

## **Sailing the Stormy Seas: The Illness Experience of Persons with Parkinson's Disease**

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*Parkinson's disease is a chronic, progressive disorder with no known cause or promising cure. While substantial information is known about the pathophysiology, little is known about the illness experience of living with the disease. A qualitative study using an ethnographic approach was conducted to provide a rich understanding of the illness experience. The illness experience was apprehended through field work in two support groups and the personal accounts of 14 participants with Parkinson's disease. The metaphor, "Sailing the Sea in The Eye of the Storm," is the overarching theme and was chosen to conceptualize the voyage of persons living with Parkinson's disease. Two prevailing sub-themes were Daily Negotiations in the Midst of Uncertainty and Reconstruction of the Self. Key Words: Parkinson's Disease, Self-Management, Chronic Illness, Metaphor, and Ethnography*

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### **Introduction**

Parkinson's disease (PD) is a progressive disorder that affects movement, muscle control, and balance. Second only to Alzheimer's disease, PD is one of the most common neurodegenerative disorders in the United States (Lai & Tsui, 2001), affecting approximately one million people in the U.S. alone (Parkinson's Disease Foundation [PDF], 2009). While the cause of Parkinson's disease remains unknown, there are certain known risk factors associated with the disease. One of the risk factors is increasing age. PD is most frequently associated with older adulthood, affecting one in 100 Americans 60 years and older (PDF). Over the next five decades, the incidence of PD is expected to triple as the average age of the population increases (Lai & Tsui). While PD is not a life-threatening disease, it results in accumulating disability until ultimately, persons are unable to move or speak (Brod, Mendelsohn, & Roberts, 1998). Little research has focused on understanding the illness experience of persons with PD. The aim of this study is to understand how persons with PD construct their illness experience and manage living with the disease on a daily basis.

Parkinson's disease is a complex, mysterious, and very individualistic disorder that affects each individual quite differently. Understanding PD from the perspective of those afflicted with the disease may assist healthcare professionals in demystifying the symptomatology and related challenges to providing holistic care for the health and comfort of patients in order to complement the medical perspective of treating the disease. My motivation to study PD arose from years of caring for my best friend and mother living with the disease and witnessing first-hand the importance of listening to the person and recognizing her astute insight into her own disorder. The desire to study PD and learn from others with the disease inspired me to embark on an academic learning

journey; however, when I decided to attain a doctorate in nursing, little did I realize how rewarding the entire dissertation process would be. I chose to study PD for a very personal reason, that being, to make a difference in caring for my best friend, my mother, as well as others who are living with the disease, as I really want to make a true contribution to nursing science.

### *Background*

While the bulk of the research in PD has focused on the biomedical model in an effort to understand the etiology and medical treatment and focused attempts to relieve symptoms, the research on how patients deal with the disease day-to-day is much more limited. The need to study the illness experience of persons living with PD stems from variations in the inevitable rate of progression among individuals and the lack of understanding of the impact on the person living with the disease. This lack of understanding may result in ineffective, fragmented care; however, incorporating a holistic assessment in caring for the individual with the disease may shed light into their individualistic and unique illness experience.

The primary author is a psychiatric mental health nurse whose base is holistic care for the health and comfort of patients to complement the medical perspective of treating the disease. This leads to the need for a more balanced perspective in health care delivery. To have this more balanced care, it is valuable for all providers to better understand the patient's experience with a chronic condition that cannot be cured by biomedicine. As a family member, it is important for family and friends to better understand the experience of someone with a chronic condition. An interdisciplinary teaching approach along with treatment and control of the disease is also needed to provide effective, comprehensive, holistic care to persons with PD.

Parkinson's disease is a chronic neurodegenerative disorder with no known cure. Treatment is symptomatic rather than curative with levodopa as the mainstay (Olanow, 2004). While there have been a number of advancements in the area of pharmacological agents for PD, the reality is that the medications work for a limited time, often requiring increasingly more medication to control the symptoms. Surgical treatments such as deep brain stimulation (DBS) are available and are reserved for those who are no longer responding to medication or for those who experience intolerable medication side effects (Piper, Abrams, & Marks, 2005). Individuals who have had DBS continue to take medication and must have routine adjustments to the neurostimulators for symptom control. Goals of treatment are aimed at alleviating symptoms and maintaining independent functioning (Olanow). While the chronic illness literature has examined the perspective of persons living with diseases such as multiple sclerosis and cancer, PD is disproportionately under-represented due to the limited number of qualitative studies conducted in this area (Thorne, Paterson, Acorn, Canam, Joachim, & Jillings, 2002).

A limited number of studies examined the illness experience of PD from the perspective of the person with the illness. Studies by Longstreth, Nelson, Linde, and Munoz (1992) and Strudwick, Mutch, and Dingwall-Fordyce (1990) examined the impact of PD on those living with the disease and their ability to perform several aspects of everyday living: personal hygiene, housework, and recreational activities. Findings of these studies concluded that persons with PD were considered disabled in all aspects of

everyday life, thus necessitating changes in both their work and family roles. Habermann (1996) further confirmed the difficulties in daily life by focusing specifically on the day-to-day demands of middle-aged patients in balancing their personal and professional roles. Using the same data set, Habermann (1999) focused on middle-aged patients' method of coping and preparedness for the future. A common element among the findings in Longstreth et al., Strudwick et al., and Habermann (1996, 1999) was the fluctuations in the PD symptoms, which were identified as primary impediments to the performing of day-to-day activities. Bromley and Eatough's (2005) phenomenological analysis of one individual's experience living with PD was congruent with other studies that examined the individual's daily struggle to maintain a sense of normalcy despite the desire to do so. Marr (1991), on the other hand, found a diminished sense of self and a perceived loss of normality in a sample of six persons aged 53-79 years.

Research has generally shown discrepancies between patients' and healthcare professionals' perceptions of the illness experience (PD in particular). Brod et al. (1998) concluded that the patients' self-perceived symptoms of functional disability were broader and included both symptoms of motor function and difficulties in functional, cognitive, and psychosocial domains, whereas the healthcare professionals focused on the observable physical motor deficits of rigidity, tremor, and bradykinesia. This was consistent with another study that reported that healthcare professionals focused almost exclusively on the motor disability and general appearance of the person with PD (Abudi, Bar-Tal, Ziv, & Fish, 1997). Healthcare professionals inaccurately identified motor symptoms as disabling whereas patients with PD identified the mental and psychosocial symptoms of PD as the most disabling. Significant variations in the perception of PD disability exist among the healthcare professionals and patients (Abudi et al.). Other studies examined the patient's perception of PD symptoms and their perceived level of disability as in the study conducted by Baker (2006) that focused on patients' perceptions of 13 Parkinsonian symptoms in terms of their intensity, frequency, duration, and level of distress and perceived level of disability.

A number of studies focused on the psychosocial consequences that result from physiological changes in PD such as difficulty swallowing (Miller, Noble, & Burn, 2006), challenges of meal preparation and shopping (Andersson & Sidenvall, 2001), and emotional exhaustion related to the increased severity in menstruation after PD onset (Schartau, Tolson, & Fleming, 2003). In addition to the psychosocial concerns, other research has focused on the social ramifications for persons living with the disease. Frazier (2000) measured mental and physical health of persons with PD and concluded that poorer outcomes were reported when the person with PD distanced themselves from others. Women with PD were found to have special needs for social support and individualized care to assist them in their adjustment to their changing perceptions of womanhood, including increasing dependency, lifestyle and relationship changes, and labile mood (Fleming, Tolson, & Schartau, 2004). However, Birgersson and Edberg (2004) in a study of professional support for persons with PD and their partners concluded that healthcare professionals did not discuss the potential impact of PD on the daily life of afflicted individuals or their partners. Philips (2006), on the other hand, studied the advice people with PD had for newly diagnosed patients. The metaphor, "dropping the bomb" was used to depict the life altering experience of living with the physical and emotional impact of PD.

This review illuminated the fact that no person with PD is untouched physically, psychologically, and/or socially by the disease. Symptoms of PD are multi-dimensional with persons experiencing a constellation of biological, psychological, and social symptoms. The majority of the research studies failed to explore what people do or how they manage their illness experience in their daily lives. The reported studies have suggested the need for further research on topics, such as comparisons of patients', partners', and healthcare professionals' perceptions of PD symptoms, a comparison of specific populations with PD based on specific demographic characteristics or communicative difficulties and other social difficulties. This study will use an ethnographic approach to elucidate the illness experience of persons with PD. This approach will give a thick description and a rich understanding of the illness experience as well as offering new insights into the persons' ability to integrate and construct their illness experience in an effort to develop response strategies to negotiate management of PD.

### *Conceptual framework*

Arthur Kleinman (1980), a medical anthropologist, developed a conceptual framework for studying patients, healers, and cultures. The model includes foundational elements of the three intersecting sectors of health care across cultures: popular, professional, and folk sectors. Kleinman's three sectors of health care model served as a conceptual approach underlying the application of ethnography to the illness experience in this study. The popular sector encompasses the health beliefs and behaviors that are informed through individual, family, and social networks. The professional or academic sector consists of health care professionals and is oriented around the biomedical model. The majority of research studies that inform the professional sector focus on the pathology, etiology, and treatment of PD. The folk sector is comprised of all other sacred and secular healers and includes much of what is currently considered complementary therapies. These sectors are interacting; for example, patients in the popular sector may be influenced by information from both the professional and folk sector. This study focused on the how the popular sector (persons with PD) construct PD and describe their illness experience.

### *Research aim*

The aim of the study was to understand how persons with PD construct their illness experience and manage living with the disease on a daily basis. There were two research questions: (1) How do people with PD construct their illness, and (2) How do people with PD manage living with the disease on a day-to-day basis?

## **Method**

The exploration of the illness experience of persons with PD was situated in ethnography. Ethnography involves the study and description of human cultures and is based upon field work which includes participant observation and in-depth interviews (Denzin & Lincoln, 2005). Ethnography is deeply rooted in medical anthropology which

has a rich tradition in studies of illness experience, and living with chronic conditions (Bloor, 2001; Kleinman, 1988; Mattingly, 1998). Kleinman (1988) eloquently situates the exploration of illness in ethnography by acknowledging these ethnographies should be about felt experiences that describe and interpret local worlds of illness and care. This study examined a group of individuals with a common experience of living with a chronic illness, in this case PD, in a local culture. The ethnographic approach has the potential to provide a thick description and a rich understanding of the illness experience and the effects of the illness on a typical day through participant observations, fieldwork, and interviews (Dewalt & Dewalt, 2002). In ethnography, the researcher is the instrument (Creswell, 1998), and emphasis is placed on the participants' natural environment and the relationship between the participants and the cultural world (Spradley, 1980). This design was employed to get "inside" the social worlds of persons with PD and see their illness experience "through their eyes" in an attempt to understand what is like to live with PD on a day-to-day basis.

### *Selection of participants*

Two support groups were purposively selected for field work, the Early-Onset PD for individuals who were diagnosed with PD under the age of 60, and the Parkinsonian's of East Texas for individuals who were over the age of 60 when diagnosed. Individual participants were purposively selected among the support group participants and the neurologists' offices who met the criteria: English speaking adults ( $\geq 21$  years old) with a known diagnosis of PD and who did not have any other neurological disorders, severe psychopathology, or impairments which would prevent them from participating in an interview about their experiences. Purposive sampling permits the selection of participants whose qualities or experiences permit an understanding of the phenomena in question (Denzin & Lincoln, 2005; Morse & Richards, 2002; Patton, 2002). For this study, key informants were purposively sampled for variation on the extent of their disease and their ability to articulate their experience.

The sample of individual participants described in this paper consisted of 14 non-hospitalized persons with PD, seven females and seven males, ranging in age from 38-82 years old, with a mean of 68.4 years. PD is conceptualized in a five stage progressive model. Stages I-V indicates relative level of disability (Hoehn & Yahr, 1967). For example, in Stage I the person experiences unilateral symptoms with no disability and stage V the final stage of PD, the person is totally disabled. The staging of the participants with PD in this study were as follows: Stage I (n=2), Stage II (n=2), Stage III (n=3), Stage IV (n=6), and Stage V (n=1).

### *Ethical considerations*

Letters of support were obtained from the support groups allowing the researcher access to the individuals who attended group meetings. Each participant was provided with written information about the study. Confidentiality was assured and informed consent was obtained in writing by the researcher. Institutional Review Board (IRB) approval was obtained from The University of Texas Health Science Center at Houston and The University of Texas at Tyler committees as well as letters of support from the

neurology offices, PD support groups, and hospital affiliates. The names used in this paper are fictitious to protect participants' identities.

### *Data collection*

Gaining entry into the field is critical in ethnographic studies (Spradley, 1980). Attending the support groups proved invaluable both in gaining initial access to participants and in gaining and maintaining their trust over the course of the study period. Two years were spent in the field, attending the support group meetings and interviewing persons with PD. Throughout this two-year study, field work included participant observations at the local PD support groups, where field notes were taken regarding the dynamics and activities of the groups. All of this contact immersed the researcher in their local culture of the group and facilitated observation of their behaviors, interactions, their discourse with each other, and how they adjusted their surroundings and adapted to living in the world (physically, emotionally, and socially). In addition, detailed field notes were kept by the researcher relative to the setting of the interviews. A reflexive journal was kept regarding interviewing skills, emotional responses to the participant interviews, and the study as it progressed. Additionally, the investigator used an on-going process of validating interpretations of participant's accounts as part of the reflective and reflexive process. This reflexive process provided an opportunity to critically examine the methods and data and to allow flexible changes in the interview process. The interviews in addition to the fieldwork provided the researcher not only with the participants' personal accounts of their disease, but also a sense of living with the disease.

In addition to the field data, individual semi-structured interviews with key informants were conducted. Spradley (1980) recommended initiating an interview with grand tour questions to enable the researcher to begin internalizing the general schema of an experience. Additional probes were used to illuminate the participants' understanding of their illness experience (Kleinman, 1988). For this study, initial grand tour questions were "What does it mean to you to have Parkinson's disease?" and "What is it like to have PD?" These questions were designed to let the participants fully describe their experience. These questions permitted participants to reflect on their experience and express it in a way that they have not otherwise articulated it in the past. Participant data from interview transcripts, participant observations, and discussions from the support groups were all incorporated into the analysis. Below is an illustration of the process of data transformation for theme one: Daily Negotiations in the Midst of Uncertainty.

Participants were asked to describe a typical day. Commonly used words to describe a typical day included inconsistent days, no typical day, uncertainty, and when asked to describe their PD, they referred to it as an unpredictable storm. In performing their activities of daily living, they had to be attuned to their bodies and adjust their medications and activities accordingly. These comments appeared in the participants' interview transcripts and in my field notes from two years of participant observation. Additionally, these comments were further validated by listening to informal conversations amongst the group at the two support groups. After identifying frequently appearing comments, I then went to a number of peer debriefing sessions in which faculty and student peers would discuss my findings. I would present excerpts of my participants' transcripts, my codes and emerging themes, which were entered into an

overall code book. The process of developing a code book was complex and dynamic and was developed iteratively on the analysis of the participant transcripts for the purpose of creating a set of codes, with definitions, and exemplar text from transcripts. The table below outlines an example of the definitions of the codes that were included in the overall code book.

Table 1

*Example of Code Book: Codes and Themes*

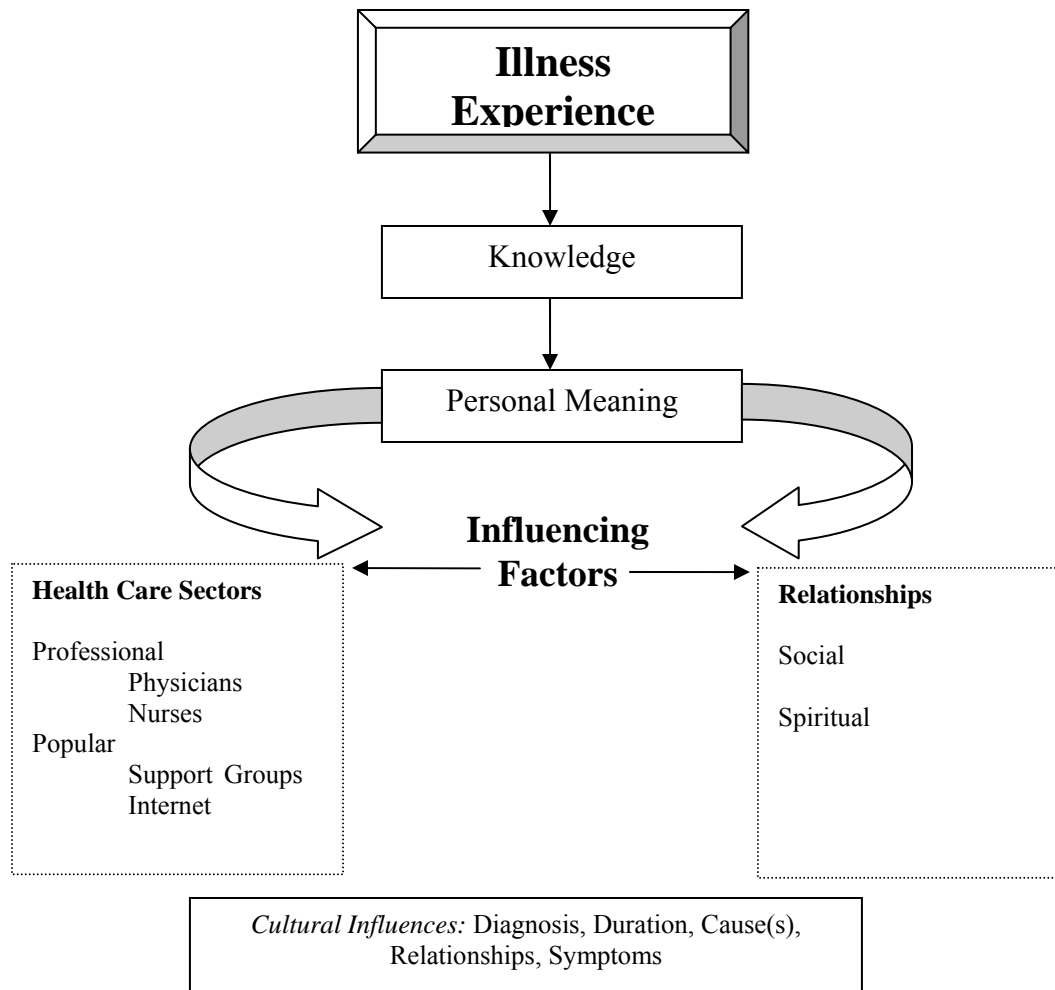
1. Daily: "Of or occurring during the day" (<http://www.thefreedictionary.com/daily>)  
From the participants' transcripts: "So I live with Parkinson's on a daily basis..." "I live one day at a time." "Parkinson's dictates my day..." Daily living requires minute-to-minute decision making skills as evidenced by the following comments: "...I never know what I am physically going to be able to do on any given day." "I don't have any consistent days..." A common theme identified among all of the participants was the reality that their day-to-day activities revolved around how they felt and their medication regimen. "My world revolves around a clock and the effectiveness of my medicine."
2. Negotiation: "The act of succeeding in accomplishing or managing" (<http://www.thefreedictionary.com/negotiate>): negotiating day-to-day activities  
From the participants' transcripts: "...I just have to adapt to it [PD] and do it slowly or do it differently..." "We were sitting at the table eating breakfast when all of a sudden my husband says, 'Let's go to Wal-Mart now.' I have to go when I feel like it. We left the breakfast table and took off." This is one example of a couples plans of tentativeness and negotiation. This was also echoed in other participants' interviews as well as informal conversations at the support groups. "I had planned to stay home and relax, but when I woke up and felt well, I decided I better go grocery shopping while I feel good." "I can time my medication and my activities, so that I can do my housework, or whatever activity I am working on at the time..."
3. Uncertainty: "The inability to determine the meaning of illness-related events" (Mishel, 1988, p. 225).  
Uncertainty
  - a. the uncertain self and future
  - b. fear of the unknown

From the participants' transcripts: "...so the uncertainty of where I will be, at what stage I will be in my disease...I don't know, see, the uncertainty..." While the uncertainty of PD on a day-to-day basis is overwhelming, uncertainty of what lies ahead was also a common concern among the participants. "My future is uncertain." "...it's the uncertainty of not knowing if I will be able to walk in a year." "I am fearful of the unknown..." The unknown is scary..."

Definitions of the commonly appearing words were examined, placed into a conceptual schema (see Figures 1 and 2), and a continual reflexive review of the participants' transcripts and field notes were challenged for accuracy and overall "fit" of the data. Schemas were developed to display the coding.

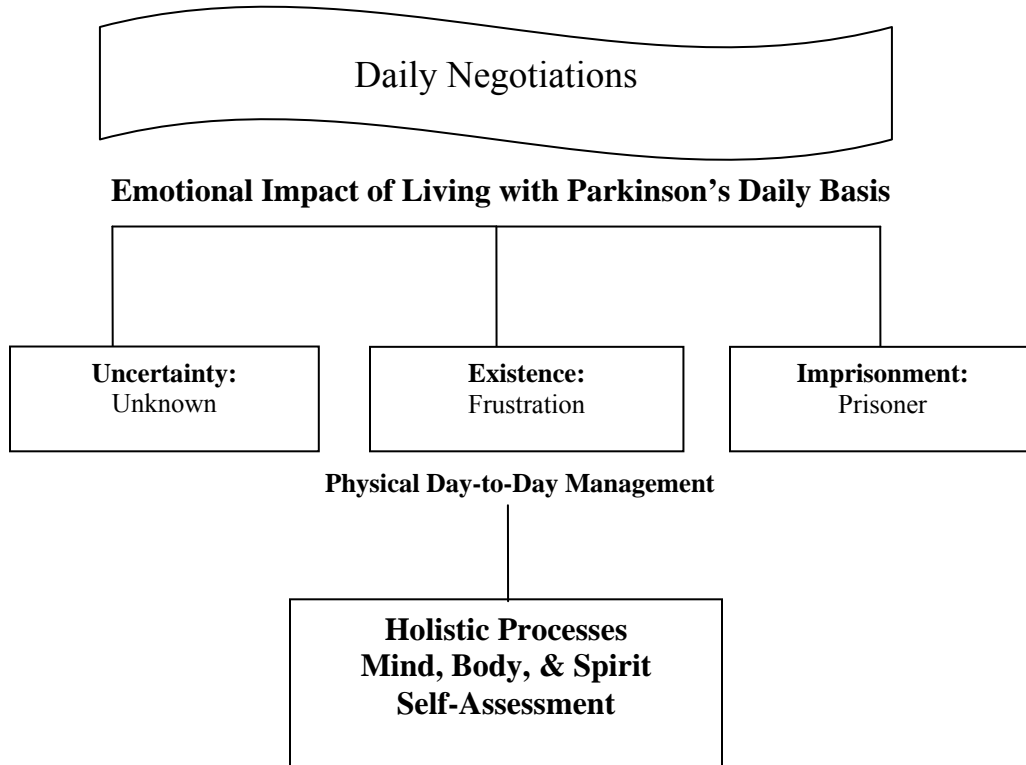
Figure 1

*Conceptual Schema for Coding 1*



This information was then placed into an overall table outlined and described in this manuscript. The metaphor "Sailing the Seas in The Eye of the Storm" emerged from this process. Many accounts of participants referring to their storm of life, which was their PD was noted in the participants' interviews as well as listening to informal conversations at the support groups. The metaphor was also presented at a number of peer debriefing sessions.

Figure 2

*Conceptual Schema for Coding 2**Data analysis*

All interviews were tape-recorded and transcribed verbatim. The transcripts were verified by the researcher to ensure accuracy. Each transcript was read multiple times and compared with field notes as a means of developing coding and categories. Analysis was concurrent with data collection. As individual interviews were completed, transcripts were read and re-read for commonalities with previous interviews. Thematic analysis was used to analyze the data (Benner, 1985; Leininger, 1994). Particular attention was paid to understanding the participants' individual contexts and experiences. As each new theme was identified, the new data was compared and contrasted with previous data. The research analysis was an iterative and reflexive process rather than a linear process. Data collection and analysis were performed concurrently. Each transcript was read and re-read before any further analysis to ensure that the developing themes were grounded in the original data. The primary objective for data collection was to represent the illness experience from the viewpoint of the person living with Parkinson's disease who shared their experiences and perceptions of living with a chronic, progressive disease.

The researcher then began to identify codes, relationships, patterns, themes, and categories related to the phenomena of study (Miles & Huberman, 1994). The use of metaphors was helpful in conceptualizing the data. Miles and Huberman's systematic

methods of qualitative data analysis also advocates free association and metaphorical thinking. As a final analysis step, the findings of this study were placed into the context of the chronic disease literature and other related PD literature. The analysis section was a laborious yet a rewarding process. The process of identifying themes was not linear rather it was a dynamic process of reviewing field notes from participant observations at the support groups, field drawings, principal investigator's (PI) reflexive journal, participants' interview transcripts, as well as a number of artifacts from the participants, i.e., drawings and poems. One participant provided me with a drawing and interpretive poem (which will be discussed in a later section), but in her poem, she referred to her Parkinson's disease as a storm. This is just one example of the validation of the metaphor, along with a number of others who made reference to a storm, sailing the sea, or weathering the storm. An iterative process continued throughout the entire analysis process to ensure that data were appropriately represented. Data were collected until saturation occurred. Data saturation was determined when rich, thick descriptions of categories were established along with well established themes. Data redundancy was identified when little new information was forthcoming (Morse & Richards, 2002).

### *Rigor*

To increase the rigor of this study, criteria developed by Lincoln and Guba (1985) and later interpreted by Sandelowski (1986) was used to address rigor. These criteria include: (a) truth, (b) credibility, (c) applicability, and (d) confirmability. Member validation was done during the interview to ensure that the participants' comments are understood (Sandelowski, 1993). As new themes or issues arose, select informants were re-interviewed to ensure accurate interpretation and allow further discussion for topics that had not been included in the initial interview. This was a nice complement to member validation. The truth value, also known as credibility, is obtained from the discovery of human experiences as perceived by the participants and is thus subjective in nature and is not defined *a priori* by the principal investigator (Lincoln & Guba). Credibility was enhanced by the recognition of multiple realities and reporting of the perspectives of the participants using terms similar to their language. Additionally, gaining entry into the field, the length of time in the field, the depth of the interview data as well as the use of member checks were other ways of supporting credibility.

As qualitative findings are always local in nature and therefore not generalizable in a statistical sense, the criteria of applicability are used. Applicability is met when the findings are viewed by others as meaningful and applicable to their own experiences. The findings should be well grounded in the life experiences studied and reflect their typical and atypical elements. Applicability was addressed by looking for patterns of repeated expressions over time. Confirmability refers to accuracy of research procedure and results (Sandelowski, 1986). As a means of confirmability, it is important to identify categories, then systematically go back to the data and ensure the data truly fits the coding. In addition, records will be kept for an audit trail. Neutrality will be addressed by continuing reflexivity, which critically identifies personal biases and makes them explicit throughout the study. Dependability and confirmability were achieved by keeping ordered and dated raw data, field notes, a strict code book, and reflexive journal records of PI's decisions throughout the process. The behaviors and experiences of the PI were described and

interpreted within the research context through journaling and analytic notes to increase the awareness of the PI's biases or preconceived assumptions. Additional peer debriefings were also conducted with attendees who were experts in PD but not qualitative research.

## Findings

The table below provides a brief synopsis of the overall findings. Each section will be described in the following paragraphs along with supportive participants' interview responses. Daily Negotiations in the Midst of Uncertainty and Reconstruction of the Self were the two content themes that emerged from this study.

Table 2

### *Overall Findings*

#### Sailing the Seas in the Eye of the Storm

1. Content theme: Daily Negotiations in Midst of Uncertainty
  - A. Uncertainty of the storm
    - a. Held captive by the storm (Imprisonment)
    - b. Quest for calmer waters (seeking the eye of the storm)
  - B. Self assessment (knowing the vessel "I know me")
  - C. Developing strategies to accommodate to the storm
  - D. Directing others in their care
    - b. An uncharted one way voyage
    - iii. Dealing with progressive nature of Parkinson's disease
2. Content theme: Reconstruction of the Self (the traveler's voyage)
  - A. Narrowing their world to the ship
  - B. Navigating the storm in an uncertain deteriorating vessel
  - C. Adapting to the voyage: Reconceptualizing the self: Integrating their former self with the self with PD (Pulling anchor)
    - a. Releasing aspects of the former self and Creating a legacy to maintain the former self ("remember me")
    - b. Creating a new identity of self with PD ("see me")
    - c. Maintaining integrity of oneself throughout ("I'm still me")
    - d. Dealing with increasing social isolation ("isolated by the storm")
      - i. Declining ability to communicate with others
      - ii. Stigmatization
      - iii. Increasing dependency on others
    - e. Support groups (the sailor's club)
  - D. Surrendering to a Higher Power to Weather the Storm
    - a. Thoughts of suicide (Avoiding abandoning ship)
    - b. Finding a deeper meaning

The metaphor, "Sailing the Sea in The Eye of the Storm," is the overarching theme that depicts the illness experience of these seven men and seven women living

with PD. The work of cognitive linguists, Lakoff and Johnson (1980), identified metaphors as a therapeutic medium that aids in communicating a deeper meaning of an experience. “Sailing the Sea in The Eye of the Storm” reflects a sense of adventure, challenge, and unpredictability that is similar to how persons with PD described their illness experience while performing daily negotiations in the management of PD.

Parkinson's disease requires participants to embark on a one-way journey into the stormy seas. The storm, PD, an unpredictable, fluctuating, and complicated voyage provides those affected with no chart or clear course. Their voyage remains stormy; a one-way journey with no return. The findings of this study are based on the accounts of the 14 participants as they continue on their journey into the storm.

The unknown etiology and unknown course of progression of Parkinson's disease makes it one of the more mysterious and complex of all neurological disorders (Fahn & Przedborski, 2000). The unpredictable and fluctuating aspects of the Parkinsonian storm evoked an array of emotions from confusion and humiliation to feelings of isolation and imprisonment in the 14 participants living with PD. A number of similarities became apparent as participants described their voyage, through their personal accounts of their illness experience. The two content themes were Daily Negotiations in the Midst of Uncertainty (the storm) and Reconstruction of the Self (the traveler's voyage).

#### *Daily negotiations in the midst of uncertainty (the storm)*

The theme, Daily Negotiations in the Midst of Uncertainty, came to light when all 14 participants reflected on their day-to-day activities in an attempt to describe their day but was unable to describe a typical day. The unpredictable nature of PD requires the person to deal with uncertainty on a daily basis, much like a sailor sailing the treacherous seas. The experience of constant change required each of them to perform a periodic holistic self-assessment in physical, psychological, and emotional areas. A common theme expressed by each participant was his/her ability to simultaneously assess his/her physical, psychological, and emotional well-being prior to determining his/her activities of daily living. While each participant's account of her/his PD symptoms varied, through personal testimonies each shared accounts of how he/she adapted his/her daily routine according to his/her labile symptoms. The researcher's interpretive analogy of each participant's assessment was identified as being similar to a sailor reading the weather signs (i.e., “how's the weather inside and out?”). It became increasingly evident in all 14 participant responses that PD determines what the person will do on any given day. They all shared personal accounts of their internal and external day-to-day checks as evidenced in the responses made by Mrs. Assess:

Parkinson's dictates my day. I mean there are days that I feel good and I want to get out and just go, go, go, but my body just won't work. My mind tells my body to go but it doesn't listen. It does me no good to plan things, because I never know what I am physically going to be able to do on any given day.

Similar responses included comments such as “I don't have any consistent days,” “My world revolves around a clock and the effectiveness of my medicine.” The need to adjust

daily activities according to their symptoms and effectiveness of their medications was also discussed frequently among the attendees at support groups.

One of the younger participants (under 40 years of age) expressed the process of daily negotiation and uncertainty of PD as such:

So I live with Parkinson's on a daily basis...I have to adjust my times...do it [daily activities] slowly or do it differently...I don't know how fast my disease is going to progress. So the uncertainty of where I will be, at what stage I will be in my disease...

I don't know, see, the uncertainty...

The unpredictability of day-to-day management, coupled with the uncertain progression of the disease, was identified as one of the primary reasons why the participants in this study could not describe a typical day; there is *no* typical day in PD. Mr. Battle eloquently described his day-to-day challenge with PD in this way: "Living with Parkinson's disease is a battle that I fight every day of my life." All participants admitted that daily living was challenging and that each day required them to battle the unpredictable storm. The challenges shared by all extended beyond the physical manifestations of not knowing if they were going to be able to perform activities of daily living (e.g., getting out of bed, getting dressed, or feeding themselves), to the minute-to-minute "battling with the storms of activities of daily living and the transitioning self," which refers to the ability to incorporate the consequences of PD into their lives. Mrs. Bath shared,

I felt pretty good one morning and decided to take a bath. After bathing, I was unable to get out of the tub and was there for over two hours, no one else was home. That's life with Parkinson's and that's who I am. And I'll take a bath next time with no reservations....You just gotta learn how to live with it.

Each participant was forced to find new ways of negotiating daily living as well as constructing meaning of his/her illness experience and perception of the self, knowing that her/his PD will never go away. The uncertainty of PD and the need to negotiate activities minute-to-minute became a constant reminder of the uncertainties of PD and the taken-for-granted aspects of day-to-day management would never be the same.

#### *Imprisonment – "Held captive by the storm"*

While all of the 14 participants shared personal accounts of their day-to-day management, the physical and emotional turmoil of living with PD gave rise to the sub-theme of Imprisonment (Stanley-Hermanns, 2008). The feelings of imprisonment may be similar to the imprisoned feelings of being held captive by the Parkinsonian storm. Mrs. Prisoner explained, "I feel like I am locked in confinement...I can't do things that I want to do," while another participant shared, "I am like a prisoner in shackles around my wrists and ankles, but I didn't commit the crime....I lived a good life, I don't deserve to have Parkinson's disease." Others referred to the imprisonment as being a strong mind in

a frail body. One of the early-onset participants stated, “My mind is active, as it should be, I mean I am young, but my body is like an 80 year old,” while similar responses echoed, “I am a prisoner of my own house and a prisoner in my own body.” Their feelings of imprisonment extended beyond the unknown trajectory of the illness to include their physical limitations of confinement, i.e., not being able to perform routine activities of daily living. Mrs. Disappointed responded:

It is frustrating. You can't do what you normally want to do or like I can't tie my shoe sometimes. Now I am to the point that I can't get dressed without help.

Everything that I go to do is hard to do. Getting the lids off of jars or opening a box or trying to read or anything I do is more difficult... Things you just take for granted until you can't do it.

As they continue to remain on the ship, their voyage becomes more lonely, uncharted, and uncertain. They yearn for the calm in “The Eye of the Storm” and a return to a safe harbor. In an effort to understand the storm they face day-to-day, participants with PD were asked what it is like to live with PD, and responses ranged from “...you have to learn to live with it” and “...you can't change it,” to “live one day at a time.” Mr. Love eloquently described living with Parkinson's disease as similar to being immersed in a new relationship. He stated: “It's like being in love, you have to learn to live with it and like what you feel like, like who you are, like everything about what you do and go on living.” From an outsider's perspective, living with PD may be viewed as a hopeless life sentence; however, the participants in this study openly discussed their daily frustrations with battling the Parkinsonian storm, yet many expressed gratitude for their current state, they all wanted a reprieve from the raging waters. In their quest for calmer waters, a common element in participants' stories revealed a sense of peace in “The Eye of the Storm.”

I'm not dying with Parkinson's disease I am living with Parkinson's disease. Even though I can't do the things I use to could do, things could be worse, I could have a brain tumor, but I don't. I have Parkinson's. Just knowing that gives me peace.

Their abilities to search for “The Eye” were internally driven, from within the self. In an effort to flesh out externally driven variables in the negotiation process, the researcher asked the support group participants how they are viewed by health care professionals. With impressive consistency, participants stated that the nurses and physicians who are not specialized in PD do not understand the idiosyncrasies of PD.

This lack of understanding was illustrated in the following responses:

I had to go into the hospital for a procedure not related to my Parkinson's and they were not giving me my Parkinson medication on their schedule and that is not the way I was supposed to take them. My husband and my daughter tried to tell them, but they didn't understand. It was not until we

insisted on contacting the nurse practitioner at the movement disorder center did I get my medication like I was supposed to. I don't think they (the healthcare professionals) really understand PD...they thought I was just being too demanding.

Understanding the uniqueness of each individual with PD, building on their strengths, recognizing the importance of the timing of medications, and identifying activities according to their current physical and psychological state is critical to caring for the person with PD and may give them a sense of peace in the storm. Sitting at the support group meetings, it became increasingly clear that their activities revolved around their medication schedule. The participants would make frequent references to the importance of listening to their body, stating "only I know how I feel" and thus, the sub-theme, "I Know Me" emerged. The sub-theme speaks to the individuals' ability to perform self-assessments to manage and negotiate daily living. This also speaks to their learning about the storm and navigating their own ship.

A stellar example of how one gentleman managed his PD by staying attuned to his body was noted at one of the more lengthy support group meetings. It was the time at which an attendee asked another attendee to drive him home that provided a real-life example of the theme, "I Know Me." The researcher and another attendee assisted the participant from inside the building to the car. At every doorway, his body would freeze. He knew how to break the freeze and shared with the researcher and the attendee to ease the transition into the car. He shared that he did not expect the support group meeting to last as long as it did, and he felt that his body was becoming more and more rigid by the minute and he knew that he needed to get home to take his medication and rest. This example exemplifies a determined sailor who did not let his physical limitations prevent him from going to the support group meeting. He stayed attuned to his body and was able to successfully negotiate management of his PD during this time of crisis. These accounts give rise to the importance of individuals to know their own body so they may develop ways to manage their PD on a day to day basis.

#### *Reconstruction of the self (the traveler's voyage)*

The reconstruction of the self is the traveler's voyage. Participants continued to reflect on their voyage of PD and its impact on the self in an attempt to redefine their own individual sense of personhood. This dynamic process involved a continual effort of examining their former self, then attaching meaning to their revised self-perceptions of the self with PD. The question "what does it mean to you to have PD?" attempted to illuminate the existential meaning of what it means to live with this disease. Participants referred to the devastation and debilitation of PD. One of the female participants at the support group provided the researcher with a drawing and at a later date, a poem. A deeper meaning of the illness experience may be expressed through metaphorical art as evidenced by her drawing of the "Old Man in the Clock," of whom she equated her current physiological state to that of "Old Man Time."

*Old Man Time*

*I was young once in my life  
 Full of wonder about tomorrow  
 Will I marry and have children  
 What's he doing at this very moment?  
 I've had my joy  
 I have seen good, bad, trouble and strife  
 Places to go, things to do, many a  
 dream  
 Primping and styling keeping up with  
 others  
 Now that I am older and married  
 Where has time gone?  
 My child is grown and gone on her own  
 With grandchildren who make our day  
 With laughter only children make  
 My journey was cut short on my pathway of  
 life  
 A storm called cancer on that dreary day  
 I managed to get through the raging waters  
 Though only for a little while.  
 Then I was back on my journey of life.  
 Many years have come and gone  
 Now I resemble Old Man Time in his clock  
 No choice but to march on.*

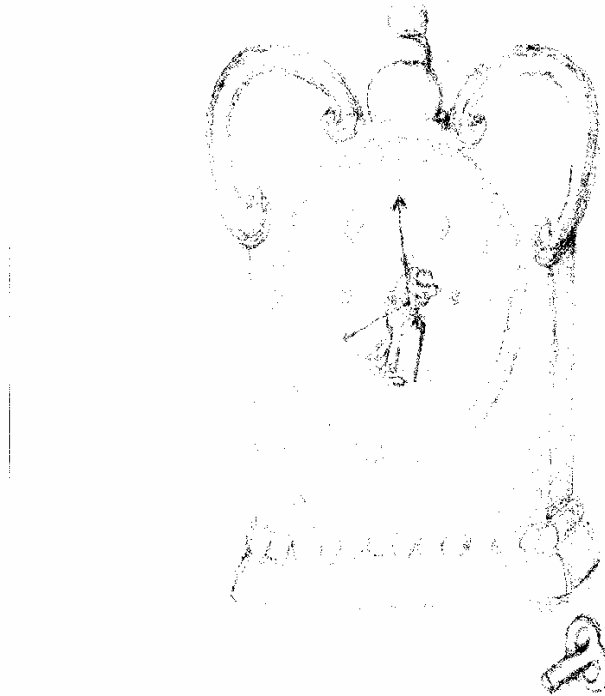
Old Man Time

I was young once in my life  
 Full of wonder about tomorrow  
 Will I marry and have children  
 What's he doing at this very moment?  
 I've had my joy  
 I have seen good, bad, trouble and strife  
 Places to go, things to do, many a  
 dream  
 Primping and styling keeping up with  
 others  
 Now that I am older and married  
 Where has time gone?  
 My child is grown and gone on her own  
 With grandchildren who make our day  
 With laughter only children make  
 My journey was cut short on my pathway of  
 life  
 A storm called cancer on that dreary day  
 I managed to get through the raging waters  
 Though only for a little while.  
 Then I was back on my journey of life.  
 Many years have come and gone  
 Now I resemble Old Man Time in his clock  
 No choice but to march on.  
 Another storm called Parkinson's has come  
 on the block  
 For time goes on, I must go on shaking and  
 shuffling  
 Never to stop  
 Like Old Man time tic tocking on  
 6/20/07

The above is an artifact that one of the female participants at the support group gave to me – it is an interpretative poem of her drawing below. Artifacts can be very powerful in ethnographic work. At a glance, the micrographia, the small cramped handwriting of her written description of the artwork, not only revealed a person with PD but was emblematic of the narrowing of her spatial, social, and temporal world. However, a deeper meaning of the illness experience was conveyed upon reading the poem. She referred to her illnesses as a “storm” which further supported the metaphor, “Sailing the Sea in The Eye of the Storm” and the traveler’s voyage. In her poem, she referred to her

life as a journey which was cut short by a storm called cancer and later another storm called Parkinson's.

*Participant's drawing of "Old Man in the Clock"*



*Reflections on the voyage of reconstruction of the self*

Parkinson's disease challenges one's life, life as they knew it, and in essence, all that their lives have stood for. The complex paradox and ongoing tension between preserving the self while releasing aspects of the former self in reconstructing the self with PD may be analogically linked to the metaphor, "Sailing the Sea," as the process of reconstructing the self is convoluted, as is the water at sea. The dominant sub-theme that emerged in many of the participants' interviews was that of frustration ("lost in the storm"). At times participants felt like they were "lost in the storm" as if they were navigating their Parkinson's ship through an uncertain storm with a deteriorating vessel. Mr. Frustrated expressed overwhelming feelings of frustration as PD unexpectedly invaded his life. Mr. Frustrated will serve as an exemplar that represents both the frustration of releasing aspects of the former self while simultaneously preserving the present self with PD as evidenced in the following responses: "Living with PD is very frustrating...sheer frustration...you can't do anything...I live a life of frustration."

Mr. Frustrated went on to say that "things that were easy to do are now impossible." Prior to PD, Mr. Frustrated served in the military, and for the past three decades, he maintained several certifications in mechanical repairs. Since his retirement, he sits in his chair and does not participate in any hobbies or social activities. He stated that the tremor in his hands prevents him from doing anything that requires fine motor

skills, all of which he was accustomed to doing to the level of being considered a master of the trade. Throughout the interview, Mr. Frustrated kept saying, "I wish you could see me the way I was, not as I am." He specifically contrasted his past and present in this way: "I wish you could see me the way that I was. I am just worthless and stupid now. I was in the military and had a sharp mind. I could build a lot of things with my hands, now my hands won't work." The source of frustration shared among the participants may have stemmed from the participants' need to maintain their sense of self while simultaneously coming to terms with the changes inherent to the disease. All of the participants had, at minimum, a high school education. They were all active, independent, and accomplished individuals whose initial symptoms were puzzling to them. Commonly shared responses included, "I was not sure what was happening to me and my body."

Following the PD diagnosis, there was a sense of relief of finally having a term for their symptoms, and why these changes were occurring. The diagnosis and symptomatology forced most participants to introspection, a process of reflecting on PD and the existential self. The introspection involved a time of examining who they were prior to the disease, who they are at present, and projecting into the future of being a person with PD. The participants were very willing to talk about their selves before and after the PD diagnosis and individually working on incorporating PD in their own terms. They all expressed a desire to be seen as a person, not as a disease. The sub-theme of "See Me" thus emerged. Comments such as "I am still the person I was with one minor adjustment; I have Parkinson's disease and "I just want people to see me" were common.

Reflecting on their disease, they gave accounts of their self and the illness experience. Mrs. Realistic humbly expressed: "...I'm still the person I was but I have to be realistic, I look different, I walk different, and shake a bit but it's me..." The personal identity of each participant emerged with a common theme of "It's Still Me." All of the participants were coming to terms with having PD, while paradoxically preserving the self (including the former self), through "I'm Still Me," and at the same time releasing aspects of the former self to actively adapt to the disease and to leave a legacy. The legacy shared by all of the interviewed participants was their desire to be remembered for the voyage in which they have traveled; their personal accounts of their illness experience of PD. "Remember Me" formed the final group of "knowing, acknowledging, and seeing" the person. At the end of Mr. Frustrated's interview, he gave the researcher a crystal rock from his personal collection. This artifact resembled who he was before PD - strong, multifaceted, and maintaining a sense of integrity - and also serves as a symbolic representation of remembering Mr. Frustrated.

An overwhelming response among the participants was that of social isolation and the sub-theme of isolation, "isolated by the storm," emerged. While social isolation may be a common response in chronic illness, it appears to be a part of everyday living with PD. The psychological aspects of isolation are feeling all alone with the disease; it is the disease that separates one from society. The participants were all aware of the progressive nature of their illness but details of when and how their condition would progress were identified as the most distressing event. The degree of their distress appeared linked to the severity of feelings of being isolated by the Parkinsonian storm. Mrs. Isolated shared:

I know my disease is going to progress, but when I don't know. There are times I feel alone as I stay at home all the time while everyone else in the

family work and are out in the public...No one ever thinks about how that makes me feel.

Some of the participants attended one of the two support groups while others rarely left their home aside from set commitments such as church and medical appointments. For those who attended the support groups (n=10), they expressed receiving physical and emotional support from the groups. Most volunteered similar issues to Mrs. Isolated, feeling isolated and alone with no support. It is noteworthy that neither Mr. Frustrated nor Mrs. Isolated had ever attended a PD support group.

Moreover, all of the participants shared a common element of feeling as if they were the only one with the disease. All of the participants were independent prior to their PD diagnosis and the possibility of dependency on others was a troublesome thought. They all were aware that their disease was chronic with no cure and feelings of isolation were evident in many of their responses. The metaphorical analogy of the one-way journey of the participants focusing on the self as a unique and separate entity speaks to the social isolation. A problematic feature of PD commonly reported by all of the participants was the facial masking, whereby persons lose the ability to form facial expressions. The participants' lack of facial expressions attests to their mounting isolation. Facial masking is one aspect of communication that highlights an important part of communication in which an individual does not have control over their physical expressions. When an individual loses the ability to communicate, both verbally and non-verbally, society tends to question one's intentions and often pulls away, all possible factors which may compound the feelings of isolation.

The following are examples of participant comments: "The number one complaint my family has is they said that I always look like I am mad. My left side of my face tends to freeze, like a zombie type and I can't talk sometimes and they always think I am mad or something." Another participant shared, "My grandchildren say, Grandma why are you always mad?" The final destination of PD is total disability which often renders the person with PD socially inept to a point in which they lose their ability to walk and talk. This may have further contributed to their feelings of isolation.

The daunting awareness that life will never be the same, and the stigmatization associated with being different appeared to compound the feelings of isolation. While many people with chronic diseases are stigmatized, society's view of physical health and beauty may contribute to the further stigmatization of persons with PD. Much emphasis is placed on how a person looks and functions. Society has little tolerance for those who are weak in body and or have an unwelcome physical appearance. A person with PD cannot hide the disease itself as there are many overt physical manifestations, such as facial masking, tremor, stooped posture, or slowed gait.

Feeling watched, criticized, and judged has a dramatic impact on the individual's social role. Many of the participants admitted to hiding their tremors. They all shared different ways to disguise the tremor. For example, one lady said that she holds onto something, usually her purse strap so she won't shake. Another participant, an older gentleman, said that he puts his hand in his pocket to hide his tremor. While many were able to describe ways in which they hid symptoms of their disease, the fact remains that they have PD and the physical, emotional, and social scars cannot be hidden. The degree of their distress appeared linked to the severity of feelings of isolation. Descriptions of

their physical, emotional, and social impact not only aided in shaping their illness experience, but their view of the self. The participants' abilities to maintain some consistency of their sense of self may assist them with the construction of new maps to help them reach a safe harbor.

The crux of the research lies in understanding how the participants faced the treacherous storm of releasing aspects of the former self. All of the 14 participants were forced to deal with the pain and suffering of the physical, psychological, and social ramifications of living with a chronic, progressive disease. The pain and suffering of the unknown voyage illuminated the realization the participants made in learning to transition their constructions of themselves to live with this progressive disease. Their focus was primarily on the voyage of living with PD, rather than the ultimate destination, profound disability and death. This started with coming to terms with the diagnosis as one person shared:

I was in denial for a couple of months after my diagnosis. Then it occurred to me that it would be better for me if I accepted the fact that I have Parkinson's. Once I got over my stubbornness, I was relieved that I was able to accept it and move forward. It was like 200 pounds lifted from my shoulders.

Others turned their imposed imprisonment to good by reaching a sense of peace in releasing aspects of the former self.

I had to come to terms with the fact that I will never be the same person ever. I've come to grips with it...I mean I had to give up a lot because of having PD, but I have learned to laugh at myself and, sometimes others, when they think I am a drunkard.

It is paradoxical that participants with PD isolate themselves because of social stigma and their difficulties communicating with others, while they become progressively more dependent on others and lose their ability to communicate. An interesting finding among the members of the support group was their socialization and communications with each other. The attendees of the groups were more socially connected in the support groups. As a group, they transcended the self. The group, as a whole, was passionate about sharing with each other their trials and tribulations in dealing with their PD. They displayed genuine concern to help each other much like those in a sailor club in which the members can appreciate each other's courage in making the voyage. Unique to this cultural group was their willingness and commitment to help with the research and their verbal expression of the value of the research.

#### *Surrendering to a higher power to weather the storm*

To weather the storm of PD, participants had to release aspects of the self, which included control over their body and their dreams, former expectations, and future plans. One way they did this was through surrendering to a Higher Power which facilitated their release. This release expressed by the participants may be metaphorically compared to

the feeling of safety in spite of the storm. Support group comments further attested to their spiritual faith, such as “I surrendered to Him; without Him I would have just given up. I know I would not have been able to accept that I can no longer work like I always had done in the past.” It is important to make a distinction between surrendering to a Higher Power and surrendering to the disease. Surrendering to the disease means that they would be giving up, whereas surrendering to a Higher Power implies hope. In their quest to discover a deeper meaning of the self, many relied on their spiritual faith:

But like I tell them, maybe God knew, and so I don't ask why, I just say here I am, Lord, you know why. I am so thankful that even if it took this, even if it took this to get my life in order and my relationship, you know, recommitting my life to God, then I am thankful for that because I know what I have to look forward to after death.

Spirituality was one of the factors that facilitated the release. Releasing aspects of the former self and examining who they have become seems to be a necessary aspect in reconstructing the identity of the self with PD. Each participant processed and integrated knowledge about PD to develop response strategies consistent with their personal values and style to reconstruct their illness experience and the self. While Parkinson's disease was not in any of the participants' original life plans, participants had to modify their plans to accommodate their disease. All of the interviewed participants expressed plans of traveling, spending time with their significant other, and enjoying their retirement years, yet the reality of their golden years is PD. “We had plans of retiring and traveling all around. I never dreamed PD would be my retirement.” “I couldn't wait to have grandchildren and now the time is here, I can't even hold them or play with them.”

As a result of the PD diagnosis, the 14 participants were forced to make meaning of their present self, the self with PD. While many admitted this was not an easy task, it required patience, perseverance, and a willingness to embrace their present self and the limitations associated with PD. Mrs. Different emphatically stated:

I realized that I would never be the same...I could never go back to being the old me, and I am okay with that, now. It took me some time to get to the point that I was okay with it...

In re-examining the metaphor, “Sailing the Sea in The Eye of the Storm,” abandoning ship through total withdrawal or even suicide were options for all of the participants, but they weathered the storm and persevered. Mrs. C. admitted that she had thoughts of suicide, but abandoned that option when she considered the effect it would have on her family. Similarly, one of the middle-aged gentlemen in the early-onset PD group shared, “I often thought about options of ending it all, but I am stronger than my disease. I want to live.” Once the PD diagnosis was established, participants indicated that there was no chance of resuming the life that they had before the disease. The awareness that their storm ship was not going to return was a reality, despite holding a compass and a reconstructed map to their final destination. Many of the participants were able to say “bon voyage” to their former self and “cast off” to the treacherous sea, leaving the researcher with their stories to share with others in hopes of continuing their legacy,

as they told their story while they still could. The entire process of reconstructing the self can be explained in nautical terms of “pulling anchor.” It was as if these participants were boarding a storm ship to embark on a long voyage to an unknown land, otherwise referred to as their voyage of what is to come, the final stage of PD.

*A creative display*

Other creative means to display the findings of the study were employed. The PI was inspired to write a poem that is based upon one of the themes that emerged from the findings of my dissertation, “See Me” as expressed by the fourteen participants (seven men and seven women) who live day-to-day with the chronic, progressive nature of the neurodegenerative disorder named Parkinson’s.

Do You See *Me*?

By: Melinda Stanley-Hermanns

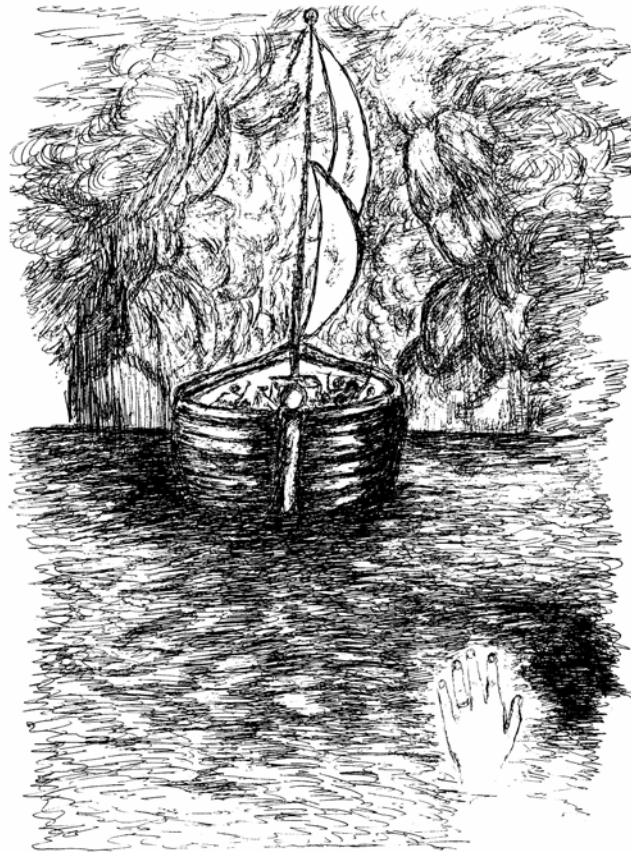
When you look at me, what do you see?  
 A shuffling gait and a shaking hand?  
 A stooped torso and a face without glee?  
 Do you know that I used to play in the band?  
 Do you know that I am a Wife, a Mother, a Grandmother, and A Nurse?  
 I used to be full of expressions.

I ask, is Parkinson’s disease a curse?  
 My body seems to be riddled with suppressions.  
 But I am here to say, Parkinson’s is not a curse.  
 On the contrary, I am Blessed.  
 I am thankful that I am still here.  
 Sure I am stressed,  
 And in a blink of an eye, a single tear,  
 For I say, Blessed are they who look at me and see me, not Parkinson’s  
 disease.

This poem is based upon one of the themes that emerged from the findings of my dissertation, “See Me” as expressed by the fourteen participants (seven men and seven women) who live day-to-day with the chronic, progressive nature of the neurodegenerative disorder named Parkinson’s. The participants wanted to be seen as a person, not just as a person with Parkinson’s. Imagine, just for a moment that you were diagnosed with Parkinson’s disease. How would you like others to see you? I was inspired to write this poem because when I look at a person with Parkinson’s disease, I see beyond the disease, I see the whole person. My participants wanted me to share with all of you the importance of seeing the person, acknowledging their past accomplishments, and embracing their present self while honoring their individual personhood.

The PI was also inspired to draw a picture depicting the participants’ illness voyage as results of doing the research (see drawing).

Drawing: “The Ship Sets Sail on an Unknown Voyage into the Storm ...But Remember Me”



This pictorial description serves as a means of continuing the legacy of the participants while honoring and remembering them. While they were all eager to share their story in hopes of helping future persons with PD, they entrusted me, the researcher, with their personal accounts to disseminate the information and contribute to the body of knowledge in nursing. As I reflect on their voyage, I realize that they were launching me into the light of the shore so that I may share their information with others. The storm ship represents the participants entering the unknown. I feel that I would be abandoning them at sea if I didn't convey the real experience of my participants and disseminate my findings. It is my duty to continue their legacy so they may always be remembered.

### **Discussion**

Sullivan, Weinart, and Cudney (2003) identified the importance of patients' sharing their reflections of their illness and concluded that these patients derived more positive outcomes from sharing personal accounts of their experience than those who did not share their experience via an asynchronous computer discussion forum. Kleinman (1985, 1988) also suggested that participants benefit from sharing their illness narratives. All of the participants explicitly stated that they positively benefitted from sharing their experience. Additionally, many admitted that they had not spoken with anyone else aside

from their health care professionals and that as a result of our interview they were going to consider talking with their family members. This study focused on the person with PD and findings were supported by the work of Kleinman (1980) who advocated that understanding the social constructions of an illness from the popular sector (i.e., persons with PD) may aid in adding to the objectively defined disease by the professional sector, (i.e., the health care professionals) and the reality of the person living with the disease. As nurses, this research has informed our professional lens. We have shared the findings of this study at a national research conference and disseminating this information to the professional sector was the major impetus for the study.

Dissemination is one means to increasing the understanding among the professional sector to improve the care of persons with PD. An example of how the personal sector might play out in the professional domain of the medical field may be elucidated in the following statements. Presenting the findings at the conference evoked an overwhelmingly positive response from a number of nurses as well as other ancillary staff who cared for patients with Parkinson's disease, many who stated that they did not realize the patients' need for daily negotiation as well as the reconstruction process. They shared that understanding these processes would have a dramatic impact on caring for future patients with PD.

The findings of this study are consistent with the emergent body of literature on the concept of integration in the experiences of persons with life changing illness. Integration is defined as a complex person-environment interaction whereby new life experiences (e.g., transitions, illness) are assimilated into the self and activities of daily living, resulting in overall life balance (Whittemore, 2005, p. 263).

While integration is often considered to be a one-time process, persons with PD experience the need for integration on a daily basis. They need to perform daily self-sorting, i.e., internal and external checks in an effort to integrate. The goal of integration in chronic illness is the achievement of optimum or maximum functioning. Whittemore (2005) reported "renewed life purpose and meaning, self-transcendence, and actualization of life potential" (p. 264) as implied consequences of integration. The need to integrate PD into their life and negotiate management of PD as described in this study was iterated by the work of Phillips (2006), who explored the feelings of being diagnosed with PD and revealed that individuals need to negotiate daily with their PD and ultimately reconstruct their life.

Kralik, Koch, Price, and Howard (2004) examined the self-management of individuals living with arthritis and found that these individuals reconfigured their daily lives and reconstructed their self-identity, similar to the participants with PD in this study. However, the focus of Kralik et al. was on the management of the disease rather than the experience of living with arthritis.

The unpredictable nature of PD requires the person with Parkinson's to deal with uncertainty on a daily basis. According to Salick and Auerbach (2006), an individual may search for "meaning in one's life" when faced with the uncertainties of a life altering illness, which is similar to the 14 participants' quest for the discovery of meaning. The participants' reflections on their illness experience and the transitioning of self in this study aided in the realization that the self is greater and deeper than the external identities defined by the social context. This finding is supported by recent works of Loughran (2006) and Chak (2006) who elaborated on the concept of self-reflection as a means of

exploration of personal knowledge of the self and the community at large. The seminal works of Dewey (1933) and Schön (1983) have been instrumental in understanding the nature of reflection as a process that extends beyond just thinking about a particular situation. In uncertain situations, the process of reflection involves a state of doubt, amazement, or confusion when thinking about the phenomenon in an effort to recapture the experience and generate a new understanding (Dewey; Schön).

This study's findings corroborate Habermann's (1999) concluding remarks that her participants maintained an intact identity through sustaining a sense of continuity. This study differed in that it added another dimension to understanding the need for daily negotiations as well as daily vicissitudes of the disease. Unique to this study is the paradoxical balancing of the participants in preserving the self while simultaneously releasing aspects of the former self to reconstruct a new self with PD. This qualitative study illuminated the struggle with dealing with the uncertainties and fluctuations of the disease while simultaneously reconstructing their perceptions of themselves.

This qualitative study attempted to give voice to the unheard in an effort to develop new knowledge and understanding of how individual's make-meaning of his/her illness experience. The "meaning" and reconstruction of their illness experience expressed by these participants will assist our understanding of the progressive, chronic nature of PD and its impact on daily functioning as described by the individual with PD. "Knowing, acknowledging, seeing, and remembering the person" was the predominant idea unifying the entire perspective in which persons with PD constructed their illness experience and navigated living with a chronic, progressive disorder. The voyage rarely remains a one-time sail for the participants with PD. Often, their odyssey is repeated, constantly sailing the waters again and again, finding themselves drifting in and out of "The Eye" and back into treacherous waters of the unpredictable manifestations of the Parkinsonian storm. Future studies on the illness experience of persons with PD may reveal new horizons in the management of chronic illness.

We thought it was important to address researcher bias and subjectivity in this study since we are nurses and the PI's mother has Parkinson's disease. Ethnographers want the investigator's perspective to be transparent. The reflexivity and critical analytic stance aided in the critical analysis of data from emic/etic perspectives. To prevent researcher bias, peer debriefings were conducted and the findings were challenged for logic and data support by a group of professionals.

### *Implications*

Johns (2007) advocates reflection on suffering and proposes that if nurses become more reflective and holistic practitioners, thereby being mindful of the patient's suffering, they could help patients to have the courage to face their own suffering. Nurses may consider incorporating a dimension of reflection in their assessment of patients with PD to allow psychosocial problems to emerge and to further understand the illness experience from the person living with the disease. This could lead to more creative nursing approaches to help patient's process and adapt to their disease.

Further understanding of the management of PD and other chronic illnesses is also needed. Funk and Tornquist (2001) advocate the need for additional research to assist healthcare professionals in managing daily activities in chronically ill individuals

and assisting with living at the highest possible level. Nursing interventions to facilitate integration may assist in alleviating uncertainty. The findings of this study have implications for holistic assessment and health promotion, areas recognized as priorities in nursing practice. Implications for nursing suggest that health care professionals should understand the holistic nature of PD and the impact of this whole-person approach on their adaptation to this progressive disease. Future research may be aimed at understanding how participants negotiate management of their disease as well as the unique constructions of their illness experience so nurses may develop more individualized approach to the care of patients with PD. Lastly, the chronic illness literature has examined self-management as a means of understanding how individuals with arthritis incorporate the illness into their daily lives, this concept has not been addressed in PD. Parkinson's disease embodies many of the aspects of self-management; therefore, more studies are needed to not only explore the experience of living with PD, but also on the meaning of self-management in persons with PD.

### Conclusion

In entering the world of PD, the PI is forever changed. As a result of conducting this study, the way I view life has changed. When I get stressed out, I stop and think about my participants and their daily struggles with PD. And in comparison, my troubles are nothing. I am making a concerted effort not to take things for granted because your life *can* be forever changed. I feel that my faith has been strengthened. This is a beginning not a means of an end. For I am thankful for the journey traveled, and look forward to continued journeys. I ask for a continued blessing for those with the disease, and may the future generation see beyond the physical manifestations of the disease and see the person!

When I think about the feedback and support from all of the participants, I helped the participants and their family step back and look at their experience with new eyes – it is like couples who don't know that their baby is going to live so they do not name it, I helped them name the PD. It's not a perfect child but it was their disease that brought them a gift – I helped them see the value of having PD. I would like to end by re-introducing the last line of my poem: For I say, blessed are they who look at me and see me, not Parkinson's disease.

At the beginning of the manuscript, I stated that my best friend, my mother, has Parkinson's disease. I wanted to share with each of you how two years in the field collecting data has impacted our relationship. The journey has allowed us to talk more openly about the Parkinson's. My mother now feels more comfortable talking with me candidly, whereas before she was hesitant to tell me how she was feeling. I believe that her comfort level has grown as she has witnessed my growth in expanding my knowledge base of Parkinson's disease as well as my overall comfort level in talking about the disease. We are learning from each other through our continual dialogue and two-way communication. Lastly and most importantly, I want to thank all of my participants for sharing their personal accounts of what it is like to live with Parkinson's disease. I pray for those with Parkinson's disease that there may be a cure – from my lips to the Higher Power's ears.

## References

- Abudi, S., Bar-Tal, Y., Ziv, L., & Fish, M. (1997). Parkinson's disease symptoms-patients' perceptions. *Journal of Advanced Nursing*, 25, 54-59.
- Andersson, I., & Sidenvall, B. (2001). Case studies of food shopping, cooking and eating habits in older women with Parkinson's disease. *Journal of Advanced Nursing*, 35(1), 69-78.
- Baker, J. H. (2006). The symptom experience of persons with Parkinson's disease. *Journal of Neuroscience Nursing*, 38(1), 51-57.
- Benner, P. (1985). Quality of life: A phenomenological perspective on explanation, prediction, and understanding in nursing science. *Advances in Nursing Science*, 8(1), 1-14.
- Birgersson, A. M. B., & Edberg, A. K. (2004). Being in the light or in the shade: Persons with Parkinson's disease and their partners experience of support. *International Journal of Nursing Studies*, 42, 621-630.
- Bloor, M. (2001). The ethnography of health and medicine. In P. Atkinson, A. Coffey, A. S. Delamont, J. Lofland, & L. Lofland (Eds.), *Handbook of ethnography* (pp. 177-187). Thousand Oaks, CA: Sage.
- Brod, M., Mendelsohn, G. A., & Roberts, B. (1998). Patients' experiences of Parkinson's disease. *Journal of Gerontological Psychological Services*, 53B(4), 213-222.
- Bromley, N., & Eatough, V. (2005). The experience of living with Parkinson's disease: An interpretive phenomenological analysis case study. *Psychology & Health*, 20(2), 223-235.
- Chak, A. (2006). Reflecting on the self: An experience in a preschool. *Reflective Practice*, 7(1), 31-41.
- Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA: Sage.
- Denzin, N. K., & Lincoln, Y. S. (Eds.). (2005). *The Sage handbook of qualitative research* (3rd ed.). Thousand Oaks, CA: Sage.
- Dewalt, K. M., & Dewalt, B. R. (2002). *Participant observation: A guide for fieldworkers*. New York: AltaMira Press.
- Dewey, J. (1933). *How we think*. Lexington, MA: D.C. Heath.
- Fahn, S., & Przedborski, S. (2000). Parkinsonism. In L. P. Rowland (Ed.), *Merritt's neurology* (pp. 679-693). Philadelphia: Lippincott Williams & Wilkins.
- Fleming, V., Tolson, D., & Schartau, E. (2004). Changing perceptions of womanhood: Living with Parkinson's disease. *International Journal of Nursing Studies*, 41(5), 515-524.
- Frazier, L. D. (2000). Coping with disease-related stressors in Parkinson's disease. *The Gerontologist*, 40, 53-63.
- Funk, S. G., & Tornquist, E. M. (2001). Chronic illness: Improving nursing practice through research. In S. G. Funk, S. G. Tornquist, J. Leeman, M. S. Miles, & J. S. Harrell (Eds.), *Key aspects of preventing and managing chronic illness* (pp. 3-11). New York: Springer.
- Habermann, B. (1996). Day-to-day demands of Parkinson's disease. *Western Journal of Nursing Research*, 18(4), 397-413.

- Habermann, B. (1999). Continuity challenges of Parkinson's disease in middle life. *Journal of Neuroscience Nursing*, 31(1), 200-207.
- Hoehn, M., & Yahr, M. (1967). Parkinsonism: Onset, progression and mortality. *Neurology*, 17(5), 427-442.
- Johns, C. (2007). Toward easing suffering through reflection. *Journal of Holistic Nursing*, 25(3), 204-210.
- Kleinman, A. (1980). *Patients and healers in the context of culture*. Berkeley: University of California Press.
- Kleinman, A. (1985). Interpreting illness experience and clinical meanings: How I see clinically applied anthropology. *Medical Anthropology Quarterly*, 16(3), 69-71.
- Kleinman, A. (1988). *The illness narratives: Suffering, healing and the human condition*. New York: Basic Books.
- Kralik, D., Koch, T., Price, K., & Howard, K. (2004). Chronic illness self management: Taking action to create order. *Journal of Clinical Nursing*, 13(2), 259-267.
- Lai, B. C. L., & Tsui, J. K. C. (2001). Epidemiology of Parkinson's disease. *British Columbia Medical Journal*, 43(3), 133-137.
- Lakoff, G., & Johnson, M. (1980). *Metaphors we live by*. Chicago: The University Press.
- Leininger, M. (1994). Evaluation criteria and critique of qualitative research studies. In J. Morse (Ed.), *Critical issues in qualitative research methods* (pp. 95-115). Thousand Oaks, CA: Sage.
- Lincoln, Y. S., & Guba, E. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage Publications.
- Longstreth, W. T., Nelson, L., Linde, M., & Munoz, D. (1992). Utility of the sickness impact profile in Parkinson's disease. *Journal of Geriatric Psychiatry and Neurology*, 5, 142-148.
- Loughran, J. (2006). A response to 'reflecting on the self'. *Reflective Practice*, 7(1), 43-53.
- Marr, J. (1991). The experience of living with Parkinson's disease. *Journal of Neuroscience Nursing*, 23, 325-329.
- Mattingly, C. (1998). *Healing dramas and clinical plots: The narrative structure of experience*. Cambridge, UK: Cambridge University Press.
- Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook*. Beverly Hills, CA: Sage.
- Miller, N., Noble, E., & Burn, D. (2006). Hard to swallow. *Age & Ageing*, 35(6), 614-618.
- Mishel, M. H. (1988). Uncertainty in illness. *Image: Journal of Nursing Scholarship*, 20, 225-232.
- Morse, J. M., & Richards, L. (2002). *Readme first for a user's guide to qualitative methods*. Thousand Oaks, CA: Sage.
- Olanow, C. W. (2004). The scientific basis for the current treatment of Parkinson's disease. *Annual Review of Medicine*, 44, 41-60.
- Parkinson's Disease Foundation [PDF]. (2009). *About Parkinson's*. Retrieved July 10, 2009, from <http://www.pdf.org/AboutPD/Patton>,
- Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.

- Phillips, L. (2006). Dropping the bomb: The experience of being diagnosed with Parkinson's disease. *Geriatric Nursing*, 27(6), 362-269.
- Piper, M., Abrams, G. M., & Marks, W. J. (2005). Deep brain stimulation for the treatment Parkinson's disease: An overview and impact on gait and mobility. *NeuroRehabilitation*, 20, 223-232.
- Salick, E. C., & Auerbach, C. F. (2006). From devastation to integration: Adjusting to and growing from medical trauma. *Qualitative Health Research*, 16, 1021-1037.
- Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Sciences*, 8(3), 27-37.
- Sandelowski, M. (1993). Rigor or rigor mortis: The problem of rigor in qualitative research revisited. *Advances in Nursing Sciences*, 16(2), 1-8.
- Schartau, E., Tolson, D., & Fleming, V. (2003). Parkinson's disease: The effects of womanhood. *Nursing Standard*, 17(42), 33-39.
- Schön, D. A. (1983). *The reflective practitioner: How professionals think in action*. New York: Basic Books.
- Spradley, J. P. (1980). *Participant observation*. New York: Harcourt Brace Jovanovich.
- Stanley-Hermanns, M. (2008). The illness experience of persons with Parkinson's disease. (Doctoral dissertation, The University of Texas Health Science Center at Houston, 2008). *ETD collection for Houston Academy of Medicine-Texas Medical Center*, AAI3308879.
- Strudwick, A., Mutch, W. J., & Dingwall-Fordyce, I. (1990). Parkinson's disease – functional impairment and who helps. *Clinical Rehabilitation*, 4, 213-216.
- Sullivan, T., Weinart, C., & Cudney, S. (2003). Management of chronic illness: Voices of rural women. *Journal of Advanced Nursing*, 44(7), 566-574.
- Thorne, S., Paterson, B., Acorn, B., Canam, C., Joachim, G., & Jillings, C. (2002). Chronic illness experience: Insights from a metastudy. *Qualitative Health Research*, 12, 437-452.
- Whittemore, R. (2005). Analysis of integration in nursing science and practice. *Journal of Nursing Scholarship*, 37(3), 261-267.
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