for this study were licensed social workers who have experience working with individuals with Parkinson's disease will be interviewed for the current study. The researcher targeted both therapists and case managers who work or have worked with individuals with Parkinson's disease. The researcher contacted social workers in the Midwest metropolitan area from both clinical and care management backgrounds. The researcher started in the Metro area for participants. However, she was able to contact social workers throughout the United States who work at Parkinson's specific organizations or clinics via public contact information.

For this study, the participants were acquired by snowball sampling. The researcher sent her research information to her committee members and a Licensed Clinical Social Worker (LCISW) who works at a clinic that specifically works with Parkinson's disease. The participants were willing to send the researchers information to other colleagues throughout the United States who exclusively work with individuals

with Parkinson's disease. The researcher also had her committee members help with acquiring more participants

### **Protection of Human Subjects**

St. Catherine's University Institutional Review Board revised the process and methods before any research was conducted for the current study. Informed-consent form (see Appendix A) was created to explain the purpose of the study, why the participants were selected, the procedure of the study, risks or benefits associated with the study, issues of confidentiality and that participation is completely voluntary. In order for a participant to agree to participate in the study, they must sign the consent form. The researcher provided a copy of the signed consent form for the participant's records. The researcher also encouraged the participants to ask questions before and after the interview to gain further knowledge about the current research study. The researcher reminded the participants that the study is voluntary and the participants were allowed to withdraw their records at any time after the interview process. Participants were informed that their identities and statements are kept confidential. A number identified each participant and no names were used in the finished written product. To ensure confidentiality, all information identifying the participants is kept in a password-protected computer. The researcher will destroy all data by May 2014.

### **Research Setting**

The research took place in the participant's office space or via Collaborate videoconference technology. The participants who were from Twin Cities Metro area were interviewed in their offices at their agencies. The individuals who were from

different from different states were interviewed via Collaborate videoconference technology.

### **Instrument**

The researcher conducted a semi-structured qualitative study that used interviews to collect information from the participants see Appendix C. The instrument helped analyze the demographics of the participants within the study. Some of the demographics addressed were: age, education, experience with Parkinson's disease, position within agency and ethnicity. The participants came from a variety of settings and the instrument helped the research analyze the differences between settings. There were ten open-ended questions that address topics of hope, resilience and quality of life for clients, as well as hope in social workers and differences in diverse agencies or organizations in regard to promoting hope in individuals with Parkinson's disease. The questions were constructed by using the information gathered from the literature review and input from committee members and research chair. The committee members and research chair helped increase the validity of the study by helping in creation of the questions.

### **Data Collection**

The researcher used a snowballing sampling technique in order to find the participants.

- 1.) The researcher used her connection with a LCISW who works specifically with individuals with Parkinson's disease and her committee members to help identify 2-3 participants who are case managers or therapists who have experience working with individuals with Parkinson's disease within the Midwest metropolitan area.

- 2.) The researcher had each committee member contact potential participants. Since the participants will be coming from a variety of settings, the committee members introduced the study using a script (see Appendix B).
- 3.) Potential participants contacted the Researcher who distributes the demographic and open-ended questions and consent form allowing potential participants to review before making the decision to continue with participating with the study.
- 4.) The researcher contacted each potential participant, informing them how they were referred to the researcher. Since the participants came from a variety of settings, the researcher introduced the study using a script (see Appendix B).
- 5.) Researcher distributed demographic and open-ended questions and consent form allowing potential participants to review before making the decision to continue with participating with the study.
- 6.) If the potential participants were interested in the study, they set up an interview with the researcher.
- 7.) If the potential participant did not call within one week, the researcher made one follow-up contact to see if they are still interested in participating.
- 8.) The interviews lasted 60 minutes and were conducted at the participant's worksite, an alternative site agreed on by researcher and participant or via Collaborate a videoconference technology through St. Catherine University.
- 9.) The interview was auto-taped and transcribed.
- 10.) Each participant received a flyer with recruiting email information and were asked to share it with two people to assist the researcher with recruiting. The data collection process was repeated until the researcher had 8 scheduled interviews.

**Data Analysis**

The interviews were audio recorded for the researcher to analyze the data. The researcher looked for themes and commonalities between the participant responses during the interviews. After the interviews are completed, the researcher transcribed the interviews and used Berg (2012) to analyze the interviews. The transcripts of interviews were read and analyzed for common themes or ideas. The themes were grouped and further explored for sub-themes. Once the transcriptions of this study were analyzed, the researcher discussed the findings in the results and discussion sections of this study.

**Researcher Bias**

The researcher was aware of her bias. The researcher's grandfather had Parkinson's disease and the researcher observed the progression of the disease. The researcher's grandfather was resilient during the progression of his disease and her grandfather is the reason why she has such an interest in assisting individuals with Parkinson's disease. Therefore, researcher's experience with Parkinson's disease might have impacted her research study. The researcher also recorded her impressions during the interview. She analyzed her impressions with her research chair. The researcher utilized her committee members and research chair to help her reduce the risk of creating narrow and leading questions. The researcher analyzed the data to find similar themes in the data collected. The researcher's experiences and passion assisted her throughout the duration of the research project. The researcher stayed motivated throughout the process of conducting the research project. After conducting her research study, she found that social workers with in a variety of settings believe that fostering hope is critical for

individual with Parkinson's disease. The researcher also found similar techniques used by her participants to help patient find hope or to be hopeful.

## Results

### Sample

Twelve participants were offered the opportunity to participate in the present study. The researcher interviewed the participants from the beginning of January until March 5, 2014. During the two months, the researcher was able to interview eight participants. Eight interviews were analyzed and used for the study. Below the table reveals the demographics of the participants. The participants were from Alberta, Winnipeg, Philadelphia, Chicago, St. Paul, and Minneapolis.

*Table 1.*

<b>Length of work with PD</b>	<b>Setting</b>	<b>Description of role</b>	<b>Age</b>	<b>Ethnicity</b>
<b>7 years</b>	<b>American Parkinson's Association</b>	<b>Program Manager for young onset Parkinson's patients</b>	<b>47</b>	<b>Caucasian</b>
<b>8 ½ years</b>	<b>Outpatient Neurology Clinic</b>	<b>Clinical Social Worker</b>	<b>38</b>	<b>Caucasian</b>
<b>8 years</b>	<b>Hospital Setting (Neurology Department)</b>	<b>Clinical Social Worker</b>	<b>41</b>	<b>Caucasian</b>
<b>2 years</b>	<b>Movement Clinic</b>	<b>Clinical Social Worker</b>	<b>47</b>	<b>Caucasian</b>
<b>6 years</b>	<b>Community Mental Health Clinic</b>	<b>Clinical Social Worker</b>	<b>56</b>	<b>Caucasian</b>
<b>17 years</b>	<b>Outpatient Neurology Clinic</b>	<b>Program Coordinator for Clinic</b>	<b>51</b>	<b>Caucasian</b>



<b>30 years</b>	<b>Hospital Setting</b>	<b>Program Coordinator at Parkinson's Center</b>	<b>65</b>	<b>Caucasian</b>
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The results of the interviews revealed new themes and topics about hope and resiliency in Parkinson's disease. Each participant brought their unique experience to the interviews. The following themes were found throughout the interview questions.

Themes were identified if three or more participants identified the same idea. Comments from the participants will be italicized.

**Positivity**

The researcher asked the participants if they could, *Briefly, in one sentence or so, summarize your understanding of hope and resilience.* The theme identified was positivity; four out of eight participants discussed how hope and resilience could be promoted through positivity.

One participant defined hope and resilience as follows:

*Ability to find something positive in life. Look toward the future in a positive way and not with dread when given difficult news like Parkinson's disease* (Transcript # 2, Page 5).

These four individuals felt that resilience and hope could assist individuals have a more positive outlook on life. The participants' understanding of hope and resilience were diverse but had common themes of positivity, accommodations, and protection. The themes analyzed in this question revealed that hope and resilience are concepts associated with finding meaning and being able to overcome adversity.

**Education**

The second question the researcher asked the participants, *how can social workers promote hope and resilience when working with persons with Parkinson's, their families*

*and the community?* The strongest theme identified in this question was education. Eight out of eight participants discussed education as a way that social workers could promote hope and resilience in individuals with Parkinson's disease, their families and the community. One of the participants stated *I do believe that if people have good education, good tools, they are going to cope better and they are going find more hope in the future* (Transcript # 2, page 8). The neurodegenerative nature of Parkinson's disease can be daunting. This particular social worker was able to discuss how education is important for an individual diagnosis with Parkinson's disease.

One participant said:

*I think about individuals I work with who have Parkinson's disease, Parkinson's interestingly enough a lot of that has to do with understanding their illness. What they can do verses what they cannot do. I think if you focus more on what a person can do then the hope follows* (Transcript # 5, page 24)

A participant commented on how education assists the family:

*Be open about the disease and ask the patient about how they foster their own hope and where are they at with their hope.* (Transcript # 3, page 14)

A participant reflected on how education can assist the community:

*I see social workers being great with providing education to community members. The community can appreciate what a person with Parkinson's can offer. The community might be struggling with and hopefully increase empathy and recognition they might need a few extra minutes and provide education and resource in case a person has a question, they can always call or ask.* (Transcript #7, page 45)

By understanding the disease and the progression, individuals and families will be able to recognize and cope with the changes of the disease. The participants discussed the importance of community education in order to promote hope and resilience. The information provided to the community about Parkinson's' disease is able to assist individuals with empathy and compassion for individuals and their families struggling with this disease.

### **Addressing hope and resilience with multiple tools**

The researcher asked the participants *Do you typically address hope and resilience in your work with persons and families with Parkinson's?* All of the participants in the research study reported that they do address hope and resilience indirectly with their clients. However, they do not use the words "hope and resilience". One participant said, *I don't use that terminology. I would say I address hope and resilience more indirectly. I talk more about involvement and getting involved.*

Another person said:

*That is good question, though I do not use those words really in my practice. I do think that hope and resilience always have a thread in what I do (Transcript #4, page 21).*

One participant said,

*My focus is very tangible. And I find pieces that will make things work for people with Parkinson's' disease. I never have a conversation with an individual or caregiver with Parkinson's been resilience doesn't come into play in one-way or another. Because you are always talking about how to adapt to the different changes (Transcript #6, page 35).*

Another participant said:

*I don't think those words come up. I will say let's look at your resilience and I might talk about coping strategies especially with the family (Transcript # 8, page 47).*

The findings for this question revealed that all of the participants discussed that they did not say the words “hope and resilience”. However, they would indirectly discuss hope and resilience with patients and their families by using different assessment tools.

The researcher asked, *What type of tool or assessment instrument do you use?* eight out of eight participants reported that they did use tools to assess hope and resilience. However, each participant discussed different assessment tools or strategies when assessing for hope and resilience. A variety of diverse practice tools were identified, such as identifying strengths, support groups, reframing, active listening, depression scales, and Cognitive Behavioral Therapy (CBT).

One participant said:

*When I am doing assessments I look for supports or skills an individual has that can either be expanded upon or if they do seem to be lacking a certain skill or support to figure out how we get that in place (Transcript #5, page 26).*

Another person said:

*I don't assess in any formal way. I think it registers with me. I can take note when a person is doing well or not (Transcript #1, page 3).*

A participant said:

*So I don't have a black and white tool that I use, I do use a PDQ38 which is a Parkinson's disease quality assessment. There is a piece on how a person copes,*

*but it is more black and white about depression. A fairly common instrument we use is the Beck depression inventory. So if their Beck score is high you might want to talk about coping and adjustment (Transcript #2, page 6).*

Another participant said:

*So we use our own mental health diagnostic assessment tool as well as CBT or DBT. Cognitive behavioral is very broad in my way of thinking of it. We work around challenging thoughts, perceptions, behaviors and how to change a behavior. We look at what kind of strengths the individual has and their interests (Transcript #5, page 27).*

The findings to this question revealed how to address hope and resilience using different tools. Each participant from the different settings utilized distinct tools. This is able to show the diverse skill set social workers have when working with clients with chronic conditions. This question demonstrated the diversity of tools and strategies when addressing hope and resilience in individuals and families who are struggling with Parkinson's' disease.

### **Hindrances When Promoting Resilience and Hope**

The next question the research asked, *What are the factors that hinder the ability to identify resilience in clients with Parkinson's with individuals; with families; with the community?* The strongest theme identified with this question was depression. The question was asked to address what hindered the participant ability to identify resiliency. However, the participants discussed what hinders an individual and family's ability to be resilient. Five out of eight participants discussed depression as being one of the most significant reasons for what hinders an individual's ability to be resilient.

One participant said:

*I keep thinking about depression, specifically undiagnosed depression and facial masking. When you think of resilience you don't think of someone just sitting there*  
(Transcript #1 page, 4).

Another participant said:

*Depression, if a person is depressed they might not be able to bring themselves to talk about it [hope or resilience] or the idea of talking about it* (Transcript #2, page 9).

One participant said:

*Sometime extreme anxiety or depression that can really hinder their ability to think good thoughts, you know they can get into really negative thinking or mood. It is hard for them to kind of change their perception. To see the world in a more colorful light than just in grays* (Transcript #4, page 21).

The next strongest theme that identified in this question was family dynamics. Four out eight participants discussed how family dynamics could influence or hinder an individual's ability to be resilient.

One participant said:

*First of all, when the individual doesn't have a lot of family support. That makes it more difficult and it gives them less to draw on. If the cheerleaders aren't there to help them along* (Transcript #6, page 37)

Another participant said:

*I believe a huge hindrance is when the family is not supportive of the individual*  
(Transcript #3, page 16).

One participant said:

*I think unsupportive family members over a long period of time can result in less resilience because the person doesn't have emotional support (Transcript #5, page 30).*

The findings from these question demonstrated that depression and mental health could greatly influence an individual's ability to be resilient. The participants discussed how, if an individual is depressed, they are less like to be involved within the community or activities. The majority of the participants discussed that individuals who were more involved in the community or in activities were more likely to be resilient. The subthemes identified in this question were cognitive impairments, family dynamics, personality, and community involvement. One participant said: *In Parkinson's disease, patients or family members who are already dysfunctional have a lot of problems even before diagnosis. It is difficult to identify resiliency because families can be resentful towards each other.* (Transcript # 6, page 37).

The second strongest theme from this question exposed that family dynamics can also influence an individual's ability to be resilience or hopeful. The participants discussed how unsupportive family members to the individuals with Parkinson's disease can reduce resiliency and feelings of hope.

### **Progression of Parkinson's and Hope and Resilience**

The next question the researcher asked, *Describe how you as a social worker address hope and resiliency as an individual progresses throughout the different stages of Parkinson's disease? How does your approach change throughout the progression of the disease?* The strongest theme discussed was an individual's approach over the course of

the disease. Seven out of eight participants discussed that their approach did not change throughout the progression of the disease.

A participant said:

*My approach stays the same but the context changes. Depending on where the client is at (Transcript #3, page 17).*

Another participant said

*It is a lot of the same, letting them know there are resources out there to help people accept help especially the caregivers (Transcript #7, page 43).*

One participant said:

*I use active listen; I expect nothing more than what the client can give. The progression is very individualized; you have to let them tell their own story (Transcript #8, page 48).*

The second strongest theme was switching the practitioner's attention to supporting the caregiver. Three out of eight participants discussed their care and attention switches to the caregiver when they are working with individuals who are in later stages of their Parkinson's disease. The subthemes of this question were reframing and planning.

A participant said:

*I do tell people very often that as the disease progresses my concern as the social worker shifts from the person with Parkinson's' to their spouse or other family members. If the main caregiver goes down than the person with Parkinson's is going down too. I try to keep them positive and upbeat (Transcript #2, page 10).*

One participant said:

*I think content changes, not my approach. I think there is a power in planning. I want to be able to take the patient's worries and turn them into action steps. I think it can give*



*them a sense of control and help them feel more hopeful. I think when you are working with someone in the later stages of Parkinson's you are planning for the future, and you are planning more for the family* (Transcript #1, page 5).

The participants discussed the importance of “meeting the client where they are at”. The participants discussed when a person is going through a progressive neurodegenerative disease, the most effective care the participant could give is client specific. The participants explained that they wanted to assist the patient with resources, emotional support and future planning or whatever they needed in the moment. A participant said *I like to provide hope in the moment. Meaning, whatever will help them to be hopeful in that very moment. If I need to provide them with resources within the community or emotional support, I will* (Transcript #2, page 8). The participants discussed the importance of having the clients' stories be heard. Individuals' diagnosed with Parkinson's disease have a unique and long, complex journey. The participants were able to discuss the importance of providing client specific care.

### **Mitigating Unrealistic Hope and Resilience**

The researcher asked , *How do you as a social worker address and mitigate unrealistic hope while still maintaining/fostering an individual's abilities to be resilient?* The strongest theme revealed in this question was communication. Four out of eight participants discussed their direct form of communication when working with the individuals with Parkinson's and their family members who are struggling with unrealistic hope.

One participant said:

*I think that is an ever-present challenging balance to manage unrealistic hope. Some*

*people have unrealistic hopes for sure. I think assessing for harm and being blunt is the way to go. If there was a cure for Parkinson's than we would be dishing it out. I don't think it is our job to tell the patient "this is [Parkinson's'] going to get you". But if these thoughts are causing harm then the unrealistic hope needs to be directly addressed* (Transcript #3, page 17).

Another participant said:

*For example, if a person wanted to stay in their home, however, the house was not safe for a person with progressed Parkinson's. You would have to address the danger. If it is dangerous situation, you have to be more forceful about the reality and really discuss the risks. You have to be realistic but not devaluating someone's feelings of control. It is important for with Parkinson's to feel like you have control over what is going on and you should try to offer people control* (Transcript #6, page 38).

One participant said:

*Social workers need to find a way to talk about hard facts about the disease. You have to take the education role even if that is discussing good or bad news. You have to take that role and be direct* (Transcript #7, page 44).

The participants discussed the importance of having direct approach of communication when dealing with unrealistic hope. The participants explained that the first action they would take would be to assess for harm for the patient or for the family members. The participants also discussed they would validate and listen to the patient. The participants explained that they would take a more direct approach because of the risks involved with unrealistic hope. The participants also explained that they would like to foster more realistic hope by providing the clients with tangible resources specific to the patient's

needs.

### **Self-Care**

The researcher asked, *As a social worker you are on part of the journey with your client. How do you stay hopeful and resilient in your professional life?* The strongest theme identified in this question were stories, five out of eight participants discussed the patient stories and experience with Parkinson's disease.

One participant said:

*I feel and have always felt that as social workers we are privy to the clients personal information is a privilege. I start everyday with that thought. Them sharing what is going on is a privilege so I take that very seriously* (Transcript #4, page 25)

Another participant said:

*This is a lot of work all of the time. You know when there are little successes that the client has, I tend to hang on to those. I am happy to be in the moment with my client and hear their experiences.* (Transcript #5, page 32).

One participant said:

*I think it is an honor to work with them because they keep going. I find that inspirational when I see them helping each other. It is an also a privilege to be a part of someone's life and to know someone so well.* (Transcript #7, page 45).

The subthemes of this question were, professional teams, separation of home and work, spiritual perspectives. Each participant discussed how they cared for themselves in order to avoid burnout and compassion fatigue.

One participant said:

*If you are overworked and underappreciated then the compassion can dwindle. Maybe*

*you have a mental health day or speak with a peer or other social worker you trust*

(Transcript # 6, page 37).

Another participant said:

*I subscribe to Buddhist publications. I read them regularly. It talks about that we are all doing to get old and die. It helps normalize the process of death. I also make sure to have my free time and recharge my battery (Transcript # 8, page 50)*

The participants discussed how the client's unique story and experience with Parkinson's inspires the participant to be resilient. The participants also discussed how the small successes or victories in the patient's life gave the participants hope in their own life. The participants also discussed the importance of self-care for themselves in order to reduce feelings burnout and compassion fatigue.

## Discussion

### Sample

The researcher interviewed eight licensed social workers with experience ranging from two to thirty plus years of experience working with individuals who had Parkinson's disease and their families. The participants were from various areas throughout the United States. Two participants worked for the Parkinson's Association, three participants worked in Movement disorder outpatient clinics, one participant worked in as a mental health therapist and two participants worked in a hospital setting. All of the participants had experience working with Parkinson's disease. However, their length of time varied, the participants experience with Parkinson's disease ranged from two years to 30 years. During the interviews the researcher discovered the amount of time each participant spent with the patients or clients in their individual settings.

The participants were in hospitals or clinic settings. The participants discussed that their time was limited when meeting with patients. Usually with a hospital setting or clinic, the participants would see the patient's when they had a doctor's appointment. This could have influenced their responses due to the length of time between visits to the clinics. The participants who worked for the Parkinson's association had less time interact with the patient due to the hotline. For example, a participant who worked for the helpline for the Parkinson's Association discussed her brief interactions with patients. She discussed that she might only talk to a person once. Therefore, she spent her time wisely and provided them with the information the caller needed. The sample might have been more representative if the researcher would have been able to interview case managers who exclusively worked with individuals with Parkinson's disease and their families.

Themes and similarities were found throughout the 8 participants responses. Therefore, the researcher would conclude that the participants' responses were generalizable within their own unique settings.

### **Themes**

#### **Positivity**

The participants summarized their understanding of hope and resilience in the first question during the interviews. One of the first themes identified this research study is the positivity in regard to promoting hope and resilience. The four participants discussed that when individuals have a more positive outlook or perception of their life they are more likely to be resilient. This theme was congruent with the literature on optimism and pessimism and Parkinson's disease. Gruber-Baldini et al. (2009) discussed individuals who were more positive or optimistic were likely to have a better quality of life. The participants in the current research study discussed their experiences with individuals with Parkinson's disease who were more positive seemed to be more resilient when confronting their symptoms with the disease. A way the participants observed their clients being resilient or positive is through involvement.

The research participants in the current study explained that they observed an individual being resilient when the individual was involved in support groups, fundraising or were more active. The participant observed their clients taking control of their disease and working towards a larger cause. This finding was congruent with previous research completed by Gruber-Baldini et al. (2009) who also discussed that individuals who were more positive were more likely to be involved with in the community. Both the current research study and Gruber-Baldini et al. (2009) discussed that the progression of Parkinson's disease and increase in disabilities are not linked to a

decrease of quality of life. Mental health and an individual's ability to be hopeful are linked to quality of life.

### **Education**

The next theme discussed was education. The research participants discussed the importance of education about the disease for the individual, family and community. The research participants discussed how it is difficult for family members to separate the patient's actions, functioning, and masking from their personality or the disease. Throughout the interviews there were many examples of the importance of education for more effective interactions with individuals with Parkinson's disease. Three experiences discussed by the research participants demonstrated the importance of education throughout the micro, mezzo and macro levels.

For example, one of the participants discussed an experience with a caregiver who was frustrated with her husband's inability to process a conversation quickly. The participant discussed that she had to spend time explaining to the caregiver that Parkinson's disease can affect an individual's ability to process information.

Rokach, Lehcier-Kimel, and Safarov (2006) discussed social expectations of individual's in North America. Rokach et al. (2006) discussed how individuals who have a physical disability are stigmatized and do not fit within "social norms". This experience can negatively influence individual's perceptions of themselves. The following examples of social expectations and Parkinson's disease, explain and emphasis the need for more education about symptoms of Parkinson's disease within the community.

Another participant discussed her own personal experience with her grandmother who had Parkinson's disease. The participant explained how neighborhood children had

tormented her grandmother because of her symptoms of masking. This experience for the participant's grandmother consistent with the research done by Tickle-Degnen and Lyons (2004) on the impact the masking symptom of Parkinson's disease has on other individuals. The results of Tickle-Degnen and Lyons (2004) research project demonstrated how masking might significantly influence an individual's perception of another person. The novice participants in the study had a difficult time correctly perceiving an individual's personality based on expressive cues. Therefore, the findings of the current research study demonstrated how the masking symptom of Parkinson's disease would cause a great deal of misconceptions and misunderstandings.

Another participant discussed her experience when she was training in an assisted living complex. The participant discussed that she witnessed a harsh interaction between three women at an assisted living complex. Two women walked by an individual and said hello. The individual at the table had Parkinson's disease and it took her longer to process the exchange. By the time the two women walked away the woman with Parkinson's vocalized "hello" in a quiet voice. However, the two women had walked away and loudly verbalized their perception the women. Therefore, education about the symptoms of Parkinson's disease is important for individuals, family members and society to understand. Education can help reduce misconceptions about an individual that may occur because of masking. Education can help provide empathy and sensitive to individuals without the disease.

### **Addressing Hope and Resilience with Multiple Tools**

Little research has been done on how social workers promote hope and resilience. The current study analyzed how social workers address hope and resilience in individuals



and family members. The strongest theme represented was direct communication when discussing unrealistic hope. Diverse strategies and tools were also strong themes within the research study. Previous research analyzed depression in Parkinson's disease; however, addressing hope and resilience by social workers was not discussed. There might be a few reasons for the lack of research for addressing hope and resilience by social workers. One might speculate that there is a lack of research because of the fact that usually older adults have this disease. The current participants discussed the importance of assessing for depression by utilizing different depression inventories or support groups. The participants discussed the importance of assessment tools that focused on the client's strength in order to be hopeful and resilient when dealing with a chronic condition like Parkinson's disease.

### **Hindrances of Hope and Resilience**

The strongest themes identified as hindering to an individual's ability to be resilient were depression and family dynamics. The current participants focused on individuals with Parkinson's disease having depression and hindering their ability to be resilient. However, the current participants did not spend much time discussing the depression of family members of individuals with Parkinson's disease. Stella et al. (2009) interviewed caregivers of patients who had dementia and Parkinson's disease. The results revealed that individuals with Parkinson's and their caregivers showed more neuropsychiatric symptoms. The caregivers in the study were observed to have more burden and depression than the other groups in the study.

### **Progression and Hope and Resilience**

Parkinson's disease is progressive disease and the challenge addressed in the current research study is how social workers continue to promote hope and resilience throughout the stages of the disease. The strongest theme identified was using a context specific approach, utilizing techniques of reframing, planning and anticipating the disease changes when working with caregivers and clients. The participants in the current study focused on client specific needs.

Previous research discusses how individual's perceptions can change through the progression of the disease (Schenkman et al., 2002). Schenkman et al. (2002) was able to highlight the importance of knowing the needs or perceptions of individuals with Parkinson's disease or any chronic illness. Schenkman et al. (2002) and the current study brief discussed how patient focused care was critical when working with individuals with Parkinson's disease.

### **Unrealistic Hope and Resilience**

When diagnosed with a chronic disease it is difficult not to hope for a cure or for a miracle to relieve the symptoms and progression of the disease. Boss (2006) discussed how an individual with a chronic illness like Parkinson's disease is often left wondering why they were diagnosed instead of someone else. The participants in the current study also discussed the grief and frustration associated with a Parkinson's disease diagnosis. However, when faced with unrealistic hope the participants in the study focused on direct communication. Three participants spent time discussing the grief and loss associated with Parkinson's disease. Boss (2006) explained the importance of helping the individual process and find meaning in the diagnosis.

Bergin and Walsh (2005) explored how social workers and therapists can help individuals with chronic conditions have realistic hope. In the subthemes of the question about unrealistic hope, individuals discussed grief and the history of the person. The participants in the current study discussed elements of challenging the unrealistic hope and how to capitalize on the individual's ability to be resilient through their stories of past experiences. The findings in the current study were consistent with the previous studies on unrealistic hope.

### **Self-Care**

The theme discussed was the participants' ability to be resilient in their own lives. The strongest theme discussed by the participants was self-care. This theme is broad and covers many subthemes. Some of the subthemes were spirituality, family and the detachment from work. Koenig and Spano (2006) discussed six components that help individuals stay hopeful, "behavioral skills, spirituality, cognitive skills, environmental skills, time-orientation and confidence". However, the previous study did not address how to professionally develop these skills. The study focused more on how the social worker needs to be aware of the components of hope for the clients. The current study allowed the participants to reflect on their own personal lives instead of keeping them solely in their professional role. The participants in the current study also discussed how their client stories assisted themselves with self-care. One participant discussed how honored she felt when the client was able to share their story with her and how often client stories allowed the social workers to reflect on their own lives.

### **Researcher Reaction**

Throughout this research project, new concepts and information has emerged about how to promote hope and resilience in individuals with Parkinson's disease. A few

experiences when interviewing stood out this researcher. For example, the researcher asked each participant if they could describe a time when they helped an individual with Parkinson's disease increase their quality of life. The reactions and stories were humbling to this new researcher. Each story was drastically different but all had a message of hope. As participants told their quality of life story, there were tender moments of silence. It was as if the patient had just spoken to the participant. This made the researcher think about her future experiences working with diverse clients and how their story becomes part of her own.

One of the other reflections the researcher had was the lack of depth of the response to the questions. The participants gave more general and surface responses to the questions. The researcher was able to send the questions to the participants as soon as the participants signed up for the research study. The researcher speculated reasons for the lack of depth in the responses. Time could have been an issue as social workers usually wear numerous hats within an agency. The majority of the participants were in large agencies. The participants might not have been able to reflect on the questions before the interview. The researcher can also speculate that another reason for the lack of depth in the answers from the participants might have been a hesitance to divulge deeper into the concept of hope and resilience. When working with individuals with chronic conditions, elements of grief and loss can surface not only for the patient but also the practitioner. Hope can be difficult to foster when faced with grief and loss, especially when someone feelings hopeless or is considered to be in a hopeless situation.

Another reflection this researcher experienced was when one of the participants discussed promoting hope and resilience. The participant stated, *There is a time to grieve,*

*who doesn't grieve their former self. Then you add a disability on top of that—It can be a sad thing. However, Parkinson's is like a watermark on a presentation. The watermark is a part of every page of their story but it is not their whole story* (Transcript #6, page 30).

This researcher was deeply moved by the metaphor. The metaphor was culmination of what the researcher was trying to do in her study. The researcher wanted to discuss how individuals with Parkinson's are more than their disease.

### **Limitations/Recommendations for Future Research**

One of the limitations of this study was the number and diversity of the participants. All of the participants were Caucasian. The study would have been more generalizable to the population if there had been a more diverse sample population. The first issue of diversity is that there were only female Caucasian participants. Therefore, this study might not be able to be generalized to all professionals who work with Parkinson's disease. The study may be influenced by the voluntary nature of this study. Individuals who have a strong passion working with Parkinson's disease might be more interested in participating in the study. This researcher suggests when recruiting, the researcher should try to recruit individuals from more diverse backgrounds, such as race, age, religion, and gender. Flyers could be handed out in different ethnic community centers or spiritual gathering establishments.

The limitation of diverse participants could be addressed in future research. For example, the researcher could look into recruiting more social workers but perhaps other professional disciplines in order to see if and how others are promoting hope and resilience in individuals and their families with Parkinson's disease. The researcher could

interview psychologists, doctors, nurses and patients to see how hope and resilience are promoted in diverse professional disciplines.

Another limitation to this study was its inability to generalize due to the qualitative nature and the small sample. For future research, sending an online survey to capture a larger population might yield other themes and more about information hope and resilience in Parkinson's disease.

### **Implications for Social Work**

#### **Practice**

Hope as described by Boss (2006) is when individuals have the ability to find new meaning. Bergin and Walsh (2005) discussed finding new meaning but also addressed unrealistic hope and how it can be damaging to individuals with chronic conditions. The participants in the study discussed unrealistic hope. Weingarten (2010) is able to further discuss the concept of *Reasonable Hope* and how this concept can assist clinicians with to their clients. Weingarten's (2010) discussed that reasonable hope can be less disappointing than regular hope. An individual's idea about hope can lead to feelings of vulnerability and hopelessness. In order for a clinician to be more effective with clients they need to understand their own stance on hope. Apathy can often occur when a clinician is working with a client who is hopeless. Therefore, when a clinician uses the concept of reasonable hope with clients the clinicians are more likely to bear witness to their clients (Weingarten, 2010). Weingarten (2010) discuss three ideas that could be used with clients to foster reasonable hope. "The practice of reasonable hope is more a course of action that allows one to follow a path toward a goal than it is a feeling. Hoping does not preclude doubt and despair. Others can help one do reasonable hope, both

imagining the goal and pathways toward it and in taking actions towards the realization of the goal” (Weingarten, 2010, p. 16). The clinician’s goal when using reasonable hope allows the client to focus on small tasks and small victories. This study sheds light on an application of how to foster reasonable hope in clients. Reasonable hope could benefit individuals with chronic condition such as Parkinson’s disease. Weingarten’s (2010) work is another application that social workers could use in their practice with individuals with chronic conditions.

The participants discussed that depression can influence family members and individuals with Parkinson’s disease. During the research study, the participant described brief depression assessment tools that were able to help the social workers understand the severity of the patient and caregiver’s depression. Depression can significantly reduce resiliency and feelings of hope. Therefore, this demonstrates the importance of social workers addressing mental health individuals and how they can obtain supportive social supports in their lives. The participants also discussed other strategies to decrease feelings of depression with activities such as mindfulness, yoga, exercise, and support groups. Social workers can assist individuals and families with finding support groups within their area. The support group link people together who are struggling with the same diagnosis. Social workers could advocate and help direct clients to online communities for people with Parkinson’s disease. The social worker can also work with family with way to be more supportive of each other when faced with a chronic disease such as Parkinson’s disease.

### **Policy**

This study revealed that education was one of the strongest themes identified in the research study. The participants discussed that education assist individuals and families with information about the disease. By families and individuals having a better understanding of the disease and the progression the symptoms appear less scary and daunting. Education for the community would also help reduce misconceptions about the disease. Many of the participants share stories about patient who were taunted and treated differently because members in the community not understanding Parkinson's disease. By increase the education in the community about the disease, there would be less stigmatization and misunderstanding about Parkinson's disease.

The research also revealed how tangible resources are important when working with individuals with Parkinson's disease. For example, a tangible resource could be a support group. There could be policies that assist with funding for more support groups. The use of groups and funding for more education about the disease would help reduce stigma within the community. Therefore, it is important that for policy makers to be aware of the steady increase of individuals being diagnosed with Parkinson's disease and how we could provide more resources to patients. Parkinson's is an expensive and progressive disease. Individuals and their families are struggling to pay for medications and services to help reduce caregiver burnout.

### **Research**

There has been little research done on how social workers promote hope and resilience in individuals with Parkinson's disease. Therefore, this research study was able to reveal a gap in research done on chronic conditions.

### **Conclusion**



The purpose of this study was to determine how social workers promote hope and resiliency in individuals with Parkinson's disease. This study is able to shed light on Parkinson's disease and how social workers can provide better care to the individual, family and community. There is not much research on how social workers promote hope and resilience in individuals with Parkinson's disease. Therefore, the research study was able to address the gaps in literature. The research study was one of the first studies to utilize online technology to interview professionals across the country. The study allowed professionals, who work with individuals with Parkinson's disease, a chance to discuss the disease and how they promote hope and resilience. The information gathered from this study can help future social workers work with individuals with Parkinson's disease. The current study is able to reveal that there is more research to be done to address hope and resilience in individual's with Parkinson's disease.

This qualitative study was able to shed light on a topic that has little research. In this study, eight licensed social workers from various parts of the United States and Canada were able to share their experiences about their client who have Parkinson's disease. These individuals have spent a great of their careers working in specialty movement clinics or mental health community agencies with individuals with Parkinson's disease. The participants assisted the researcher in finding out information on how social workers promote hope and resilience.

The research study revealed the importance of positivity. The current research study and previous research discuss that individuals with Parkinson's disease who were more positive seemed to be more resilient when confronting their symptoms with the disease. The participants discussed that when an individual is more actively seeking

resources the more resilient the individual tend to be. For example, the research participants in the current study explained that they observed an individual being resilient when the individual was involved in support groups, fundraising and exercising. The participant observed their clients who took control of their disease and working to for a larger cause seemed more hopeful.

Education was another important finding from the current research study. The research participants discussed the difficulties individual's, family members and the communities have with distinguishing a patient's actions, functioning, and masking from their personality or the disease. Misconceptions and misunderstanding can often lead to negative perception individual with Parkinson's disease. Education about Parkinson's disease for individuals, families and communities would assist in more sensitivity and empathy for people who are suffering from this disease. For example, social workers are able to address some of the barriers families face with a chronic condition. Social worker can assist families with the transition and grief throughout the stages of the disease.

Hope and resilience are often hindered by depression and complex family dynamics. Unrealistic hope can also be a challenge when trying to promote hope and resilience. The current research study revealed the importance of having social workers with this population to address concerns with mental health and unrealistic hope. A way to do this is by being context specific approach and supporting caregivers by reframing, planning and anticipating the disease changes. Weingarten's (2010) application of reasonable hope is another example of a framework social workers could use to reduce unrealistic hope.

Another important finding to reiterate is the importance of self-care for patients as well as the health care professionals. The current study allowed the participants to reflect

on their own personal lives instead of keeping them in their professional role. The participants also discussed the importance of the client's story. For many of the participants it was both an honor and overwhelmingly cathartic hear about the client stories. The participants explained that their clients were the experts on their condition and the clients were able to become educated about what it was like to live with a chronic condition.

Parkinson's is more than a neurodegenerative disease. Parkinson's disease creeps into every aspect of the patient's social and professional life. Often the disease can shatter an individual's dream for the future. The progression of the disease can cause tension between families' members. Hopelessness and grief overcome an individual and family when faced with new physical, mental and emotional challenges. Parkinson's disease symptoms can be managed by medication, surgery and rigorous exercise. However, there is no cure for this disease. Therefore, it is important to promote and empower individuals who are faced with a daunting diagnosis to utilize different techniques and strategies to stay emotionally resilient. Social workers are able to be present in an individual's intimate journey of the disease. Social workers can help individual's aspire to have new hopes and new dreams for themselves.

“Parkinson's wins if it makes me focus on the long term – and give up. My strategy is to concentrate on the short term – and keep going...Parkinson's has given me new respect for the human mind. I have come to admire the brain's infinite complexity, to respect all it can do and to forgive it for what it cannot...And it has infused in me a deep appreciation of family. Of my parents, for the values they left me. And for my

wonderful family. Parkinson's, do your worst. You can't rob me of that" (Havemann, 2004, p. 161).

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## Appendix A

**Promoting Hope and Resilience in Individuals with Parkinson's Disease****INFORMATION AND CONSENT FORM****Introduction:**

This study is being conducted by Emily Brunner, a graduate student at **St. Catherine University and University of St. Thomas** under the supervision of Dr. Michael Chovanec, a faculty member in the School of social work. I am conducting a study regarding how social workers promote hope and resilience in individuals with Parkinson's disease. You were selected as a possible participant in this research because of your experience working with individuals with Parkinson's disease and their families. Either Ted Bowman, Gretchen Scheffel, Joan Hlas or Dr. Mike Chovanec referred your name to the researcher. Please read this form and ask questions before you agree to be in the study.

**Background Information:**

The purpose of this study is to determine what methods or strategies social workers use to promote hope and resilience in individuals with Parkinson's disease. Approximately 10 people are expected to participate in this research.

**Procedures:**

If you decide to participate, you will be asked to complete either a face-to-face audio taped interview or a recorded interview via virtual conferencing provided by St. Catherine's University. The interviews will last for 90 minutes.

**Risks and Benefits of being in the study:**

The study has minimal risks. There are no direct benefits to you for participating in this research study.

**Confidentiality:**

Any information obtained in connection with this research study that can be identified with you will be disclosed only with your permission; your results will be kept confidential. Quotes will be used in the written report or publication, however, no one will be identified or identifiable. The data will be secured in a password-protected computer and only the researcher and faculty advisor will have access to the data. All data will be destroyed by May 15, 2014.

**Voluntary nature of the study:**

Participation in this research study is voluntary. Your decision whether or not to participate will not affect your future relations with St. Catherine University or University of St. Thomas any way. If you decide to participate, you are free to stop at any time without affecting these relationships. You are free to withdraw from the study after the interview has been completed. You may also call the researcher one week after the interview was completed to remove your information from the present research study.

**Contacts and questions:**

If you have any questions, please feel free to contact the researcher, Emily Brunner at (XXX) XXX-XXX. You may ask questions now, or if you have any additional questions later, the faculty advisor, Dr. Michael Chovanec (XXX-XXX-XXX), will be happy to answer them. If you have other questions or concerns regarding the study and would like to talk to someone other than the researcher(s), you may also contact Dr. John Schmitt, Chair of the St. Catherine University Institutional Review Board, at (XXX-XXX-XXX).

You may keep a copy of this form for your records.

**Statement of Consent:**

You are making a decision whether or not to participate. Your signature indicates that you have read this information and your questions have been answered. Even after signing this form, please know that you may withdraw from the study at any time.

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I consent to participate in the study, I agree to be videotaped and auto recorded.

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Signature of Participant	Date
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Signature of Researcher	Date
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## Appendix B

## Recruitment Script

Date:

Dear \_\_\_\_\_,

My name is Emily Brunner and I am a graduate student at St. Catherine University/University of St. Thomas School of Social Work. I received your contact information from Tanya Rand clinical social worker at Bethesda Outpatient services. I am conducting a research project on how social workers promote hope and resilience in individuals with Parkinson's disease. I would like to conduct interviews with social workers that have experience working with individuals with Parkinson's disease. Interviews can be in person or via videoconference technology, which is available through St. Catherine University. Video technology could be utilized to assist individuals who work a considerable distance away from the Midwestern Metropolitan area. The interviews can be scheduled at the time and location of your choosing. Interviews are designed to take 90 minutes and will be audio recorded. The interview process will take place throughout the months of January and February of 2014. After the interview has been completed I may possibly contact you after the interview for clarification on any questions that I have as I analyze the information collected during the interview. Throughout the research process your identity will be kept confidential. Your participation is voluntary and you may withdraw your information at any time after the interview process. Your participation in this research project will in no way affect your current or future relationship with the St. Catherine University or University of St. Thomas. There are no direct benefits to participating in the study, and participants will not be compensated.

If you are interested in participating in this research project as an interviewee or have any questions, please feel free to contact me at (XXX-XXX-XXX) or XXXX@gmail.com I look forward to talking with you soon.

Sincerely,

Emily Brunner, B.A.

Clinical Masters of Social Work Student

St. Catherine University/ University of St. Thomas

## Appendix C

**Promoting Hope and Resilience in individual's with Parkinson's Disease**

Please complete the following demographic information and identify any key ideas for interview questions and bring with to the interview.

**Interview Questions****Demographics**

- 1) How long have you worked with individuals with Parkinson's disease? Please fill in the circle next to the answer that best describes you.

- Less than one year
- 1 to 3 years of experience
- 3 to 5 years of experience
- Greater than 5 years of experience

If greater than five year please list approximately how many years have you worked with individuals with Parkinson's disease? \_\_\_\_\_

- 2) What is the setting in which you work?

- Hospital
- Outpatient Clinic
- Nursing Home or Assisted Living Facility
- Mental Health Agency or Clinic
- Other, Please list agency or organization \_\_\_\_\_

Please list your specific role within your place of employment

\_\_\_\_\_

- 3) Please list your age \_\_\_\_\_

- 4) What ethnicity do you identify with?

- Hispanic/ Latino

- Black or African American
- White/Caucasian
- Native American or American Indian
- Asian/ Pacific Islander
- Other, Please list the ethnicity you identify with \_\_\_\_\_

- 5) Briefly, in one sentence or so, summarize your understanding of hope and resilience.

### **Open-Ended Question Related to Parkinson's disease**

1. How can social workers promote hope and resilience when working with persons with Parkinson's? How can social workers promote hope and resilience in family members? How can social workers promote hope and resilience for persons and families living with Parkinson's in the community?
2. Do you typically address hope and resilience in your work with persons and families with Parkinson's? If so, how?
3. How do you assess hope and resilience? What type of tool or assessment instrument do you use? What are the factors that help you in identifying resilience in clients with Parkinson's with individuals; with families; with the community?
4. What are the factors that hinder the ability to identify resilience in clients with Parkinson's with individuals; with families; with the community?
5. Describe how you as a social worker address hope and resiliency as an individual progresses throughout the different stages of Parkinson's disease? How does your approach change throughout the progression of the disease?
6. How do you as a social worker address and mitigate unrealistic hope while still

maintaining/fostering an individual's abilities to be resilient?

7. Can you provide a case example where you were able to identify strengths/resilience of a client who had Parkinson's and how this helped improve the client's quality of life?
8. As a social worker you are on part of the journey with your client. How do you stay hopeful and resilient in your professional life?
9. Is there anything else that you think would be useful to me in my study?

Thank you for your time and input!

## Appendix D

## Researcher's Script

“Hello, and thank for participating in this study. My name is Emily Brunner and I am a master of social work student at St. Thomas/St. Catherine’s University who is conducting a research project. You have been chosen to participate because of your experience working with individuals with Parkinson’s disease. This study is of a voluntary nature, therefore you can withdraw from the study at any time. All of the information discussed will be kept confidential and any identifying information will be kept on a password locked computer. Please feel free to ask any questions before and after the study for further clarity of the current study. Thank you again for your participation in this study.”