PRESERVING SELF: THE CHALLENGING AND STRATEGIC PROCESSES FOR PEOPLE WITH PARKINSONISM

by

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ABSTRACT

The purpose of this constructivist grounded theory study was to identify and examine challenges and strategies used by people with parkinsonism to maintain identity. These concerns were explored within the context of daily life, vital relationships, and familiar roles. The setting was three Midwestern states during historic winter weather conditions (2013-2014). Illness descriptions were obtained through medication logs and two scales: Hoehn and Yahr staging and activities of daily living. Qualitative data consisted of 62 in-depth interviews, photos, videos, fieldnotes, and memos.

Twenty-five volunteers (10 female/15 male; ages 40-95) with self-reported Parkinson disease participated. Range of disease duration was 3 months to 30 years. Disease staging: I (n = 0), II (n = 14), IV (n = 8), and V (n = 3). Stage III participants completed daily living activities at an independence level of 60 to 80%, while stage V participants ranged from 20 to 30%. Twenty-one participants used carbidopa-levodopa.

Analytic coding procedures generated the theory of *Preserving self*. This clinically logical 5-staged theory represents social and psychological processes for maintaining identity while living with a life-limiting illness. The stages and transitions are: (1) *Making sense of symptoms* describes noticing and taking action prediagnosis. *Transition: Finding out* the diagnosis was shocking, but time-limited. (2) *Turning points* confronted abilities with demanding tasks and strong emotions. *Transition: Unsettling reminders* of losses were perpetual. (3) *Dilemmas of identity* are the difficulties relinquishing comfortable self-attributes. *Transition: Sifting and sorting* is a time of grieving, letting go, and considering new self-identities. (4) *Reconnecting the self* synthesizes former and current identities. *Transition: Balancing risks and rewards* compares a lost past with possible futures. (5) *Envisioning a future* demonstrates planning pragmatically with tunnel vision.

Creative methods were developed for maintaining independence; abilities were frequently overestimated. An interesting finding was the use of self-adjusted carbidopa-levodopa beginning during *Sifting and sorting* continuing through *Reconnecting the self*. Medication was used as a social prosthesis to function normally, maintain valued relationships, and roles. People with parkinsonisim desperately seek normalcy. Recommendations include medication instruction to bridge wearing-off effects and sensory integrative activities as a self-reconnecting technique.

To my daughter, Ariel, with whom I learned the meaning of love and commitment.

To Peter, who demonstrated love and commitment.

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CHAPTER 1

INTRODUCTION

This chapter begins with the story of Marion and Louis, married study participants¹ and describing the circumstances of one family provides a frame of reference for the study context.

Marion and Louis

Marion (age 64) and Louis (age 68) married over 35 years ago. They were young, in love, and believed strongly in themselves and each other. A good life seemed guaranteed by developing careers and raising healthy children. Supporting these beliefs was a trust in the "American Dream"² of opportunities to achieve their goals and realize hopes. Their home does not have a white picket fence. Instead, apple trees in the back yard represent, for Marion and Louis, their individualities and family uniqueness.

Their dreams have not been realized. Marion and Louis both have Parkinson disease. Louis is nearing the later stages of the illness. He works full-time, returning home at noon to continue working while providing care to his wife. Marion is in the last stages of illness. She needs assistance with eating, personal care, and no longer walks. Marion is never left home alone. Louis takes this responsibility seriously, representing his marriage vows.

Marion has had Parkinson disease for 24 years. Her illness had progressed substantially by the time Louis was diagnosed (12 years ago). Marion needed more and more care due to increasing dependencies. Louis immediately began taking dopamine replacement medication (L-dopa) when diagnosed, using it liberally to function normally. Eventually, the medication lost effectiveness and permanent side effects became visible. The writhing involuntary movements did not stop Louis from working, driving, or completing household chores. Louis' weight loss concerns Marion; she attributes this to the constant dyskinesias. The children are grown with families of their own. Even so, Marion and Louis continue living in the same large home. The split-level design means long narrow hallways, multiple stairs to enter or exit, and small closet-sized bathrooms. The home is older and requires increasing maintenance. Louis takes care of all the internal and exterior home repairs, although, last year, a landscaper was hired to remove the leaves and pine needles. This tedious chore requires hours of standing and repetitive arm movements to rake the fall debris. Louis cannot do this anymore.

The neighborhood is changing, which has not surprised Marion and Louis. Neighborhood relationships are few and lack closeness. Marion had enjoyed sitting at the front window watching neighborhood activities, but now, adults hurry from their cars and children no longer play outside. The local grocery store (the only one within a 20-minute drive) recently closed, resulting in a greater driving burden to obtain necessary supplies. Louis makes "a darn good apple pie" but routine meal preparation is rarely done. They rely on packaged roast chicken, canned soups, cereal, and bagged prewashed lettuce. Fortunately, church friends have been bringing prepared meals several times a week.

New housing developments and growing businesses brought increased speed limits, traffic congestion, and a widened highway. Louis's comfort level is diminishing for all but essential driving. There is one exception. On Sundays, Louis places a wheelchair into the car, mostly carries Marion downstairs, and places her into the car for church services, followed by a restaurant dinner. Louis grins when Marion states, "I have complete confidence in his driving."

They have changed physicians several times. Marion has seen a specialist since receiving the diagnosis. She feels understood by her neurologist and hopes she can continue traveling for the appointments because the medical office has a "home-like" atmosphere. Louis preferred the neighborhood doctor, "He's a nice guy." However, the medical doctor explained that he cannot treat Parkinson disease and referred Louis to a specialist. For convenience, they see the same neurologist. It has been a hardship to drive an hour (two hours with weather or traffic) for twice-yearly appointments. No other transportation options are available.

Louis must continue to work. The monthly income is needed to pay for a recently purchased second home, the nursing aides for Marion, and to maintain their health insurance.

Neither qualifies for Medicare benefits due to Louis' employment. The new home is closer to their daughter. Marion wants to see the grandchildren more often and Louis knows he will be needing help. However, an economic recession has prevented the sale of their current residence. An additional pressing reason for not moving now is Marion's difficulty adjusting to the new environment, "It's that bed, that's why I wake up feeling agitated." A permanent move has been postponed.

Marion and Louis discovered that deciding to remain in their home, through sickness and health, created challenges for their marriage, their family, and individually. They are growing weary but remain unwilling in allowing Parkinson disease to dominate their lifestyle.

Statement of the Problem

The story of Marion and Louis evokes emotion, contains depth, and provides context. Life-altering and frequently devastating consequences accompany Parkinson disease; highlighting a surprising fact: large percentages (90 to 95%) of people with this condition remain living in the community (Jones, Dwyer, Bercovitz, & Strahan, 2009).

A great number of public health challenges are encountered by people with Parkinson disease. With an expensive lifestyle of maintaining a chronic illness and increasing anonymity in our society, it seems living with this condition may have insurmountable problems. It is in this environment of increasing losses that presents as opportunities for the researcher. It enables "seeing" the strategies used by the person with Parkinson disease to slow or possibly reverse processes of self-loss.

Purpose of the Study

The purpose of this study was to identify and examine the struggles that confront people with parkinsonisim through daily life. By examining the emotional and social consequences of these struggles, the strategies used will be explored in light of how people maintain their identity.

Background and Context

Chronic Conditions

Approximately half of all adults have one or more chronic health conditions while one of four adults has two or more (Ward, Schiller, & Goodman, 2014). Complexities are multiplied with increasing factors, as one of the less well known or understood chronic illnesses, Parkinson disease is associated with at least two other chronic conditions, ongoing depression and dementia. Chronic conditions are often incurable, progressively debilitating, require ongoing medical attention, and eventually limit activities of daily living (Anderson, 2010). Disorders that affect movement (such as parkinsonisim) can be especially distressing because the extent of physical, social, and psychological changes deeply influence a person's identity.

Parkinsonism

Parkinsonian neurodegenerative diseases are characterized by a combination of motor symptoms with overlapping nonmotor features including cognitive and psychiatric disorders.³ Cardinal motor symptoms include bradykinesia, tremor, muscle rigidity, and postural instability. The core problem of neurodegeneration is a wearing out and loss of functioning of the dopamine transmitter or transmission system; both are crucial for human movement (Bartels & Leenders, 2009). Parkinson disease comprises the largest proportion (up to 80%) of cases of parkinsonism (Dickson, 2012) and is the focus of this manuscript.

Parkinson disease is a growing epidemic. It affects approximately 1 of 250 people older than 40, about 1 of 100 people older than 65, and about 1 of 10 people older than 80 (Eidelberg & Pourfar, 2007). Speculations indicate that within 20 years, the number of individuals 65 years or older with this condition will increase by 77% (Dorsey et al., 2007). Gender differences in prevalence rates are significant only in the 50-59 age range; three times as many men have Parkinson disease (Pringsheim, Jette, Frolkis, & Steeves, 2014). This may point to greater subtlety of symptom onsets related to the lingering protective effects of estrogen (Haaxma et al., 2007). An aging population with increasing life expectancies will experience substantial burdens from parkinsonisim.

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Subtle symptoms begin years before medical consultation (Gaig & Tolosa, 2009). Diagnostic decisions are formed through observation and clinical judgement. There are no confirmatory laboratory tests or procedures (Olanow, Stern, & Sethi, 2009); autopsy remains the definitive diagnostic standard (Hughes, Daniel, Kilford, & Lees, 1992). Treatments provide limited remedy, often cause symptom worsening, and do not slow illness progression. The increase in symptom severity is insidious. After the diagnosis, remaining life is spent in various and increasing stages of disability (Olanow et al., 2009). People with Parkinson disease have a shorter lifespan compared with the general population; reports indicate a survival time of 8 to 10 years after the formal diagnosis (Elbaz et al., 2003). Death is generally due to infection (for example, pneumonia) or an accidental injury (Pennington, Snell, Lee, & Walker, 2010).

Parkinson disease has traditionally been considered a problem with body movements (motor symptoms). It is now becoming established as including cognitive and psychological components (Weintraub, Cornella, & Horn. 2008). Each of these symptoms, alone, is a cause of significant concern. However, the presence of more than one produces additive and complicating effects, resulting in public health concerns.

Major Public Health Issues

Depression. Depression is of epidemic proportions in the U.S. with many people suffering alone without helpful intervention (Lepine & Briley, 2011). It is painful, elusive, and one of the most frequent sources of suffering for older adults (Blazer, 2003). Although depression may be seen as a normal part of aging, it is not. Older adults and people with long-term illnesses are at particular risk as physical, social, or psychological losses may precede or precipitate depressive symptoms (Chapman & Perry, 2008). Symptoms of depression may include slowness of movement and thinking, apathy, loss of appetite and weight, fatigue, sleep difficulties, or psychosis (Chen & Marsh, 2013).

Approximately 30 to 90% of people with Parkinson disease have significant symptoms of depression (Reijnders, Ehrt, Weber, Aarsland, & Leentjens, 2008) thereby limiting physical functioning, diminishing motivation for activities of daily living, and restricting social participation. Depression can be difficult to distinguish from the physical changes of Parkinson disease due to

overlapping symptoms. Gait disturbances and falls have been correlated with depression, while symptoms of dementia are mimicked and worsen (Scherder et al., 2007; Milisen, Braes, Fick, & Foreman, 2006).

Dementia. Dementia elicits fear, hopelessness, and stigma. It has been considered one of the greatest anxieties for the "Baby Boomers" (Corner & Bond, 2004). There are no effective treatments to alleviate the suffering people experience (Chapman et al., 2006). Dementia has been implicated as causative of gait impairment, while movement slowness and stiffness clearly suggests potential for imbalance and subsequent falls (Yogev-Seligmann, Hausdorff, & Giladi, 2008; Harlein, Dassen, Halfens, & Heinze, 2009).

The prevalence of dementia for older adults over age 65 is 11% (Gaugler, James, Johnson, Scholz, & Weuve, 2015). In comparison, Parkinson disease dementia prevalence ranges from 20 to 40% (Marder, 2010). There are reports of cumulative prevalence rates ranging to 80% for those who survive 10 years after diagnosis. The average time from diagnosis until dementia is 10 years. Some people develop impairments early, while others may not become impaired at all (Aarsland & Kurz, 2010), demonstrating unpredictable and considerable variations.

Falls. Falls are a major public health problem (Centers for Disease Control and Prevention, 2016). Moderately severe injuries such as lacerations, fractures, and head trauma occur in 20 to 30% of the people who fall (Alamgir, Muazzam, & Nasrullah, 2012). Even without an injury, falls bring consequences: anxiety, depression, social withdrawal, and declining function (Berry & Miller, 2008). People with Parkinson disease are five times more likely to fall than similar aged peers in the community; this ratio is nearly similar for dementia (Homann et al., 2013). As motor function deteriorates, falls increase. Falls usually begin in the later part of the middle stages. Most people (up to 60%) with Parkinson disease fall, many (40%) have repeated falls (Allen, Schwarzel, & Canning, 2013).

Falls have been identified as a major contributor to care partner burden and influence nursing home placement (Abendroth, Lutz, & Young, 2012). The chronic illness and Parkinson disease literature have addressed fear of falling as contributing to isolation and self-imposed immobility (Rahman, Griffin, Quinn, & Jahanshahi, 2011; Schepens, Sen, Painter & Murphy, 2012).

Sociodemographic Concerns

Diminishing access to healthcare and services. Access to primary and specialty care physicians is limited due to proximity of services, limited transportation options, (Syed, Gerber, & Sharp, 2013), and decreasing numbers of specialty providers (Dall et al., 2013). The cost of healthcare services also reduces access to services. Professional homecare has restrictive Medicare payment guidelines for restorative services. The total 2014 reimbursement rate for combined physical and speech therapy services was \$1920 (Centers for Medicare & Medicaid Services [CMS], 2014 January). The total 2015 reimbursement rate for these same services increased by \$20 for a total of \$1940 (CMS, 2014 December). For people without insurance, fees for a single physical therapy session range from \$50 to \$350 and are dependent on session length, services provided, and the type of provider. Hospital-based services are more expensive than community-based programs ("How much ...," 2015). Additionally, community programs for older adults have experienced drastic service reductions (National Council on Aging, 2016). Consequently, people need to make do with what is available or do without needed services.

Living arrangements. Most people want to remain living in their own homes and communities as they age (Fox-Grage & Walls, 2013). However, aging and chronic illness increase obstacles which may prevent achievement of this goal (Cornwell, 2014). Social isolation occurs when changing neighborhoods bring unfamiliarity or worries of personal concern (Aneshensel et al., 2007), while suburban living requires driving distances to obtain supplies or meet friends.

Changing family roles. It has become increasingly common for the home environment to become the setting for long-term care (Gitlin, 2003). Subsequently, family members and friends perform personal care, household chores, and complex medical or nursing tasks formerly completed in hospitals. Untrained, unsure, and burdened with mounting responsibilities, places many families in positions of having to make decisions (Fox-Grage, & Walls, 2013). With increasing anonymity in the American social world, resulting in greater isolation, fewer close

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relationships, smaller families, and social networks, there may not be family care partners (Davey & Takagi, 2013). Individuals with parkinsonism may be on their own to face challenges.

The Losses of Parkinson Disease

Receiving a diagnosis of Parkinson disease is a critical turning point (Pinder, 1992); the present and the future are no longer sensible or cohesive. Unpredictable and insidious symptom development alters movement, limits mobility, inhibits speech, and diminishes expression (Miller, Noble, Jones, & Burn, 2006); all of which silence the personality and increasingly prohibits everyday life participation (Wressle, Engstrand, & Granérus, 2007). Eventually, people can no longer walk without assistance, perform the simplest of self-care activities (Pretzer-Aboff, Galik, & Resnick, 2009), or participate in conversations. Valued relationships lose closeness partially due to deteriorating communication (Jaywant & Pell, 2010), increasing depression, or the isolating lonely nature of the illness (Wressle, Engstrand, & Granérus, 2007). Social isolation may become a strategy to avoid public display and humiliation (Nijhof, 1995). The physical, social, and psychological losses contribute to a state of frailty (Fried, Ferrucci, Darer, Williamson, & Anderson, 2004).

Changing capabilities, lowered self-worth, pain, suffering, and hopelessness cause a reconfiguration of lifestyles. Coupled with the potential for feeling unworthy of respect or becoming a target of intentional disregard creates a perpetual cycle for a growing loss of one's dignity. This way of living limits the function, productivity, and satisfying participation in life activities for the affected people and their families (Charmaz, 1983; 1991; Strauss, 1984; Institute of Medicine, 2012). Through this insidious process, the sense of self may become distorted, diminished, or lost (Charmaz, 1983; 1991).

Significance

Living in the community and primarily receiving care from family members, the parkinsonian life is shielded through isolating privacy. People with Parkinson disease and their families are left on their own to handle whatever comes their way and to plan for a future with little guidance about the usual or expected outcomes. We do not know the frustrations and grief felt as people recognize their own declining abilities. Nor do we understand how their families respond to the changing characteristics of their family member. Most importantly, we do not know what subtle or purposeful routines, roles, or rituals that are used to support the ill person's self-identity.

Because of these factors and an insufficient literature base, we know little of the day-today workings of how families live or how people face challenges while living with Parkinson disease. Investigating these concerns would provide information permitting community health nurses, social workers, or volunteers to support families affected individuals in their quest to maintain normalcy and self-identity.

Research Questions and Aims

The specific aims and questions for this research are:

Aim 1. To identify, explore, and examine the challenges of living with Parkinson disease and the strategies used to maintain self-identity.

RQ 1: What are the challenges facing the person with Parkinson disease?

RQ 2: What are the strategies used that have been helpful or not helpful for maintaining self-identity?

Aim 2. To develop an empirically based midrange theory describing the processes of self-identity maintenance for people with Parkinson disease.

RQ 3: How do people with Parkinson disease maintain self-identity?

Research Approach

Sensitizing 7 oncept

Preserving self is an emerging concept and at a descriptive level of development. The working definition of *Preserving self*, for this study, was derived through the contextual descriptions of prior research ((Morse & Johnson, 1991; Charmaz, 1994; King & Jensen, 1994; Howard, Balneaves, Bottorff, & Rodney, 2011; Morse, 2012). Common attributes of this concept are striving, asserting, protecting, defending, and engaging. *Preserving self* represents the struggles, transitions, and strategies for an affected person within the context of familiar roles and relationships. This concept describes a way of being that maintains self-identity through everyday activities and attitudes. Sharing special occasions with family or friends, going to work, and mundane tasks of dressing, are activities representing a person's self. Strategies to preserve are understood by examining the behaviors and emotions of people. Here, the concept of *Preserving self* is used as a frame for the inductive building of interpretative understandings, reflecting the process of maintaining self-identity by people with Parkinson disease.

Methodology

Constructivist grounded theory (Charmaz, 2014) was the approach used for this study. It shares the theoretical framework of symbolic interactionism, builds on the pragmatic perspective, and develops the constructionist point of view through interpretative understandings of the personal experience of individuals (Charmaz, 1990; 2014). This interactive method uses a problem-solving approach through its pragmatic roots. By focusing "on process, patterns, and meaning of experiences within contexts of daily lives, roles, and relationships" (Tweed & Charmaz, 2012), researchers can view the problems to be solved from the participants perspective.

Key Terminology

Challenges" The obstacles or hurdles people encounter through routine life, which may be accentuated by illness issues. Challenges represent the personally defined meanings attributed to psychological, social, and physical changes.

Preserving self" Preserving self represents a domain of activity; strategies or actions which people (or their families) use as an aid in maintaining self-identity (Morse & Johnson, 1991; Charmaz, 1994; King & Jensen, 1994; Howard et al., 2011; Morse, 2012).

Strategies" The coping methods and techniques people use to face challenges.

The self"Here, the concepts of *self* and *identity* are based on principles of symbolic interactionism (Mead, 1934; Blumer, 1969). People are actively involved in constructing their own views of the world that are shaped by relationships with others. Through these interactions, individuals experience, sustain, and transform their sense of self. We use these notions (our

concept of self) as a frame of reference for making decisions and guiding our subsequent behaviors. The self is a template of action (Mead, 1934; Blumer, 1969; Charmaz, 1983; 1991). Forming a self involves a sense of continuity across time that involves intertwining of the past and an orientation towards a possible future (Giddens, 1991).

Organization of the Dissertation

This six-chapter manuscript contains the following chapters:

Chapter 1. Introduction

- Chapter 2. Background and Literature Review
- Chapter 3. Methods
- Chapter 4. Article submission #1: *Preserving Self*: The Social and Psychological Processes of Parkinson disease
- Chapter 5. Article submission #2: Medication as a Social Prosthesis
- Chapter 6. Discussion

Endnotes

¹ Identifying information was changed for confidentiality.

² "...that dream of a land in which life should be better and richer and fuller for everyone, with opportunity for each according to ability or achievement..." (Adams, 1931, p. 214-215).

³ Parkinson disease is one of several progressive neurodegenerative parkinsonian disorders. These disorders may be difficult to distinguish from nonprogressive forms of parkinsonism (such as drug induced). Diagnostic accuracy is low for all forms of parkinsonism because people without obvious drug induced or vascular causes may eventually be determined to have other atypical forms of neurodegenerative parkinsonism as the disease progresses. Examples of more serious forms of atypical neurodegenerative parkinsonism include multiple system atrophy, progressive supranuclear palsy, or corticobasal degeneration. Diagnosis can only be confirmed with autopsy (Dickson, 2012; Wenning, Krismer, & Poewe, 2011).

References

- Aarsland, D., & Kurz, M. W. (2010). The epidemiology of dementia associated with Parkinson disease. *Journal of the Neurological Sciences*, 289(1–2), 18-22. doi:10.1016/j.jns.2009.08.034
- Abendroth, M., Lutz, B. J., & Young, M. E. (2012). Family caregivers' decision process to institutionalize persons with Parkinson's disease: A grounded theory study. *International Journal of Nursing Studies*, 49(4), 445-454. doi:10.1016/j.ijnurstu.2011.10.003
- Adams, J. T. (1931). *The epic of America.* Boston: Little, Brown, and Co. Retrieved from https://openlibrary.org/books/OL6763688M/The_epic_of_America
- Alamgir, H., Muazzam, S., & Nasrullah, M. (2012). Unintentional falls mortality among elderly in the United States: Time for action. *Injury*, 43(12), 2065-2071. doi:10.1016/j.injury.2011.12.001
- Allen, N. E., Schwarzel, A. K., & Canning, C. G. (2013). Recurrent falls in Parkinson's disease: A systematic review. *Parkinson's Disease*, 2013,(16). doi: 10.1155/2013/906274
- Anderson, G. (2010). *Chronic conditions: Making the case for ongoing care.* Retrieved from Robert Wood Johnson Foundation website: http://www.rwjf.org/en/library/research/2010/01/chronic-care.html
- Aneshensel, C. S., Wight, R. G., Miller-Martinez, D., Botticello, A. L., Karlamangla, A. S., & Seeman, T. E. (2007). Urban neighborhoods and depressive symptoms among older adults. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 62*(1), S52-S59. Retrieved from http://psychsocgerontology.oxfordjournals.org/content/62/1/S52.abstract
- Bartels, A. L., & Leenders, K. L. (2009). Parkinson's disease: The syndrome, the pathogenesis and pathophysiology. *Cortex*, 45(8), 915-921. doi:10.1016/j.cortex.2008.11.010
- Berry, S., & Miller, R. (2008). Falls: Epidemiology, pathophysiology, and relationship to fracture. *Current Osteoporosis Reports, 6*(4), 149-154. doi:10.1007/s11914-008-0026-4
- Blazer, D. G. (2003). Depression in late life: Review and commentary. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 58(3), M249-M265. doi: 10.1093/gerona/58.3.M249
- Blumer, H. (1969). *Symbolic interactionism: Perspective and method.* Berkeley, Ca: University of California Press.
- Centers for Disease Control and Prevention, National Center for Injury Prevention and Control. (2016). Important facts about falls. Retrieved from http://www.cdc.gov/HomeandRecreationalSafety/Falls/adultfalls.html
- Centers for Medicare & Medicaid Services [CMS]. (2014, January). *Medicare limits on therapy* services. (CMS document No. 10988). Retrieved from https://www.medicare.gov/Pubs/pdf/10988.pdf
- Centers for Medicare & Medicaid Services [CMS]. (2014, December). Your Medicare coverage: Physical therapy/occupational therapy/speech-language pathology services. Retrieved from http://www.medicare.gov/coverage/pt-and-ot-and-speech-language-pathology.html

- Chapman, D. P. & Perry, G. S. (2008). Depression as a major component of public health for older adults. *Preventing Chronic Disease*, 5(1), A22. Retrieved from http://www.cdc.gov/pcd/issues/2008/jan/07_0150.htm
- Chapman, D. P., Williams, S. M., Strine, T. W., Anda, R. F., & Moore, M. J. (2006). Dementia and its implications for public health. *Preventing Chronic Disease*, *3*(2), A34. Retrieved from <u>http://www.cdc.gov/pcd/issues/2006/apr/05_0167.htm</u>
- Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. Sociology of Health & Illness, 5(2), 168-195. doi: 10.1111/1467-9566.ep10491512
- Charmaz, K. (1990). 'Discovering' chronic illness: Using grounded theory. Social Science & Medicine, 30(11), 1161-1172. doi: 10.1016/0277-9536(90)90256-R
- Charmaz, K. (1991). Good days and bad days: The self in chronic illness. New Brunswick, NJ: Rutgers University Press.
- Charmaz, K. (1994). Identity dilemmas of chronically ill men. Sociological Quarterly, 35(2), 269-288. doi: 10.1111/j.1533-8525.1994.tb00410.x
- Charmaz, K. (2014). Constructing grounded theory (2nd ed.). Thousand Oaks, CA: Sage.
- Chen, J. J. & Marsh, L. (2013). Depression in Parkinson's disease: Identification and management. *Pharmacotherapy: The Journal of Human Pharmacology and Drug Therapy, 33*(9), 972-983. doi:10.1002/phar.1314
- Corner, L., & Bond, J. (2004). Being at risk of dementia: Fears and anxieties of older adults. *Journal of Aging Studies, 18*(2), 143-155. doi: 10.1016/j.jaging.2004.01.007
- Cornwell, E.Y. (2014). Social resources and disordered living conditions: Evidence from a national sample of community-residing older adults. *Research on Aging, 36*(4), 399-430. doi: 10.1177/0164027513497369
- Dall, T. M., Storm, M. V., Chakrabarti, R., Drogan, O., Keran, C. M., Donofrio, P. D., . . . Vidic, T. R. (2013). Supply and demand analysis of the current and future US neurology workforce. *Neurology*, *81*(5), 470-478. doi: 10.1212/WNL.0b013e318294b1cf
- Davey, A., & Takagi, E. (2013). Adulthood and aging in families. G. W. Peterson & K. R. Bush (Eds.), *Handbook of Marriage and the Family* (pp. 377-399). Retrieved from http://dx.doi.org/10.1007/978-1-4614-3987-5_17
- Dickson, D. W. (2012). Parkinson's disease and parkinsonism: Neuropathology. Cold Spring Harbor Perspectives in Medicine, 2(8). doi: 10.1101/cshperspect.a009258
- Dorsey, E. R., Constantinescu, R., Thompson, J. P., Biglan, K. M., Holloway, R. G., Kieburtz, K., . . . Tanner, C. M. (2007). Projected number of people with Parkinson disease in the most populous nations, 2005 through 2030. *Neurology, 68*(5), 384-386. doi: 10.1212/01.wnl.0000247740.47667.03
- Eidelberg, D., & Pourfar, M. (2007). Parkinson's disease. In R. S. Porter & J. L. Kaplan (Eds.), The Merck Manual: Home health handbook. Whitehouse, NJ: Merck, Sharp, & Dohme Corp.
- Elbaz, A., Bower, J. H., Peterson, B. J., Maraganore, D. M. M., Shannon K., Ahlskog, J. E., Schaid, D. J., & Rocca, W. A. (2003). Survival study of Parkinson disease in Olmsted County, Minnesota. Archives of Neurology, 60(1), 91-96. doi: 10.1001/archneur.60.1.91

- Fox-Grage, W. & Walls, J. (2013). State studies find home and community-based services to be cost effective. AARP Public Policy Institute, 1-24. Retrieved from <u>http://www.aarp.org/health/medicare-insurance/info-03-2013/state-studies-find-hcbs-tobe-cost-effective-AARP-ppi-ltc.html</u>
- Fried, L. P., Ferrucci, L., Darer, J., Williamson, J. D., & Anderson, G. (2004). Untangling the Concepts of disability, frailty, and comorbidity: Implications for improved targeting and care. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 59(3), M255-M263. doi: 10.1093/gerona/59.3.M255
- Gaig, C., & Tolosa, E. (2009). When does parkinson's disease begin? *Movement Disorders,* 24(S2), S656-S664. doi:10.1002/mds.22672
- Gaugler, J., James, B., Johnson, T., Scholz, K., & Weuve, J. (2015). 2015 Alzheimer's disease facts and figures. Retrieved from Alzheimer's Association website: https://www.alz.org/facts/downloads/facts_figures_2015.pdf
- Giddens, A. (1991). *Modernity and self-identity: Self and society in the late modern age*. Stanford, CA: Stanford University Press.
- Gitlin, L. N. (2003). Conducting research on home environments: Lessons learned and new directions. *The Gerontologist, 43*(5), 628-637. doi: 10.1093/geront/43.5.628
- Haaxma, C. A., Bloem, B. R., Borm, G. F., Oyen, W. J. G., Leenders, K. L., Eshuis, S., . . . Horstink, M. W. I. M. (2007). Gender differences in Parkinson's disease. *Journal of Neurology, Neurosurgery & Psychiatry, 78*(8), 819-824. doi:10.1136/jnnp.2006.103788
- Härlein, J., Dassen, T., Halfens, R. J. G., & Heinze, C. (2009). Fall risk factors in older people with dementia or cognitive impairment: a systematic review. *Journal of Advanced Nursing*, 65(5), 922-933. doi:10.1111/j.1365-2648.2008.04950.x
- Homann, B., Plaschg, A., Grundner, M., Haubenhofer, A., Griedl, T., Ivanic, G., Hofer, E., Fazekas, F., & Homann, C. N. (2013). The impact of neurological disorders on the risk for falls in the community dwelling elderly: A case-controlled study. *BMJ Open, 3*(11). doi:10.1136/bmjopen-2013-003367
- How much does physical therapy cost? (2015) Retrieved from Cost Helper website: http://health.costhelper.com/physical-therapist.html
- Howard, A. F., Balneaves, L. G., Bottorff, J. L., & Rodney, P. (2011). Preserving the self: The process of decision making about hereditary breast cancer and ovarian cancer risk reduction. *Qualitative Health Research*, 21(4), 502-519. doi:10.1177/1049732310387798
- Hughes, A. J., Daniel, S. E., Kilford, L., & Lees, A. J. (1992). Accuracy of clinical diagnosis of idiopathic Parkinson's disease: a clinico-pathological study of 100 cases. *Journal of Neurology, Neurosurgery & Psychiatry, 55*(3), 181-184. doi: 10.1136/jnnp.55.3.181
- Institute of Medicine (IOM). (2012). *Living well with chronic illness: A call for public health action.* DC: The National Academies Press.
- Jaywant, A., & Pell, M. D. (2010). Listener impressions of speakers with Parkinson's disease. Journal of the International Neuropsychological Society, 16(1), 49-57. doi: 10.1017/s1355617709990919

- Jones, A. L., Dwyer, L. L., Bercovitz, A. R., & Strahan, G. W. (2009). The National Nursing Home Survey: 2004 overview. National Center for Health Statistics. *Vital and Health Statistics, 13*(167). *Data from the National Health Survey*. Retrieved from http://www.cdc.gov/nchs/products/series/series13.htm
- King, K. M., & Jensen, L. (1994). Preserving the self: Women having cardiac surgery. *Heart & Lung*, 23(2), 99-105.
- Lepine, J. P. & Briley, M. (2011). The increasing burden of depression. *Neuropsychiatric Disease* and Treatment, 7(Suppl 1), 3-7. doi:10.2147/ndt.s19617
- Marder, K. (2010). Cognitive impairment and dementia in Parkinson's disease. *Movement Disorders, 25*(S1), S110-S116. doi:10.1002/mds.22787
- Mead, G. H. (1934). Mind, Self, and Society: From the Standpoint of a Social Behaviorist (C. W. Morris Ed. reprint ed.). Chicago, IL: University of Chicago Press.
- Milisen, K., Braes, T., Fick, D. M., & Foreman, M. D. (2006). Cognitive assessment and differentiating the 3 Ds (Dementia, Depression, Delirium). *Nursing Clinics of North America*, 41(1), 1-22. doi:10.1016/j.cnur.2005.09.001
- Miller, N., Noble, E., Jones, D., & Burn, D. (2006). Life with communication changes in Parkinson's disease. *Age and Ageing*, *35*(3), 235-239. doi: 10.1093/ageing/afj053
- Morse, J. M. (2012). *Qualitative health research: Creating a new discipline*. Walnut Creek, CA: Left Coast Press.
- Morse, J. M., & Johnson, J. (1991). Toward a theory of illness: The illness constellation model. In J. M. Morse & J. Johnson (Eds.), *The illness experience: Dimensions of suffering* (pp. 315-342). Newbury Park, CA: Sage.
- National Council on Aging (NCOA). (2016). *Protecting programs that improve the lives of seniors.* Public Policy & Action, Federal Budget. Retrieved from https://www.ncoa.org/public-policy-action/federal-budget/
- Nijhof, G. (1995). Parkinson's Disease as a problem of shame in public appearance. Sociology of Health & Illness, 17(2), 193-205. doi: 10.1111/1467-9566.ep10933386
- Olanow, C. W., Stern, M. B., & Sethi, K. (2009). The scientific and clinical basis for the treatment of Parkinson disease (2009). *Neurology*, 72(21 Supplement 4), S1-S136. doi: 10.1212/WNL.0b013e3181a1d44c
- Pennington, S., Snell, K., Lee, M., & Walker, R. (2010). The cause of death in idiopathic Parkinson's disease. *Parkinsonism & Related Disorders, 16*(7), 434-437. doi:10.1016/j.parkreldis.2010.04.010
- Pinder, R. (1992). Coherence and incoherence: Doctors' and patients' perspectives on the diagnosis of Parkinson's disease. Sociology of Health & Illness, 14(1), 1-22. doi: 10.1111/j.1467-9566.1992.tb00111.x
- Pretzer-Aboff, I., Galik, E., & Resnick, B. (2009). Parkinson's disease: Barriers and facilitators to optimizing function. *Rehabilitation Nursing, 34*(2), 54-60. doi: 10.1002/j.2048-7940.2009.tb00249.x

- Pringsheim, T., Jette, N., Frolkis, A., & Steeves, T. D. L. (2014). The prevalence of Parkinson's disease: A systematic review and meta-analysis. *Movement Disorders*, 29(13), 1583-1590. doi:10.1002/mds.25945
- Rahman, S., Griffin, H. J., Quinn, N. P., & Jahanshahi, M. (²011). On the nature of fear of falling in Parkinson's disease. *Behavioural Neurology*, 24(3), 219-228. doi:10.3233/BEN-2011-0330
- Reijnders, J.S.A.M., Ehrt, U., Weber, W.E.J., Aarsland, D., & Leentjens, A.F.G. (2008). A systematic review of prevalence studies of depression in Parkinson's disease. *Movement Disorders*, 23(2), 183-189. doi: 10.1002/mds.21803
- Schepens, S., Sen, A., Painter, J. A., & Murphy, S. L. (2012). Relationship between fall-related efficacy and activity engagement in community-dwelling older adults: a meta-analytic review. *The American Journal of Occupational Therapy*, *66*(2), 137-148. doi:10.5014/ajot.2012.001156
- Scherder, E., Eggermont, L., Swaab, D., van Heuvelen, M., Kamsma, Y., de Greef, M., ... Mulder, T. (2007). Gait in ageing and associated dementias; its relationship with cognition. *Neuroscience & Biobehavioral Reviews*, *31*(4), 485-497. doi:10.1016/j.neubiorev.2006.11.007
- Strauss, A. L., Corbin, J., Fagerhaugh, S., Glaser, B. G., Maines, D., Suczek, B., & Weiner, C. L. (Eds.). (1984). *Chronic illness and the quality of life* (2nd ed.). St. Louis, MO: C. V. Mosby.
- Syed, S., Gerber, B., & Sharp, L. (2013). Traveling towards disease: Transportation barriers to health care access. *Journal of Community Health*, 38(5), 976-993. doi:10.1007/s10900-013-9681-1
- Tweed, A. & Charmaz, K. (2012). Grounded theory methods for mental health practitioners. In D. Harper & A. R. Thompson (Eds.), *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners* (pp. 131-146). West Sussex, UK: John Wiley & Sons, Ltd.
- Ward, B. W., Schiller, J. S., & Goodman, R. A. (2014). Multiple chronic conditions among US adults: A 2012 update. *Preventing Chronic Disease, 11*, E62. doi:10.5888/pcd11.130389
- Weintraub, D., Comella, C. L., & Horn, S. (2008). Parkinson's disease--Part 1: Pathophysiology, symptoms, burden, diagnosis, and assessment. *American Journal of Managed Care*, 14(2 Suppl), S40-48. Retrieved from <u>http://www.ncbi.nlm.nih.gov/pubmed/18402507</u>
- Wenning, G. K., Krismer, F., & Poewe, W. (2011). New insights into atypical parkinsonism. *Current Opinion in Neurology, 24*(4), 331-338. doi:10.1097/WCO.0b013e3283480569
- Wressle, E., Engstrand, C., & Granérus, A.-K. (2007). Living with Parkinson's disease: Elderly patients' and relatives' perspective on daily living. *Australian Occupational Therapy Journal*, 54(2), 131-139. doi: 10.1111/j.1440-1630.2006.00610.x
- Yogev-Seligmann, G., Hausdorff, J. M., & Giladi, N. (2008). The role of executive function and attention in gait. *Movement Disorders, 23*(3), 329-342. doi: 10.1002/mds.21720

CHAPTER 2

REVIEW OF THE LITERATURE

The problems of everyday living for people with Parkinson disease are rarely considered. Healthcare providers do not understand and lack confidence in their clinical knowledge of neurological disorders (Counihan & Anderson, 2011). Believing they have little possibility of developing this illness, the lay public reacts with fear and worries (Werner & Korczyn, 2010). Societal misunderstandings towards and about those with parkinsonism limits healthcare, potentiates stigmatizing attitudes, and contributes to social isolation.

The purpose of this chapter is to consider aspects of everyday life within the context of personal situations and relationships that influence the challenges and strategies of maintaining identity for people with parkinsonism. In keeping with the grounded theory method (Glaser & Strauss, 1967), this preliminary literature review was developed to identify a range of issues surrounding the phenomena of interest and serves to set the stage for subsequent chapters. Thus, this chapter is a foundation for the developing conversations throughout this dissertation (Charmaz, 2014).

This chapter is presented in several sections. The sensitizing concept, *Preserving self* (Johnson, 1991), and its relevance for people with parkinsonisim is discussed. The consequence of not being able to *Preserve self* is the loss of self (Charmaz, 1983). An overview of symptoms is provided to facilitate interpretation of how people with Parkinson disease might understand the information. For example, motor symptoms are defined alongside how these symptoms might be experienced. I describe everyday life and its relationship with identity. The research on living with parkinsonism and its influence on identity will be analyzed. Other illnesses or conditions may be integrated into this review for purposes of comparison. An overall summary is provided at the end of this chapter.

The Sensitizing Concept: Preserving Self

A sensitizing concept provides an organizing frame of reference that suggests directions for forming interview questions, listening to participants, and thinking about data (Blumer, 1954; 1956; Charmaz, 2006a). In my research, *Preserving self* was used as a conceptual frame for inductively building interpretations, understanding, and developing a theory reflecting processes of identity maintenance by people with Parkinson disease.

The concept of *Preserving self* was identified by Johnson (1991) as an element of the recovery process for women who had experienced a myocardial infarction (MI). Becoming a heart attack victim meant physical restrictions and beliefs that each woman was "less than" and could never be as she was before. They experienced changes in self-confidence, worth, and independence. It was difficult for the women to watch others do "their work." Role transitions were managed by "bending the rules" to participate in restricted activities, rather than watching and feeling dependent. These women preserved self by working to gain control by asserting themselves.

Other studies have described *Preserving self* within the context of physical or psychological threats. Experiences of interest included preillness decision-making (Howard, Balneaves, Bottorff, & Rodney, 2011), diagnostic waiting (Morse et al., 2014), surgical recovery (King & Jensen, 1994), traumatic injuries (Morse & O'Brien, 1995; Zamanzadeh, Valizadeh, Lotfi, & Salehi, 2015), and chronic illness (Charmaz, 1994; 2006b). Additionally, the concept of *Preserving self* and the nursing profession has been discussed in the literature, for example, Irurita & Williams (2001). Discussions in this manuscript focus on patient-centered research.

There are differences in the *Preserving self* research. Methodologically, content analysis was used by Zamanzadeh et al. (2015) while Howard et al. (2011) extensively analyzed the context of women's decision-making. More importantly, participants were primarily females experiencing a healthcare crisis. However, Johnson's study (1991) included a subset of men and women within four years of an MI and Morse and Obrien (1995) spoke with participants after time had elapsed since the traumatic injury. Both of these instances point to situations of chronicity. Participants of two studies (Charmaz, 1983; 2006b) were specifically selected because of a

chronic illness. Female participants outnumbered men for seven of the eight studies (88 F/ 51 M). Charmaz (2006b) did not quantify gender distribution and, instead, reported the total data as the number of interviews. This might suggest that *Preserving self* is a process experienced predominately by females facing a crisis. Instead, a second consideration is that the aims of prior study focused on women. The strategies used to *Preserve self* were similar between the genders regardless of the study method or context. Table 2.1 describes the aims, study design, and participants of prior *Preserving self* research.

Author (year)	Study Aim	Design	Participants
Johnson (1991)	To gain an understanding of experiences following an MI	Grounded theory	n=14 (7 F/ 7 M)
Charmaz (1994)	To describe men's experiences of identity issues in chronic illness	Grounded theory	n=20 (20 M)
King & Jensen (1994)	To explore processes women undergo when having cardiac surgery	Grounded theory	n=10 (10 F)
Morse & O'Brien (1995)	To examine the experience of traumatic injury To describe becoming a victim through to disabled person	Grounded theory	n=19 (3 F/ 16 M)
Charmaz (2006b)	To describe how chronically ill people use pursuits for assessing their health rather than symptoms	Grounded theory	165 qualitative interviews
Howard et al. (2011)	To gain an understanding of hereditary breast and ovarian cancer risk-reducing decision- making processes of women with BRCA1/2 mutations	Grounded theory	n=22 (22 F)
Morse et al. (2014)	To describe women's emotional responses when facing possibility of breast cancer	Grounded theory	n=37 (37 F)
Zamanzadeh et al. (2015)	To investigate burn patients' experiences of preserving self after burn injury in Iran	Content analysis	n=17 (9 F/ 8 M)

Table 2.1. Aims, design, and participants of prior *Preserving self* research.

The Loss of Self

If *Preserving self* strategies are not successful, the consequence is the loss of self (Charmaz, 1983). "Loss of self symbolizes more than bodily losses. It means loss of the ways people know, define, and feel about themselves" (Charmaz, 2011, p. 178). Multiple and repeated losses of valued physical, social, and psychological functioning are demonstrated through passivity, lowered self-worth, and social withdrawal. This loss of personal identity is continuum based with varying levels of vulnerability, sensitivity, and loss (Charmaz, 1983).

Health care professionals have opportunities to work effectively with people by recognizing inherent illness challenges, potentials for suffering, and loss of self. Expanding professional capabilities to include techniques of empathic understanding becomes supportive of an ill person's everyday activities and attitudes in order to *Preserve self*. I will return to this discussion of the self in Parkinson disease, following a discussion of symptom impact and social context.

Symptoms of Parkinson Disease

People have knowledge about their condition (some of which is accurate and some is not) and throughout their stories, illness characteristics are mentioned. Because this study examines everyday illness experience from personal perspectives, a description of major symptoms is provided.

Nonmotor Symptoms

All symptoms that are not movement-related (motor) are considered nonmotor. These symptoms are common, wide-ranging, and significantly influence life by effecting every social, psychological, and physical function. People do not always report these symptoms nor are they easily recognized by health care professionals (Chaudhuri, Odin, Antonini, & Martinez-Martin, 2011). These encompassing symptoms become a preoccupation through daily life. Table 2.2 (p. 22) summarizes the nonmotor symptoms.

Category	Neuropsychiatric	Sensory	Autonomic function	Drug-induced
Symptoms	Apathy Anxiety Dementia Depression	Pain Paresthesias Visual disturbances Olfactory	Constipation Bladder disturbances Dysphagia Drooling	Psychosis Impulse control disorders Dyspnea Skin reactions
		changes		

Table 2.2. Range of nonmotor symptoms in Parkinson disease.

Adapted from: Chaudhuri et al., 2011; Weintraub, Comella, & Horn, 2008.

Motor Symptoms

The three cardinal movement symptoms are bradykinesia, tremor, and rigidity. Postural instability is a major symptom, but generally appears later. Changes in movement and balance continue through the illness until eventually the person becomes bed-bound, requiring complete assistance with all activities of living (Dickson, 2012). Table 2.3 (p. 23) describes these symptoms with examples of daily life impact.

Disease staging. The Hoehn and Yahr (HY) Disease Staging Scale (Hoehn & Yahr, 1967) is the traditional parkinsonian staging criteria for describing motor impairment and balance; it does not rate function. The Movement Disorder Society recommends, "rate what you see" (Goetz et al., 2004); this is important considering the presence of multiple chronic illnesses. Purposes for measuring impairment include describing clinical status, determining interventions, planning for the next phase of disability, and aiding with prognostic significance (Goetz et al., 2004; Hoehn & Yahr, 1967). HY staging is discussed further in Chapter 3, Methods.

Several qualitative researchers (for example, Hermanns, Deal, & Hass, 2012) have expressed concern about motor staging. Studies lacking descriptions of participant's levels of impairment have been pointed to as examples of design weakness. Yet, simultaneously, these same researchers argue that the presence of motor staging potentially represents poor methodological construction due to the availability of multiple scales. These concerns represent a lack of knowledge regarding the purpose administration techniques of individual scales. Yet the HY is simple, easily administered, and provides a visual image of impairment (Goetz et al., 2004; Hoehn & Yahr, 1967). This is the rationale for selecting this instrument.

Symptom	Description	Example of Personal Impact
Bradykinesia	Changes in movement rate and quality Delayed initiation Slowness Minimal movement Reduced spontaneity Example: blinking, smiling, and grimacing, which gives the face a mask-like, expressionless appearance	Often noticed first by family & friends Movements take more time Movement ability unpredictable day to day or moment to moment Turning becomes increasingly difficult Sensation of being 'stuck' to the ground Former spontaneous movements may need conscious effort: Clearing the throat, blinking, swallowing, or changing position Difficulties with: Cutting food, eating, buttoning shirts, tying shoelaces Handwriting becomes slower and smaller Walking becomes slower with shuffle Steps can become quick and precipitous as if falling forward Swallowing, digestion, and bowel movements become slower.
Tremor	A repetitive back-and-forth movement occurring when that part of the body is not actively moving Can affect hands, feet, jaw, head, trunk	Embarrassment Shame Difficulties eating, dressing The tremor is most marked at rest Improves when performing a task or during sleep
Rigidity	Increased resistance to passive joint movement Increased muscular tone	Described as an uncomfortable sensation of feeling stiff May experience: Problems turning around, getting out of a chair, rolling over in bed, making fine finger movements Stooped posture Difficulty making facial expressions
Postural Instability	Impaired recovery or reaction when balance is thrown off Balance and posture can deteriorate during later stages	Problems with walking and turning around Difficulty rolling over in bed & getting in and out of chair Potential for falling

Table 2.3. The primary motor symptoms of Parkinson disease.

Adapted from Mazzoni, Shabbott, & Cortés, 2012

Other qualitative researchers provide HY staging results but do not correlate levels of impairment or disease burden in the results or discussion sections (e.g., Wressle, Engstrand, & Granérus, 2007 or Hodgson, Garcia, & Tyndall, 2004). Some researchers ask participants to rate and report their own HY stage (Phillips, 2006) without discussing the reliability and validity of this approach. While still others used terms such as "advanced" or "late stage" without defining these illness measurements (Williams & Keady, 2008).

The Institute of Medicine (2012) describes the impact of symptoms, functional impairment, and requirements for care as representing "the disparate patterns of human suffering" (p. 52). These patterns are defined as early, moderate, and late stage chronic illness. Early stage illnesses cause little or no impairment and others have little burden. Moderate stage illnesses have a moderate degree of impairment, higher management needs, and often interfere with a person's lifestyle. Late or advanced stages represent illnesses with high levels of impairment and significant care needs. This stage is generally considered terminal. The categorical HY descriptions represent the motor disability, while the broader terms of mild, moderate, and advanced indicate the lifestyle impairment. Both sets of terms are used, as applicable, in this manuscript to ensure descriptive clarity.

Everyday Life for People K ith Parkinson Disease

Everyday life is mundane, routine, familiar, and habitual (Bennett & Watson, 2002). It represents where and how people learn about and demonstrate who they are. When looking at the actualities of life for people with parkinsonisim, we are provided a glimpse into the harsh realities of physical and emotional struggles while trying to live normally. Successfully balancing the responsibilities of daily life with the routines of illness are goals for people wishing to remain living at home.

Language and Communication

How we understand people and circumstances is based on shared meanings achieved through communication. Language-based socialization develops our identities and organizes behavior with templates of action based on societal and family norms (Blumer, 1969; Mead, 1934; Schwalbe, 1983). We express, present, and transform our selves through language. Specialized terminology, unclarified nonverbal communication, and atypical voice or speech patterns affect a speaker's ability to be understood and ultimately influencing the speaker's identity through selfevaluations (Schwalbe, 1983).

Speech and voice characteristics. Changes in speech and language production begin early in the disease process effecting 70 to 90% of people. The voice develops softness,

diminished strength, hoarseness, and eventually becomes unintelligible (Pinto et al., 2004). All stages of language production are affected including content of information, spoken grammar, disrupted fluency, and reduced complexity (Altmann &Troche, 2011). Quantitative researchers have suggested these deficits result from impaired breathing and swallowing coordination (Gross et al., 2008), laryngeal disorders (Hammer & Barlow, 2010), diminished dopamine (Goberman & Coelho, 2002), cognitive impairment (Monetta & Pell, 2007), or depression (Fernandez et al., 2009).

While some qualitative researchers mention communication difficulties for people with parkinsonisim and their families (Hounsgaard, Pedersen, & Wagner, 2011; Hudson, Toye, & Kristjanson, 2006), there is but a single frequently cited study examining the experience of communication difficulties. As part of a larger quantitative study, Miller, Noble, Jones, and Burn (2006) conducted a content analysis with constant comparison to consider the impact of communication changes on the lives of people with Parkinson disease. The 37 volunteers (23 M/14 F) were purposively selected to include varying disease stages, duration, gender, and speech difficulties (notably voice strength and intelligibility). Participant descriptions included mental status, depression rating, HY, disease duration, and speech intelligibility that were provided in table format and with each narrative. However, these quantitative descriptions and the relevance for communication changes were not discussed.

Home-based semistructured interviews focused on speech changes, their impact, and strategies used to manage the changes (Miller et al., 2006). Of greatest concern for these participants was their (in) ability to be understood. The speakers thought listeners did not appreciate their speaking difficulties and talked over or for them. People felt they were labeled as stupid or inadequate through their continual efforts to participate in conversations, highlighting the stigmatizing impact of speech difficulties. Frequent responses included depression and withdrawal. Types of coping strategies were inconsistently used and depended on fatigue, competing illness symptoms, and the number of people involved in the conversation. Parr (2007) points to a lack of research involving people with speech and communication disorders. The available qualitative research is disproportionately vast when compared with Parkinson disease.

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We might assume these findings can be applied to all speech and communication disorders, but evidence is lacking.

Medical language. Analogies and metaphors can be helpful when explaining concepts. Nonetheless, when explanations about an illness or symptoms depend solely on literary devices, any information provided can lead to confusion and misunderstanding. For example, the reduced spontaneity of facial musculature (hypomimia) is typically referred to as facial masking.

Research was not identified which examined lay understanding of neurological terms; although general medical literature discusses assumptions and misunderstandings between health providers and lay people. Surprisingly, few lay people understand anatomy, body functioning, and related medical terminology. This is true regardless of age or health status. Chapman and colleagues (2003) investigated lay knowledge of cancer terms and anatomy and found only 52% of their sample understood "the tumor is progressing" was a phrase meant to imply bad news. Three (2.7%) of 111 adolescent females were able to write an accurate definition for the term Pap smear, while 68% thought a pap smear was the same as a pelvic examination (Blake, Weber, & Fletcher, 2004).

Healthcare providers commonly assume or overestimate lay people's understanding of medical information; while simultaneously, the lay public may overestimate their comprehension (Engel et al., 2009). Kelly and Haidet (2007) suggest this discrepancy may be a source of incongruous care goals.

Conclusion. Language is inextricably bound with identity. As a major influence on selfworth, isolation, and stigma, a concerning lack of research has been done in the area of Parkinson disease communication. The essential role of speech and language for maintaining roles, relationships, and one's self-identity have not been sufficiently explored. Unwittingly, clinicians may be contributing to misunderstandings with the use of jargon, specialized terminology, or assuming nonclinician's knowledge of bodily functions.

Mobility and Movement

How we understand the world, relationships, and ourselves are through sensory experiences of vision, smell, hearing, touch, or movement. Consequently, we do not exist as separate entities from our bodies. The psychological, physical, and sensory elements of our identities are not individually distinct nor concretely fastened together but are a vacillating form. These statements represent the concept of embodiment. Illness brings the body into awareness, disrupting the background synchrony of identity (Merleau-Ponty, 1962).

Falls. Older adults and people with chronic illness commonly experience falls and subsequent physical, social, and psychological consequences. Quantitative Parkinson disease research has focused on predicting, estimating prevalence, and preventing falls. Although numerous qualitative studies examine falls, illnesses of participants are rarely specified. This may be because the purpose of most of the qualitative studies is to gather data for developing fall prevention programs. Qualitative fall research have described common aims for developing fall prevention programs (Hanson, Salmoni, & Doyle, 2009; Bailey, Jones, & Goodall, 2014; Nyman, 2011; Shaw, Connelly, & McWilliam, 2015). There has been no research specifically examining falls in Parkinson disease.

Fall risk factors are dissimilar among chronic illnesses and the general population. Balance problems while dressing was the strongest fall risk factor for women one year poststroke, while residual motor symptoms were not (Lamb et al., 2003). The lung hyperinflation and inspiratory muscle weakness of chronic obstructive pulmonary disease (COPD) increases reliance on ankle proprioceptive signals thereby decreasing the needed reliance on back musculature, subsequently causing postural instability (Janssens et al., 2013). Anxiety has been associated with falls; however, the relationship has not been clearly defined (Hallford, Nicholson, Sanders, & McCabe, 2016). Because of gait and posture changes, fall occurrence increases and falls should be expected throughout the course of Parkinson disease.

One group of qualitative researchers commented that while people with parkinsonisim periodically spoke of falls, this was not the aim of their study (daily activities) and was not explored with participants (Benharoch & Wiseman, 2004).

Conclusion. As a traumatic consequence of physical losses and contributing to a person's future, falls present as an unexplored influence in loss of self. The qualitative literature is lacking in examining the falls of Parkinson disease. Considering the declaration of falls as a

major public health concern (Center for Disease Control, 2014), this is a major omission.

Freezing of gait. The term freezing is used to describe a lack of movement or a sudden unpredictable inability to move during walking or other activities (Nutt et al., 2011). This is a symptom unique to Parkinson disease. These episodes are considered a response to decreasing availability of systemic levodopa or the disease process. Additionally, strong emotions (such as anxiety) may precipitate freezing during stressful situations, in crowds, and when encountering narrow hallways or stairs (Rahman, Griffin, Quinn, & Jahanshahi, 2008; Ehgoetz Martens, Ellard, & Almeida, 2014). However, the cause is speculative.

While describing overall experiences of Parkinson disease, qualitative studies frequently (but briefly) mention gait freezing. These narratives relate the intensity of freezing to be socially isolating, incapacitating, immobilizing, unpredictable, causing havoc, and limiting activities (Nijhof, 1995; 1996; Benharoch & Wiseman, 2004; Marr, 1991; Stanley-Hermanns & Engebretson, 2010; Wressle et al., 2007). Participants of two quantitative nursing studies (Abudi, Bar-Tal, Ziv, & Fish, 1997; Backer, 2006) rated freezing of gait as one of the most distressing symptom experiences with reverberating detrimental effects. Freezing contributes to daily life difficulties and is a major antecedent to falls (Schrag & Quinn, 2000).

This phenomenon has been primarily studied by neurology and physical therapy. It can be difficult to elicit freezing of gait in a laboratory or clinical setting (Nieuwboer & Giladi, 2008), participants often do not understand the terms, resulting in the use of video presentations of freezing examples. (Nieuwboer et al., 2009; Snijders, Haaxma, Hagen, Munneke, & Bloem, 2012). Questionnaires for measuring freezing were developed using a patient-derived phrase, "feeling like being glued to the floor," also resulted in many participants not understanding. Interviews designed to elicit an understanding of each person's definition would likely yield more useful study data.

A single qualitative study was identified which specifically examined freezing. Redmond and Suddick (2012) used an interpretive phenomenological approach to understand experiences of gait freezing. Semistructured interviews (one in-person and five telephone) were completed with six participants. Data was analyzed thematically. There are several concerns with the study design. First, the participant characteristics were not sufficiently described to visualize or understand home environments, medication, or degrees of motor impairment. Second, although the investigators reported the duration of illness (7 to 17 years) and length of time experiencing freezing (6 months to 13 years), this information is not connected to the results, not discussed further, thereby becoming irrelevant. Third, phone interviews limit depth of disclosure and prevent observing environments, triggers, or potential freezing episodes.

Conversely, the results and discussion are presented with insightful sensitivity. Freezing in public brought humiliation, shame, and avoidance of others. During the experience, people felt intense anxiety, building to panic, and depression. Participants varied in precipitating factors, how the freezing was experienced, and styles of attempting to overcome the episodes. Planning was "senseless" as everything stopped; it controlled all activities and relationships. The results identified one major theme, freezing was a larger than life entity. Most felt that they had to handle the situation on their own, reporting that no information had been received from their healthcare provider (Redmond & Suddick, 2012).

There are discrepancies between research perspectives. Quantitative research has reported freezing episode durations from seconds to minutes with more severe episodes lasting approximately 30 s (Giladi & Nieuwboer, 2008). These findings are not confirmed by Redmond and Suddick (2012), instead, they report narratives describing freezing episodes lasting for several hours. Quantitative researchers made a point of defining freezing of gait, whereas Redmond and Suddick did not do this, adding that this was a limitation to their study. The participant's understanding of freezing was used but not explicitly stated.

Conclusion. All researchers agree freezing of gait is common, is caused by and produces anxiety, and contributes to falls. However, consistent definitions are lacking. Little attention has been given to the contextual experience or participants' descriptive terminology for freezing of gait episodes. Qualitative research has contributed little evidence to this poorly understood phenomenon.

Activities of daily living. Cognitive impairment, depression, lower frequency of social contacts, and low physical activity levels are most strongly associated with declining functional

status (Stuck et al., 1999). Decreasing activity of daily living (ADLs) performance has been associated with increased mortality regardless of gender, or form of chronic illness (Millán-Calenti et al., 2010).

The continually declining motor function of Parkinson disease has a profound effect on abilities to complete ADLs, increase dependency, and may influence the capability for community living (Pretzer-Aboff, Galik, & Resnick, 2009; Wressle et al., 2007). Over time, navigating through the environment and performing basic tasks as dressing, eating, or toileting become increasingly difficult and time-consuming (Pretzer-Aboff et al., 2009). Daily routines are further complicated by speech difficulties, drooling, difficulty swallowing, and unpredictable symptom fluctuation (Schrag & Quinn, 2000). Eventually, the ability to manage personal care and routines is lost. Responsibilities fall onto family members or friends who are untrained, unsure, and experiencing difficulties of their own frustrations or illness (Caap-Ahlgren, Lannerheim, & Dehlin, 2002; Edwards & Scheetz, 2002; Davey, Wiles, Ashburn, & Murphy, 2004).

Conclusion. The ability to perform personal hygiene, eat, or use the toilet produce diminishing independence, changing relationships, and predict a shortened life span; thereby, directly affecting a person's sense of self.

Driving. The inability to drive is a major contributor to social isolation. Roles in the family, perceptions of independence, access to services such as healthcare, and the shaping of one's self are all influenced by the ability to drive. Becoming an ex-driver limits activities outside of the home, reduces opportunities for socialization, and is associated with increasing symptoms of depression (Marottoli et al., 1997; Ragland, Satariano, & MacLeod, 2005). The pervasiveness of this loss is described by Rothe (1994) as a stressful life event, comparable to widowhood or retirement.

Controlling Motor Symptoms

Medications. Currently, antiparkinsonian medications effectively, but temporarily, relieve many motor and nonmotor symptoms. However, disabling side effects appear within approximately 8 years, medications eventually become ineffective (Olanow, Stern, & Sethi, 2009). Medication takes a larger than life role as people strive to find relief. People with Parkinson

disease have a special relationship with medication that is bound with contrasting sentiments of hope, despair, independence versus dependence, and symbolic representations of individualism and personal control (Levin & Idler, 1983). All of the qualitative research makes note of medications. Three themes have been identified: thinking about medications, balancing symptoms, and adherence.

Thinking about medications. This theme represents general descriptions of how people think about medications. Daily activities are a struggle, with much effort spent determining medication timing for controlling symptoms and obtaining relief (Habermann, 1996; Phillips, 2006; Stanley-Hermanns & Engebretson, 2010). People worry about when wearing-off might occur, being without needed medication (Redmond & Suddick, 2012), or wonder if the self-adjusted dose taken was enough or too much (Marr, 1991). Reluctance to start antiparkinson medications has been associated with fears of side effects (Mestre et al., 2014), developing a drug immunity, concerns of future deterioration, or developing a drug addiction. Hopes for disease altering medications were common (Phillips, 2006; Stanley Hermanns & Engebretson, 2010). Essentially, the literature describes people with Parkinson disease as being overly preoccupied with medications. Joachim and Acorn (2000) discussed pervasive medication preoccupations in chronic illness as contributing to isolation.

Balancing symptoms. People learned about medication for decisively controlling their symptoms. In the early stages, information was obtained from the internet, lay publications, or support groups. During the early honeymoon years of the illness, medications are generally effective: symptoms are managed, people are able to work, and routines continue without major disruption (Ghoche, 2012). Book knowledge was set aside when symptoms progressed to the middle stages (HY III to early IV); symptoms became a controlling force (Habermann, 1996). Practical knowledge developed over time by experimenting with medication doses, frequency, and paying attention to physical responses (Habermann, 1996). People became their own experts, learning to evaluate sensory premonitions and physical signs for planning activities and determining dosing strategies. Some paid attention to diet and exercise as a means to improve medication benefits (Habermann, 1996; Marr, 1991; Stanley-Hermanns & Engebretson, 2010).

Nightmares, a medication side effect, necessitated separate beds for partners, causing a change in the sense of closeness (Habermann, 2000).

It is difficult to hide parkinsonisim when tremors are visible or with public freezing episodes. Successfully alleviating (hiding) symptoms contributed to detailed preoccupations regarding medication timing (Joachim & Acorn, 2000) to ensure socializing, driving, and working. Conversely, medication side effects may call attention to the condition. One couple had not shared the diagnosis with other family members, but eventually misunderstandings forced disclosure of the illness. The adult child would not let her children be alone with the couple because she believed the grandparent with Parkinson disease was "stoned". The altered mentation and physical signs seen by the adult child were actually medication side effects (Hodgson et al., 2004).

Middle-aged midstage people with Parkinson disease spoke at length about medications and relationships with their healthcare provider. Interactions centered on drug frequency and dosing. Participants felt they had to lie about how they actually used prescribed medication. Although they knew about medications from symptom responses to experimentations, they did not speak about this with their physician. Providers were viewed solely as the medication source (Habermann, 1996).

Adherence. Issues of compliance, adherence, and coherence were addressed in a recent study of people with Parkinson disease and their medication use. The findings imply participants altered prescribed medication regimes to serve personal needs, such as looking attractive for a party (Drey, McKeown, Kelly, & Gould, 2012). A second study (Low, 2004) suggested that people with Parkinson disease likely demonstrated poor judgment when considering alternative treatments. The meaning of the risk-taking for the people was not explored.

Conclusion. Autonomous decisions for care at home are logical and necessary (Strauss et al., 1984). However, our idealized pictures of individualism do not reflect how people come to rely on their own decision-making capabilities (Levin & Idler, 1983). Independent medication decisions can be considered attempts to gain control over symptoms, one's life, and an unknown

future. Medications represent issues of power and control between prescribers and people taking the medication.

Relationships and Commitments

Families. During times of trouble, stress seems less painful with the presence of a supportive family. The family unit eventually becomes the source of emotional, physical, and financial support for people with Parkinson disease. However, needing or providing this support can be difficult for each family member. The concept of caregiver burden is well established in the literature. Depression, fatigue, faced with personal declining health and the loss of a valued partner are common experiences in the caregiver literature of chronic illness and Parkinson disease. Caregiver burden may be a universal experience.

To further understand caregiver burdens, Burton and colleagues (2012) conducted a cross sectional analysis involving 139 dyads with three chronic illnesses, cancer, heart failure, and COPD. Although differences were noted in patient functioning, illness severity and caregiver sociodemographic data, results indicated few differences in caregiver burden or psychosocial status by diagnosis. The predominant indicator of burden was an anxiety-driven need for more help with daily tasks. Similar results were found in a longitudinal cohort study conducted with 179 caregivers and their partners with advanced cancer, heart failure, or COPD (Garlo, O'Leary, Van Ness, & Fried, 2010).

Nevertheless, there are exceptions to the notion of caregiver universality. Men and women experience similar challenges in caregiving relationships; however, women experience greater anxiety if the partner's major symptom is cognitive impairment. The disproportionate number of dementia caregiving studies may skew this finding (Hooker, Manoogian-O'Dell, Monahan, Frazier, & Shifren, 2000).

Quantitative and qualitative Parkinson disease research provides consistent and congruent findings. Difficulties of providing informal care at home increase with increasing disability and symptoms, especially depression, confusion, hallucinations, or falls (Schrag, Hovris, Morley, Quinn, & Jahanshahi, 2006). One phenomenology studied the influence of Parkinson disease on marriages (Hodgson et al., 2004). Ten married couples were interviewed; the

affected partner had an average severity rating of HY stage III (n = 6). Some of the relationships had problems while others improved. All of the couples felt overwhelmed and felt an optimistic attitude was important to develop. Because couples were interviewed together, individual experiences were not a focus.

Divergent experiences were described for middle-aged spouses (Habermann, 2000) and their partners with midstage Parkinson disease (Habermann, 1996). Spouses became more involved in their own lives with friendships, careers, or school while describing a renewed sense of closeness with their ill partners. They were not aware of diminishing involvements, loss of closeness, or suffering experienced by their partner. Nor were they involved in day-to-day symptom management or care provision. It was challenging to watch their ill partner struggle, subsequently considering their role to be providers of support and encouragement (Habermann, 2000).

These middle-aged partners provide a strong contrast to the challenges faced by older female spouses caring for their husbands with Parkinson disease and psychotic symptoms (Williamson, Simpson, & Murray, 2008). Although illness durations were similar, symptom experiences were dramatically different. Spousal responsibilities increased with advancing illness and age.

The husbands experienced psychotic symptoms ranging from illusions, paranoia, to hallucinations, beginning about eighteen months prior to the study (Williamson et al., 2008). How wives responded to their husbands reflected anger and frustration that matched the increasing intensity of the psychosis. Sometimes wives reminded their partner that the symptom was not real, other times they played along to support any delusional fears, for example, by locking doors. At other times, wives spoke sharply or simply ignored their ill husbands. No longer knowing their husbands was very upsetting; his identity was becoming lost to the illness. One wife described how she divided her husband into two separate people to help her make sense of the situation. The accumulation of behavioral changes, psychosis, and continuing physical deterioration contributed to their loss experience (Williamson et al., 2008).

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Nursing home placement is influenced by increasing caregiving burdens in Parkinson disease; hallucinations are the single greatest precipitant (Goetz & Stebbins, 1993; Aarsland, Larsen, Tandberg, & Laake, 2000). One qualitative study used a grounded theory design to explain placement decisions as being caused by increasing physical demands placed on the caregiver, safety concerns due to repeated falls or hallucination directed behavior, and diminishing support services. Increasing caregiver strain corresponded to symptom severity (Abendroth, Lutz, & Young, 2012). This study confirmed prior knowledge regarding caregiver burden: (1) increasing disease severity requires major lifestyle adjustments, and 2) particular symptoms exacerbate a need for out-of-home placement. This study contributes to our understanding of dynamic process experienced by families while facing major decisions; ultimately influencing the identity of every family member.

Children and grandchildren. The parent-child bond is one of the most enduring relationships. It is realistic that most parents and children will spend more than 50 years of their life together, while grandchildren may spend a major portion of their lives with both parents and grandparents. Adult children may assume caregiver duties while facing their own chronic illness. Subsequently, grandchildren gain responsibilities for both parents and grandparents (Fingerman, Pillemer, Silverstein, & Suitor, 2012; Silverstein & Bengtson, 1997).

The earliest qualitative research involving children and parental Parkinson disease was done by in the United Kingdom by Roger Grimshaw (1991). His studies were built around social contexts and life stage concepts of the family unit by focusing on perspectives of children (ages 5 to 12) and young people (ages 16 to 24). Grimshaw's findings highlighted issues regarding deleterious effects on the children's social and emotional development including changing roles and relationships at home.

Several families were comprised of a parent with Parkinson disease and dependent children. They reported challenges involving waning energy levels and changing financial situations (Hodgson et al., 2004). Their children had difficulty accepting the illness, its prognosis, and losing a parent role model. Other children provided physical care and conversation. The married couples of Hodgson's study (2004) had adult children that were invited to participate in a second phenomenological study designed to explore their experiences (Blanchard, Hodgson, Lamson, & Dosser, 2009). The adult children were not primary care givers. Inner turmoil developed while the adult children watched the deteriorating effects of the illness on their parent. It became even more difficult when their own children no longer wanted to visit ailing grandparents. Many adult children wondered and worried about their future health. They hoped and wished their own children would remain close and provide care for them through aging and ill health.

Conclusion. Families nourish, nurture, creating a sense of connectedness and belonging. These relationships become a foundational source for identity development and maintenance. A proverbial line in the sand is drawn, indicating the end of caregiving. What the chronic illness and Parkinson disease literature largely demonstrates are viewpoints of the care giving spouse. Descriptions of family relationships from the perspective of people with the illness are pointedly missing.

The Self in Parkinson Disease

The Qualitative Literature

Circling identity issues in Parkinson disease research. Qualitative research, thus far, has not specifically examined self-identity. Instead, authors suggest the studied phenomena may have implications for the self (or identity). Several examples are presented. Caap-Ahlgren and her colleagues (2002) used a phenomenological design aimed at understanding experiences of living with Parkinson disease and its effect on life quality for eight older women. The analysis resulted in four themes: (1) wishing for a stable body image, (2) wishing to keep traditional female role, (3) needing to feel accepted, and (4) perceptions of stigma. These results were represented as having "a great impact" on the women; yet, concepts, concerns, or issues regarding the self-concept were not discussed. Self-identity terms or related concepts were not mentioned. Yet these findings have a direct influence on identity; the reader is left to consider potential relationships between the study findings and the self.

The phenomenological study of Todd et al. (2010) had two goals, to explore what delusional experiences mean for people with Parkinson disease and to examine how social or psychological factors contribute to these delusional beliefs. The analysis produced four themes all reflecting the following relationships between delusions and identity: (1) the emotional experience associated with delusions, (2) a sense of uncertainty and of losing control, (3) the loss of identity and sense of self, and (4) acceptance and adjustment to experience of delusions. Psychological interventions are suggested for reducing delusion-induced stress instead of medication treatment alone. A definition of the self is not provided nor is the relationship of the self-identity and delusions discussed theoretically.

Dementia and identity. Contrasting with the suggestions of self in the Parkinson disease qualitative literature, dementia research has extensively examined self-identity from various perspectives, such as continuity or interventions to maintain identity. People with dementia are often aware of their changing identity due to loss of role capabilities. There is evidence that people with dementia try to maintain a sense of identity while accommodating to changes (Clare, 2002; MacRae, 2010). Trying to keep up appearances or presenting themselves as normal are methods used to maintain a sense of identity (Pearce, Clare, & Pistrang, 2002), while continuing involvement in familiar activities can affirm and reinforce valued aspects of one's previous life (Kleiber, Hutchinson, & Williams, 2002).

Genoe and Dupuis (2011) conducted a phenomenological study to consider the role of leisure in recreating and sustaining identity in four people with early-stage memory loss. Participant losses contributing to identity assaults included occupation, abilities to perform household duties, loss of independence, and changing relationships. It was a difficult struggle for these people to face stigmatizing images of dementia and lowered expectations (often infantilizing). The findings suggested that identity was upheld through leisure activities by sustaining valued aspects of the self and emphasizing abilities.

Identity research and Parkinson disease. Three studies examine self-identity, two are grounded theory, and the third is a phenomenology. Although the grounded theory studies present interesting findings, inconsistencies are noted in methodological adherence.

Communication and relationships. Communication between people with Parkinson disease and their support person was examined in the first grounded theory study (Roger & Medved, 2010). Participants described how the diagnosis forced them to communicate with their support person about physical changes, fears, and new dependencies. The illness changed the content and form of the communication styles. It was important to be considered a partner and not a patient; they wanted to remain themselves. Finding normalcy was seen along a continuum, ranging from initial actions of what had been before through evolvement later in the illness as a new normal.

Theoretical sampling is a concern. The authors aimed for equal representation between two sample categories: people with Parkinson disease (n = 4) and care partners (n = 4). Although the authors reported theoretical sampling was used, it is not clear if this technique was actually implemented. This lack of clarity is due to highly specific inclusion criteria, needing sample representation, and a statement indicating an "initial hypotheses" directed the theoretical sampling. Later, the authors mention that they had searched for participants to provided data confirming the categories. The interview questions were stated to be open-ended but were presented as an initial structured interview guide, raising questions about the forcing of data to fit predetermined categories.

The authors (Roger & Medved, 2010) report Parkinson disease is a terminal illness, but they do not compare the terminal features of this condition with more commonly accepted terminal illnesses. Issues of chronicity are not discussed. The diagnosis of a changed identity is presented without description. This highlights a point made by Caddell and Clare (2013): without clearly identifying the framework used for the construct of self, it is difficult to draw conclusions or place the findings within the context of current literature. The findings contribute to our understanding for a continuum of communication changes between people with Parkinson disease and their support systems. Intimate relationships of long duration influence an individual's identity, in addition to parkinsonisim.

Biographies, bridging, and relationships. The purpose of Williams and Keady's study (2008) was to understand the experience of increasing disabilities and transitions of people with

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late-stage Parkinson disease and their families. Constructivist grounded theory was the study design. The authors described participants as being coresearchers; this process was not described or discussed. A visual technique of sequential diagrams depicting people's biographical stories was used for engaging participants. The study design and methods are unique and were described, but at times seems to represent a mixing of methods. Life history research, life story, time lining, the life history calendar, biographical narratives, and constructivist grounded theory are examples of the methods used or implied.

The center-stage diagram represented which symptom was important (at the time), what was done, and how it was managed. A biographical perspective connected events with life of the past, present, and future. The concept of bridging was used to connect time phases and was described as a way of understanding day-to-day living and decision-making.

People needed to review their life and reframe their perspectives In order to make sense of their present circumstances, Maintaining closeness required individuals and their care partner to understand their shared history of personal and shared significant events throughout life. Past experiences helped people shape identities, understand what was happening, and create a new life while facing the challenges of Parkinson disease. Bridging had three stages: (1) building on the past, (2) bridging the present, and (3) broaching the future. As the illness progressed, identity was (re)negotiated between the person, their care partner, and the healthcare professional. Framing and reframing past events created continuity and a shared sense of identity. Finding meaning in and protecting daily routines required establishing a pattern of responses to the symptoms. The final stage, broaching the future, was a balance between failing memory, difficulties in relationships, and failing health.

Nonadherence to the hallmark characteristics of grounded theory is noted: theoretical sampling was not used, constant comparison might be assumed, and theory development is present. The authors state constructivist grounded theory was chosen due to sharing of created knowledge and for theory generation. One of the goals of this study was to develop interventions from the findings, although preliminary results were presented before the last category was fully described (saturated). The data collection process of cocreated diagrams may have been a

preconceived intervention.

This study offers several contributions to the literature: (1) the processes of time and illness changes are integrated into phases, (2) potential influences for a changing self- identity are apparent, and (3) the authors suggestion that relationships are central to maintaining quality in life for people with Parkinson disease and their support people.

Case studies and continuity. The third study is a phenomenological secondary analysis (Habermann, 1999) of an earlier study (Habermann, 1996) of middle-aged midstage people with Parkinson disease. Three paradigm cases were used to describe how people faced the challenges of a life-long illness. The findings suggested that individuals maintained an intact identity by retaining a sense of continuity with their preillness self and keeping open to a range of future possibilities. Although Habermann described the study design and analytic methods, the construct of self was not defined.

Seeing the Challenges and Strategies

Our ability to make decisions and effectively act in the world is directly associated with our self-identity (self-concept). "What should I do?" "How should I act in this situation?" (Vandemark, 2007). To participate meaningfully in daily life requires these questions be answered; we need to make sense of the circumstances in front of us in order to act accordingly. Prescriptively, it may be thought that the action chosen may be one of two choices: this path or the other path. The dynamic responsive self relies on the inner socially created templates for action. The choices are not clear without prior context, socialization, or language experiences to form these templates. How a person derives their understanding of themselves is through relationships and vital social interactions. The person with Parkinson disease experiences multiple physical, social, and psychological losses that must be interpreted and reinterpreted within the social context of their daily lives to understand who they are, what to do, and how to act. If the care partner repeatedly ignores or speaks harsh, what then does the afflicted person know himself to be? If the older man with parkinsonisim sits in his favorite chair, there is continuity of a familiar self. Learning new communication skills requires a person to develop new self-understandings.

The opportunity to see the strategies used by people with Parkinson disease to reverse processes of losing the self occurs within the context of losses. Reversing this process refers to the struggles and strategies to maintain normal activities associated with the person, while these very abilities to maintain normal diminish. *Preserving self* is a social process of making new meanings for the person with Parkinson disease and then taking action based on these meanings and understandings. It is an attitude and a way of life.

Summary

The social and psychological aspects of a parkinsonian lifestyle remain poorly explored. While qualitative research has begun to describe the experience of Parkinson disease, further questions and deeper concerns have been elicited. Descriptions initiate deeper exploration. We do not know how the afflicted and their families handle these devastating changes on the person's self-concept. Subsequently, we do not understand the experience of facing challenges or the strategies used to *Preserve self*. What are the challenges and strategies used by people with parkinsonisim for maintaining identity? This research aims to increase our depth of understanding by considering these timely and relevant questions.

References

- Aarsland, D., Larsen, J. P., Tandberg, E., & Laake, K. (2000). Predictors of nursing home placement in Parkinson's disease: A population-based, prospective study. *Journal of the American Geriatrics Society, 48*(8), 938-942. doi:10.1111/j.1532-5415.2000.tb06891.x
- Abudi, S., Bar-Tal, Y., Ziv, L., & Fish, M. (1997). Parkinson's disease symptoms 'patients' perceptions. *Journal of Advanced Nursing*, 25(1), 54-59. doi:10.1046/j.1365-2648.1997.1997025054.x
- Abendroth, M., Lutz, B. J., & Young, M. E. (2012). Family caregivers' decision process to institutionalize persons with Parkinson's disease: A grounded theory study. *International Journal of Nursing Studies*, 49(4), 445-454. doi:10.1016/j.ijnurstu.2011.10.003
- Altmann, L. J., & Troche, M. S. (2011). High-level language production in Parkinson's disease: A review. *Parkinsons Disease, 2011*, 238956. doi:10.4061/2011/238956
- Backer, J. H. (2006). The symptom experience of patients with Parkinson's disease. *Journal of Neuroscience Nursing, 38*(1), 51-57. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/16568814
- Bailey, C., Jones, D., & Goodall, D. (2014). What is the evidence of the experience of having a fall across the life course? A qualitative synthesis. *Disability and Health Journal*, 7(3), 273-284. doi:10.1016/j.dhjo.2014.02.001
- Bennett, T. & Watson, D. (2002). Understanding everyday life. Oxford: Blackwell.
- Benharoch, J., & Wiseman, T. (2004). Participation in occupations: Some experiences of people with Parkinson's disease. *The British Journal of Occupational Therapy*, 67(9), 380-387. doi:10.1177/030802260406700902
- Blake, D. R., Weber, B. M., & Fletcher, K. E. (2004). Adolescent and young adult women's misunderstanding of the term Pap smear. *Archives of Pediatrics & Adolescent Medicine*, 158(10), 966-970. doi:10.1001/archpedi.158.10.966
- Blumer, H. (1954). What is wrong with social theory? *American Sociological Review*, *19*(1), 3–10. Retrieved from <u>http://www.jstor.org/stable/2088165</u>
- Blumer, H. (1956). Sociological analysis and the "variable." *American Sociological Review*, 21(6), 683–690. Retrieved from <u>http://www.jstor.org/stable/2088418</u>
- Blumer, H. (1969). *Symbolic interactionism: Perspective and method*. Berkeley, CA: University of California Press.
- Blanchard, A., Hodgson, J. H., Lamson, A., & Dosser, D. (2009). Lived experiences of adult children who have a parent diagnosed with Parkinson's disease. *The Qualitative Report*, *14*(1), 61-80. Retrieved from <u>http://www.nova.edu/ssss/QR/QR14-1/blanchard.pdf</u>
- Burton, A. M., Sautter, J. M., Tulsky, J. A., Lindquist, J. H., Hays, J. C., Olsen, M. K., . . . Steinhauser, K. E. (2012). Burden and well-being among a diverse sample of cancer, congestive heart failure, and chronic obstructive pulmonary disease caregivers. *Journal* of Pain and Symptom Management, 44(3), 410-420. doi:10.1016/j.jpainsymman.2011.09.018

- Caap-Ahlgren, M., Lannerheim, L., & Dehlin, O. (2002). Older Swedish women's experiences of living with symptoms related to Parkinson's disease. *Journal of Advanced Nursing*, 39(1), 87-95. doi:10.1046/j.1365-2648.2002.02245.x
- Caddell, L. S., & Clare, L. (2013). Studying the self in people with dementia: How might we proceed? *Dementia*, *12*(2), 192-209. doi:10.1177/1471301211418486
- Chapman, K., Abraham, C., Jenkins, V., & Fallowfield, L. (2003). Lay understanding of terms used in cancer consultations. *Psycho-Oncology*, *12*(6), 557-566. doi:10.1002/pon.673
- Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. Sociology of Health & Illness, 5(2), 168-195. doi:10.1111/1467-9566.ep10491512
- Charmaz, K. (1994). Identity dilemmas of chronically ill men. *Sociological Quarterly, 35*(2), 269-288. doi:10.1111/j.1533-8525.1994.tb00410.x
- Charmaz, K. (2002). The self as habit: The reconstruction of self in chronic illness. *The Occupational Therapy Journal of Research, 22*, 31S-42S. doi:10.1177/15394492020220S105
- Charmaz, K. (2006a). Constructing grounded theory: A practical guide through qualitative analysis. Thousand Oaks, CA: Sage Publications.
- Charmaz, K. (2006b). Measuring pursuits, marking self: Meaning construction in chronic illness. . International Journal of Qualitative Studies on Health and Well-Being, 1(1), 27-37. doi:10.3402/qhw.v1i1.4906
- Charmaz, K. (2011). A constructivist grounded theory analysis of losing and regaining a valued self. In F. J. Wertz, K. Charmaz, L. M. McMullen, R. Josselson, R. Anderson, & E. McSpadden (Eds.), *Five ways of doing qualitative analysis*. (pp. 165-203). NY: Guilford.
- Charmaz, K. (2014). Constructing grounded theory (2nd ed.). Thousand Oaks, CA: Sage.
- Chaudhuri, K. R., Odin, P., Antonini, A., & Martinez-Martin, P. (2011). Parkinson's disease: The non-motor issues. *Parkinsonism & Related Disorders, 17*(10), 717-723. doi:10.1016/j.parkreldis.2011.02.018
- Clare, L. (2002). We'll fight it as long as we can: Coping with the onset of Alzheimer's disease. Aging & Mental Health, 6(2), 139-148. doi:10.1080/13607860220126826
- Counihan, T. J. & Anderson, D. C. (2011). Stamping out neurophobia: A new hypothesis? *Neurology*, 77(14), 1328-1329. doi:10.1212/WNL.0b013e318231531b
- Davey, C., Wiles, R., Ashburn, A., & Murphy, C. (2004). Falling in Parkinson's disease: The impact on informal caregivers. *Disability and Rehabilitation*, 26(23), 1360-1366. doi:10.1080/09638280400000195
- Dickson, D. W. (2012). Parkinson's disease and parkinsonism: Neuropathology. *Cold Spring Harbor Perspectives in Medicine, 2*(8). Retrieved from http://perspectivesinmedicine.cshlp.org/content/2/8/a009258.abstract
- Drey, N., McKeown, E., Kelly, D., & Gould, D. (2012). Adherence to antiparkinsonian medication: An in-depth qualitative study. *International Journal of Nursing Studies, 49*(7), 863-871. doi:10.1016/j.ijnurstu.2012.01.012

- Edwards, N. E., & Scheetz, P. S. (2002). Predictors of burden for caregivers of patients with Parkinson's disease. *Journal of Neuroscience Nursing, 34*(4), 184-190. Retrieved from <u>http://www.ncbi.nlm.nih.gov/pubmed/12197259</u>
- Ehgoetz Martens, K. A., Ellard, C. G., & Almeida, Q. J. (2014). Does anxiety cause freezing of gait in Parkinson's disease? *PLoS One*, 9(9), e106561. doi:10.1371/journal.pone.0106561
- Engel, K. G., Heisler, M., Smith, D. M., Robinson, C. H., Forman, J. H., & Ubel, P. A. (2009). Patient comprehension of emergency department care and instructions: Are patients aware of when they do not understand? . *Annals of Emergency Medicine*, *53*(4), 454-461. doi:10.1016/j.annemergmed.2008.05.016
- Fernandez, H. H., See, R. H., Gary, M. F., Bowers, D., Rodriguez, R. L., Jacobson, C., & Okun, M. S. (2009). Depressive symptoms in Parkinson disease correlate with impaired global and specific cognitive performance. *Journal of Geriatric Psychiatry and Neurology*, 22(4), 223-227. doi:10.1177/0891988709335792
- Fingerman, K. L., Pillemer, K. A., Silverstein, M., & Suitor, J. J. (2012). The baby boomers' intergenerational relationships. *The Gerontologist*, 52(2), 199-209. doi:10.1093/geront/gnr139
- Garlo, K., O'Leary, J. R., Van Ness, P. H., & Fried, T. R. (2010). Burden in caregivers of older adults with advanced illness. *Journal of the American Geriatrics Society*, 58(12), 2315-2322. doi:10.1111/j.1532-5415.2010.03177.x
- Genoe, M. R., & Dupuis, S. L. (2011). "I'm just like I always was": A phenomenological exploration of leisure, identity and dementia. *Leisure/Loisir, 35*(4), 423-452. doi:10.1080/14927713.2011.649111
- Ghoche, R. (2012). The conceptual framework of palliative care applied to advanced Parkinson's disease. Parkinsonism & Related Disorders, 18, Supplement 3, S2-S5. doi:10.1016/j.parkreldis.2012.06.012
- Giladi, N., & Nieuwboer, A. (2008). Understanding and treating freezing of gait in parkinsonism, proposed working definition, and setting the stage. *Movement Disorders, 23*(S2), S423-S425. doi:10.1002/mds.21927
- Glaser, B., & Strauss, A. (1967). The discovery of grounded theory: Strategies for qualitative research. NY: Aldine de Gruyter.
- Goberman, A. M., & Coelho, C. (2002). Acoustic analysis of Parkinsonian speech II: L-Dopa related fluctuations and methodological issues. *NeuroRehabilitation*, 17(3), 247-254. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/12237506
- Goetz, C. G. & Stebbins, G. T. (1993). Risk factors for nursing home placement in advanced Parkinson's disease. *Neurology*, *43*(11), 2227-2229. doi:10.1212/wnl.43.11.2222
- Grimshaw, R. (1991). *Children of parents with Parkinson's disease*. London: National Children's Bureau.
- Goetz, C. G., Poewe, W., Rascol, O., Sampaio, C., Stebbins, G. T., Counsell, C., . . . Seidl, L. (2004). Movement disorder society task force report on the Hoehn and Yahr staging scale: Status and recommendations *Movement Disorders*, *19*(9), 1020-1028. doi:10.1002/mds.20213

- Gross, R. D., Atwood, C. W., Ross, S. B., Eichhorn, K. A., Olszewski, J. W., & Doyle, P. J. (2008). The coordination of breathing and swallowing in Parkinson's disease. *Dysphagia*, 23(2), 136-145. doi:10.1007/s00455-007-9113-4
- Habermann, B. (1996). Day-to-day demands of Parkinson's disease. Western Journal of Nursing Research, 18(4), 397-413. doi:10.1177/019394599601800403
- Habermann, B. (1999). Continuity challenges of Parkinson's disease in middle life. Journal of Neuroscience Nursing, 31(4), 200-207. Retrieved from <u>http://www.ncbi.nlm.nih.gov/pubmed/10553567</u>
- Habermann, B. (2000). Spousal perspective of Parkinson's disease in middle life. *Journal of Advanced Nursing*, *31*(6), 1409-1415. doi:10.1046/j.1365-2648.2000.01457.x
- Hallford, D. J., Nicholson, G., Sanders, K., & McCabe, M. P. (2016). The association between anxiety and falls: A meta-analysis. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*. doi:10.1093/geronb/gbv160
- Hammer, M. J., & Barlow, S. M. (2010). Laryngeal somatosensory deficits in Parkinson's disease: Implications for speech respiratory and phonatory control. *Experimental Brain Research*, 201(2), 401-409. doi:10.1007/s00221-009-2048-2
- Hanson, H. M., Salmoni, A. W., & Doyle, P. C. (2009). Broadening our understanding: Approaching falls as a stigmatizing topic for older adults. *Disability and Health Journal*, 2(1), 36-44. doi:10.1016/j.dhjo.2008.11.001
- Hermanns, M., Deal, B., & Hass, B. (2012). Biopsychosocial and spiritual aspects of Parkinson's disease: An integrative review of the literature. *Journal of Neuroscience Nursing*, 44(4), 194-205. doi:10.1097/JNN.0b013e3182527593
- Hodgson, J. H., Garcia, K., & Tyndall, L. (2004). Parkinson's disease and the couple relationship: A qualitative analysis. *Families, Systems, & Health, 22*(1), 101-118. doi:10.1037/1091-7527.22.1.101
- Hoehn, M., & Yahr, M. D. (1967). Parkinsonism: Onset, progression, and mortality. *Neurology, 17*(5), 427-442. doi:10.1212/wnl.17.5.427
- Hooker, K., Manoogian-O'Dell, M., Monahan, D. J., Frazier, L. D., & Shifren, K. (2000). Does type of disease matter? Gender differences among Alzheimer's and Parkinson's disease spouse caregivers. *The Gerontologist, 40*(5), 568-573. doi:10.1093/geront/40.5.568
- Hounsgaard, L., Pedersen, B., & Wagner, L. (2011). The daily living for informal caregivers with a partner with Parkinson's disease – an interview study of women's experiences of care decisions and self-management. *Journal of Nursing and Healthcare of Chronic Illness*, 3(4), 504-512. doi:10.1111/j.1752-9824.2011.01126.x
- Howard, A. F., Balneaves, L. G., Bottorff, J. L., & Rodney, P. (2011). Preserving the self: The process of decision making about hereditary breast cancer and ovarian cancer risk reduction. *Qualitative Health Research, 21*(4), 502-519. doi:10.1177/1049732310387798
- Hudson, P. L., Toye, C., & Kristjanson, L. J. (2006). Would people with Parkinson's disease benefit from palliative care? *Palliative Medicine, 20*(2), 87-94. doi:10.1191/0269216306pm1108oa

- Janssens, L., Brumagne, S., McConnell, A. K., Claeys, K., Pijnenburg, M., Burtin, C., Janssens, W., Decramer, M., & Troosters, T. (2013). Proprioceptive changes impair balance control in individuals with chronic obstructive pulmonary disease. *PLoS One*, *8*(3), e57949. doi:10.1371/journal.pone.0057949
- Joachim, G., & Acorn, S. (2000). Stigma of visible and invisible chronic conditions. *Journal of Advanced Nursing*, *3*2(1), 243-248. doi:10.1046/j.1365-2648.2000.01466.x
- Johnson, J. L. (1991). Learning to live again: The process of adjustment following a heart attack. In J. M. Morse & J. L. Johnson (Eds.), *The illness experience: Dimensions of suffering* (pp. 13-88). Newbury Park, CA: Sage.
- Kelly, P. A., & Haidet, P. (2007). Physician overestimation of patient literacy: A potential source of health care disparities. *Patient Education and Counseling*, 66. doi:10.1016/j.pec.2006.10.007
- King, K.M. & Jensen, L. (1994). Preserving the self: Women having cardiac surgery. *Heart & Lung, 23*(2), 99-105. Retrieved from <u>http://www.ncbi.nlm.nih.gov/pubmed/8206780</u>
- Kleiber, D. A., Hutchinson, S. L., & Williams, R. (2002). Leisure as a resource in transcending negative life events: Self-protection, self-restoration, and personal transformation. *Leisure Sciences*, 24(2), 219-235. doi:10.1080/01490400252900167
- Lamb, S. E., Ferrucci, L., Volapto, S., Fried, L. P., Guralnik, J. M. (2003). Risk factors for falling in home-dwelling older women with stroke: The Women's Health and Aging Study. *Stroke*, 34(2), 494-501. doi:10.1161/01.str.0000053444.00582.b7
- Levin, L. S., & Idler, E. L. (1983). Self-care in health. *Annual Review of Public Health, 4*(1), 181-201. doi:10.1146/annurev.pu.04.050183.001145
- Low, J. (2004). Managing safety and risk: The experiences of people with Parkinson's disease who use alternative and complementary therapies. *Health:*, *8*(4), 445-463. doi:10.1177/1363459304045698
- MacRae, H. (2010). Managing identity while living with Alzheimer's disease. *Qualitative Health Research, 20*(3), 293-305. doi:10.1177/1049732309354280
- Marr, J. (1991). The experience of living with Parkinson's disease. *Journal of Neuroscience Nursing*, *23*(5), 325-329. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/1835998
- Marottoli, R. A., Mendes de Leon, C. F., Glass, T. A., Williams, C. S., Cooney, L. M., Jr., Berkman, L. F., & Tinetti, M. E. (1997). Driving cessation and increased depressive symptoms: Prospective evidence from the New Haven EPESE. Established populations for epidemiologic studies of the elderly. *Journal of the American Geriatrics Society, 45*(2), 202-206. doi:10.1111/j.1532-5415.1997.tb04508.x
- Mazzoni, P., Shabbott, B., & Cortés, J. C. (2012). Motor control abnormalities in Parkinson's disease. Cold Spring Harbor Perspectives in Medicine, 2(6), 1-18. doi:10.1101/cshperspect.a009282
- Mestre, T. A., Teodoro, T., Reginold, W., Graf, J., Kasten, M., Sale, J., . . . Marras, C. (2014). Reluctance to start medication for Parkinson's disease: A mutual misunderstanding by patients and physicians. *Parkinsonism & Related Disorders, 20*(6), 608-612. doi:10.1016/j.parkreldis.2014.03.001

- Mead, G. H. (1934). *Mind, self, and society: From the standpoint of a social behaviorist* (C. W. Morris Ed. reprint ed.). Chicago, IL: University of Chicago Press.
- Merleau-Ponty, M. (1962) Phenomology of perception, trans. C. Smith, London: Routledge and Kegan Paul.
- Millán-Calenti, J. C., Tubío, J., Pita-Fernández, S., González-Abraldes, I., Lorenzo, T., Fernández-Arruty, T., & Maseda, A. (2010). Prevalence of functional disability in activities of daily living (ADL), instrumental activities of daily living (IADL) and associated factors, as predictors of morbidity and mortality. *Archives of Gerontology and Geriatrics, 50*(3), 306-310. doi:10.1016/j.archger.2009.04.017
- Miller, N., Noble, E., Jones, D., & Burn, D. (2006). Life with communication changes in Parkinson's disease. *Age and Ageing*, *35*(3), 235-239. doi:10.1093/ageing/afj053
- Monetta, L., & Pell, M. D. (2007). Effects of verbal working memory deficits on metaphor comprehension in patients with Parkinson's disease. *Brain and Language*, 101(1), 80-89. doi:10.1016/j.bandl.2006.06.007
- Morse, J. M., & O'Brien, B. (1995). Preserving self: From victim, to patient, to disabled person. Journal of Advanced Nursing, 21(5), 886-896. doi:10.1046/j.1365-2648.1995.21050886.x
- Morse, J. M., Pooler, C., Vann-Ward, T., Maddox, L. J., Olausson, J. M., Roche-Dean, M., . . . Martz, K. (2014). Awaiting diagnosis of breast cancer: strategies of enduring for preserving self. *Oncology Nursing Forum*, 41(4), 350-359. doi:10.1188/14.onf.350-359
- Nieuwboer, A., & Giladi, N. (2008). The challenge of evaluating freezing of gait in patients with Parkinson's disease. *British Journal of Neurosurgery*, 22(s1), S16-S18. doi:10.1080/02688690802448376
- Nieuwboer, A., Rochester, L., Herman, T., Vandenberghe, W., Emil, G. E., Thomaes, T., & Giladi, N. (2009). Reliability of the new freezing of gait questionnaire: Agreement between patients with Parkinson's disease and their carers. *Gait & Posture, 30*(4), 459-463. doi:10.1016/j.gaitpost.2009.07.108
- Nijhof, G. (1995). Parkinson's disease as a problem of shame in public appearance. Sociology of Health & Illness, 17(2), 193-205. doi:10.1111/1467-9566.ep10933386
- Nijhof, G. (1996). Uncertainty and lack of trust with Parkinson's disease. *The European Journal of Public Health, 6*(1), 58-63. doi:10.1093/eurpub/6.1.58
- Nutt, J. G., Bloem, B. R., Giladi, N., Hallett, M., Horak, F. B., & Nieuwboer, A. (2011). Freezing of gait: Moving forward on a mysterious clinical phenomenon. *The Lancet Neurology*, *10*(8), 734-744. doi:10.1016/S1474-4422(11)70143-0
- Nyman, S. R. (2011). Psychosocial issues in engaging older people with physical activity interventions for the prevention of falls. *Canadian Journal on Aging/La Revue Canadienne du Vieillissement, 30*(01), 45-55. doi:10.1017/S0714980810000759
- Olanow, C. W., Stern, M. B., & Sethi, K. (2009). The scientific and clinical basis for the treatment of Parkinson disease (2009). *Neurology, 72*(21 Supplement 4), S1-S136. doi:10.1212/WNL.0b013e3181a1d44c
- Parr, S. (2007). Living with severe aphasia: Tracking social exclusion. *Aphasiology, 21*(1), 98-123. doi:10.1080/02687030600798337

- Pearce, A., Clare, L., & Pistrang, N. (2002). Managing sense of self: Coping in the early stages of Alzheimer's disease. *Dementia*, *1*(2), 173-192. doi:10.1177/147130120200100205
- Phillips, L. J. (2006). Dropping the bomb: The experience of being diagnosed with Parkinson's disease. *Geriatric Nursing*, 27(6), 362-369. doi:10.1016/j.gerinurse.2006.10.012
- Pinto, S., Ozsancak, C., Tripoliti, E., Thobois, S., Limousin-Dowsey, P., & Auzou, P. (2004). Treatments for dysarthria in Parkinson's disease. *The Lancet Neurology*, *3*(9), 547-556. doi:10.1016/S1474-4422(04)00854-3
- Pretzer-Aboff, I., Galik, E., & Resnick, B. (2009). Parkinson's disease: Barriers and facilitators to optimizing function. *Rehabilitation Nursing*, 34(2), 54-60. doi:10.1002/j.2048-7940.2009.tb00249.x
- Rahman, S., Griffin, H. J., Quinn, N. P., & Jahanshahi, M. (2008). Quality of life in Parkinson's disease: The relative importance of the symptoms. *Movement Disorders, 23*(10), 1428-1434. doi:10.1002/mds.21667
- Ragland, D. R., Satariano, W. A., & MacLeod, K. E. (2005). Driving cessation and increased depressive symptoms. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 60(3), 399-403. doi:10.1093/gerona/60.3.399
- Redmond, L., & Suddick, K. (2012). The lived experience of freezing in people with Parkinson's: An interpretive phenomenological approach. *International Journal of Therapy and Rehabilitation, 19*(3), 169-177. doi:doi:10.12968/ijtr.2012.19.3.169
- Roger, K. S., & Medved, M. I. (2010). Living with parkinson's disease-managing identity together. International Journal of Qualitative Studies on Health and Well-being, 5(2), 1-8. doi:10.3402/qhw.v5i2.5129
- Rothe, J. P. (1994). Beyond traffic safety. Piscataway, NJ: Transaction Publishers.
- Schrag, A., & Quinn, N. (2000). Dyskinesias and motor fluctuations in Parkinson's disease: A community-based study. *Brain, 123*(11), 2297-2305. doi:10.1093/brain/123.11.2297
- Schrag, A., Hovris, A., Morley, D., Quinn, N., & Jahanshahi, M. (2006). Caregiver-burden in Parkinson's disease is closely associated with psychiatric symptoms, falls, and disability. *Parkinsonism & Related Disorders, 12*(1), 35-41. doi:10.1016/j.parkreldis.2005.06.011
- Schwalbe, M. L. (1983). Language and the self: An expanded view from a symbolic interactionist perspective. *Symbolic Interaction, 6*(2), 291-306. doi:10.1525/si.1983.6.2.291
- Scott, S. (2009). Making sense of everyday life. Malden, MA Polity Press.
- Shaw, J. A., Connelly, D. M., & McWilliam, C. L. (2015). The meaning of the experience of anticipating falling. *Ageing & Society*, 35(09), 1839-1863. doi:10.1017/S0144686X14000798
- Silverstein, M., & Bengtson, V. L. (1997). Intergenerational solidarity and the structure of adult child–parent relationships in American families. *American Journal of Sociology*, 103(2), 429-460. doi:10.1086/231213
- Snijders, A. H., Haaxma, C. A., Hagen, Y. J., Munneke, M., & Bloem, B. R. (2012). Freezer or non-freezer: Clinical assessment of freezing of gait. *Parkinsonism & Related Disorders*, 18(2), 149-154. Doi:10.1016/j.parkreldis.2011.09.006

- Stanley-Hermanns, M., & Engebretson, J. (2010). Sailing the stormy seas: The illness experience of persons with Parkinson's disease. *The Qualitative Report*, *15*(2), 340-369. Retrieved from http://eric.ed.gov/?id=EJ875259
- Strauss, A. L., Corbin, J., Fagerhaugh, S., Glaser, B. G., Maines, D., Suczek, B., & Weiner, C. L. (Eds.). (1984). *Chronic illness and the quality of life* (2nd ed.). St. Louis, MO: C. V. Mosby.
- Stuck, A. E., Walthert, J. M., Nikolaus, T., Büla, C. J., Hohmann, C., & Beck, J. C. (1999). Risk factors for functional status decline in community-living elderly people: A systematic literature review. Social Science & Medicine, 48(4), 445-469. doi:10.1016/S0277-9536(98)00370-0
- The Institute of Medicine. 2012. *Living well with chronic illness: A call for public health action.* DC: The National Academies Press
- Todd, D., Simpson, J., & Murray, C. (2010). An interpretative phenomenological analysis of delusions in people with Parkinson's disease. *Disability and Rehabilitation*, 32(15), 1291-1299. doi:10.3109/09638280903514705
- Vandemark, L. M. (2007). Promoting the sense of self, place, and belonging in displaced persons: The example of homelessness. Archives of Psychiatric Nursing, 21(5), 241-248. doi:10.1016/j.apnu.2007.06.003
- Weintraub, D., Comella, C. L., & Horn, S. (2008). Parkinson's disease—part 1: Pathophysiology, symptoms, burden, diagnosis, and assessment. *American Journal of Managed Care, 14*, S40-S48. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/18402507
- Werner, P. & Korczyn, A. D. (2010). Lay persons' beliefs and knowledge about Parkinson's disease: Prevalence and socio-demographic correlates. *Parkinsonism & Related Disorders*, 16(6), 415-417. doi:10.1016/j.parkreldis.2009.12.008
- Williams, S., & Keady, J. (2008). 'A stony road... a 19 year journey': 'Bridging' through late-stage Parkinson's disease. *Journal of Research in Nursing*, 13(5), 373-388. doi:10.1177/1744987108095160
- Williamson, C., Simpson, J., & Murray, C. D. (2008). Caregivers' experiences of caring for a husband with parkinson's disease and psychotic symptoms. *Social Science & Medicine*, 67(4), 583-589. doi:10.1016/j.socscimed.2008.04.014
- Wressle, E., Engstrand, C., & Granérus, A.-K. (2007). Living with Parkinson's disease: Elderly patients' and relatives' perspective on daily living. *Australian Occupational Therapy Journal*, *54*(2), 131-139. doi:10.1111/j.1440-1630.2006.00610.x
- Young, M. E., Norman, G. R., & Humphreys, K. R. (2008). The role of medical language in changing public perceptions of illness. *PLoS One*, 3(12), e3875. doi:10.1371/journal.pone.0003875
- Zamanzadeh, V., Valizadeh, L., Lotfi, M., & Salehi, F. (2015). Preserving self-concept in the burn survivors: A qualitative study. *Indian Journal of Palliative Care*, 21(2), 182-191. doi:10.4103/0973-1075.156492

CHAPTER 3

METHODS

This chapter contains a discussion of constructivist grounded theory and the rationale for its use in this study. Sample characteristics are provided in narrative and table format. The study setting and recruitment strategies are described; data collection methods are presented. Also discussed in this chapter are the analytic strategies of coding, constant comparison, and theoretical sampling. Theory is generated through these strategies. Standards of rigor, ethical considerations, and approval from the University of Utah Institutional Review Board (UU IRB) are presented. The chapter concludes with a summary.

Research Approach

Constructivist grounded theory was the approach used for this study. Grounded theory methods provide flexible analytic guidelines to investigate people's understanding of their experiences and subsequent actions. These methods "focus on process, patterns, and meaning" (Tweed & Charmaz, 2012) of experiences within contexts of daily lives, roles, and relationships (Charmaz, 2014).

Falling under the grounded theory umbrella, constructivist grounded theory shares the theoretical framework of symbolic interactionism, builds on the pragmatic perspective, and develops the constructionist point of view through interpretative understandings. There are three main variations of grounded theory: (1) constructivist, (2) objectivist, and (3) postpositivist. A primary difference between the approaches center on foundational assumptions defining reality, truth, and knowledge. Objectivist grounded theory leans toward positivism and understands reality as based in fact, assumes that facts are the truth, and researchers are neutral. Postpositivist methods suggest there is an objective reality and aims for unbiased data collection, and representation of participants experience as being a reality (Charmaz, 2009).

Constructivist grounded theory views identity, knowledge, and action as socially created; thereby confirming naturalistic settings as the ideal environment for studying patterns of social life (Charmaz, 2000). This is an interactive method; the interview becomes a shared reality between participant and researcher. The many perspectives of each are recognized and acknowledged as the truth for each person involved. The constructivist reflexivity involves deeper levels of analytic reflection in the thoughtful comparison of situations, thoughts, and actions of participants and researchers (Charmaz, 2014).

Rationale

Although there is a broad base of qualitative neurological research (Audulv, Packer, & Versnel, 2014), little attention has been given to the study of social and psychological processes for people with parkinsonisim. Grounded theory methods are beneficial in minimally examined areas due to the exploratory, descriptive, and theory generating strategies (Morse & Richards, 2002). Additionally, individual symptom variations contribute to the unique life challenges for each person. Constructivist grounded theory techniques allow researchers to understand the personal experience of individuals (Charmaz, 1990, 2005). This becomes a problem-solving approach because of its pragmatic roots; the resulting theory is logical, useful, and practical (Strubing, 2007). People with Parkinson disease warrant consideration from a naturalistic interpretative viewpoint and justifies the constructivist grounded theory approach.

The Setting

The primary setting for data collection was the home of each participant. These environments ranged from trailer parks to single-family residences. Every home reflected the occupant's personality and lifestyle. Additionally, multiple safety hazards were present, such as dim lighting, floor clutter, or steep internal stairs. Various states of disrepair were also present.

This community-based study took place in several Midwestern states: Illinois, Wisconsin, and Minnesota. This area has a diverse mix of cultural, racial, and socioeconomic groups ranging from the wealthiest in the U.S. to some of the very poorest. The residents of this region live in culturally rich, dense urban concentrations extending to isolated picturesque rural areas.

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This is a land of contrasts; there are those who have and those that do not have: housing structures are aging, public transportation is limited, grocery stores are a considerable distance, and access to healthcare is trying.

Hazards were present in the environmental setting. The winter brought historic proportions of snow and cold temperatures (Erbentraut, 2014) while late spring brought flooding (Rathbun & Gottfried, 2014). Usual distances and access to food, medication, and healthcare became an even greater concern for people during these trying times.

The Sample

Characteristics and Description

The sample consisted of 25 volunteers (15 M/10 F) with self-reported Parkinson disease. Ages ranged from 40 to 95 years. Participants came from diverse backgrounds, occupations, and economic situations. The sample was predominately Caucasian with a mix of ethnic and racial groups. Living arrangements included living with spouses (n = 13), alone (n = 3), and assisted living homes (n = 1). Many participants lived with children (n = 9), while one married couple with Parkinson disease provided full-time care for a grandchild under age 2 years. Three married couples participated; each of the six spouses had Parkinson disease. Sociodemographic characteristics are summarized on Table 3.1 (p. 53).

The duration of illness ranged from 3 months to over 30 years. HY staging (Hoehn & Yahr, 1967) indicated most participants were in the middle stages of illness disability: stage I (n = 0), stage II (n = 0), stage III (n = 14), stage IV (n = 8), and stage V (n = 3). The Schwab and England (ADL) scale (Perlmutter, 2009) demonstrated a range of performance abilities. Most individuals scored at 60% to 80% of independence levels; no one was completely independent. Table 3.2 (p. 54) summarizes illness characteristics. Every participant used prescription and non-prescription medication. Dopamine replacement medication was used by 21 participants in addition to other antiparkinsonian drugs. Table 3.3 (p. 54) lists the antiparkinson medications used.

Age Group		40's	50's	60's	70's	80's	90's	Total gender (%)
Gender	М	1 (4%)	0	6 (24%)	6 (24%)	0	2 (8%)	15 (60%)
	F	0	3 (12%)	6 (24%)	1 (4%)	0	0	10 (40%)
Total by age (%)		1 (4%)	3 (12%)	12 (48%)	7 (28%)	0	2 (8%)	
Living arrangements		With spouse only	alone	Assisted living home	With spouse & children (< age18)		With spouse & children (> age18)	
	М	7 (28%)	2 (8%)	1 (4%)	3 (12%)		2 (8%)	
	F	6 (24%)	1 (4%)	0	1 (4%)		2 (8%)	
Total (%)		13 (52%)	3 (12%)	1 (4%)	4 (16%	6)		4 (16%)

Table 3.1. Sociodemographic characteristics of the study sample.

Inclusion criteria. Inclusion criteria were designed to involve people throughout the course of illness. The criteria were:

- o Self-reported Parkinson disease
- o Community dwelling (own homes or assisted living facilities)
- Age range: 40 years and upward through the lifespan

Initially, volunteers were sought with mid-stage illness of at least five years duration. After the first two interviews, theoretical sampling directed broader inclusion criteria with no boundaries placed on duration or disability levels.

Exclusion criteria. The exclusion criteria were brief to allow exploration of the study concepts with people who had a range of experience through the illness progression

- Skilled nursing home residency
- o Non-English speaking

Duration of Parkinson disease												
Years		< 1 year	1	to 5	6 to	10	11 to	9 15	15 t	o 20	20 +	
<u>Gender</u>	М	2 (8%)		0	1 (40	0 %)	2 (8%	6)	()	1 (4%))
	F	0	(4	1 \$%)	5 (20	5 %)	3 (129	%)	()	1 (4%))
<u>Total by y</u> <u>(%)</u>	<u>ears</u>	2 (8%)	(4	1 4%)	1 (60	5 %)	5 (209	%)	()	2 (8%))
Hoehn & Yahr												
<u>Stage</u>		<u> </u>		II	II		IV	1	١	/		
<u>Gender</u>	M (%)	0	0		9 4 (36%) (16%)		2 (8%)					
	F (%)	0	0		5 (20%) (*		4 (169	4 (16%)		1 (4%)		
Schwab & England												
ADL ab	lity %	0	10	20	30	40	50	60	70	80	90	100
	n (%)	0	1 (4%)	3 (12%)	0	0	2 (8%)	8	5 (20%)	5 (20%)	1 (4%)	0

Table 3.2. Participant's illness characteristics.

Table 3.3. Antiparkinson medications used by participants.

Drug class	Examples	Number of People
Dopamine replacement	Sinemet	21
Dopamine Agonists	Pramipexole, Ropinirole	7
MAO-inhibitors	Selegiline, Rasagiline	3
COMT-inhibitors	Entacapone, Tolcapone	3
Other Pharmacological	Amantadine	2
Approactics	Anticholinergics	0

Care partners. The original study design included care partners as primary participants. An amendment was submitted to the UU IRB to remove the inclusion criteria requiring a care partner. This was done based on feedback from potential participants who wished to volunteer but did not meet this requirement. Frequently, care partners were present in the home environment during the interview and wished to participate. These individuals were over age 21 and completed the consenting process. Their comments were added when contributing to the analysis and findings.

Recruitment

Goals. The recruitment goal of this study was to engage the involvement of people who might typically be hard to find: (1) chronically ill older adults, (2) people with Parkinson disease, (3) people with mobility problems, or (4) isolation related to stigmatization.

Primary approach. The technique of purposive sampling identified the initial participant. A professional colleague was given study information and flyers for distribution to people who had been seeking participation in Parkinson disease research. The first study participant contacted the investigator after receiving the study flyer. After completing the study interview, the first participant was asked to refer friends or associates with this condition for study enrollment. Purposive, snowball, and theoretical sampling techniques identified the remaining participants. Recruitment through snowball sampling is a social network sampling technique for studying hard to find populations, such as chronically ill people and older adults (Anderson & Hatton, 2000; Penrod, Preston, Cain, & Starks, 2003).

Strategies. Recruitment flyers were created and entitled "An Invitation to Participate in Parkinson's Research". Appendix A (p. 143) contains the recruitment flyer. It was distributed to libraries, community settings, and professional colleagues. Participants were asked to share this information with people they knew. Two presentations were conducted at support groups; the first was a young onset meeting and the second was a general group.

Information about this study was posted on the Michael J. Fox Foundation's Trial Finder (FTF) (2013) website after providing UU IRB approval to the Fox Foundation. Essentially, people were able to see the recruitment notice. Individuals contacted me through an internal FTF email

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system expressing their interest. The FTF website recruitment posting is presented in Appendix B (p. 144).

Data Collection

Data was collected over a 15-month period, September 2013 through December 2014. The completion of data collection was signaled by interpretative sufficiency (discussed later).

Demographic Data

Demographic information was obtained from each individual. This information included contact information and living arrangements. Appendix C (p. 145) is the data collection form.

Descriptive Data

Medications. A list of current medications was obtained by examining the medication containers (when possible) of prescription and nonprescription products. More commonly, the participants offered a narrative report, explaining how they used the medication. Hand-written or typed medication lists were sometimes provided. Medication purposes and side effects as reported by the participant or observed by the researcher were noted. I adapted a medication data tool from The National Institute of Neurological Disorders and Stroke Common Data Elements (Grinnon et al., 2012). This form is contained in Appendix D (p.146).

Disease staging. The HY is a 5-point descriptive and categorical scale describing the clinical presence of motor disability. Higher numbers indicate a more severe stage of motor disability (Hoehn & Yahr, 1967). The Movement Disorder Society recommends, "rate what you see" (Goetz et al., 2004); including motor disabilities due to other conditions. I completed the HY. Table 3.2 (p. 54) lists disease staging for the participants. Appendix E (p. 147) displays the scale.

Activities of daily living. The Schwab and England Scale for the Capacity for Daily Living (ADLs) is a traditional neurological tool used to evaluate functional levels for parkinsonism. This descriptive 10 item scale ranks, by estimation, a person's independence in daily self-care. A score of 100% represents complete independence, while a score of 0% indicates a vegetative state (Perlmutter, 2009). Appendix F (p. 148) presents the scale. I completed the scale through observation and asking participants about their abilities. A summary of the information is found on Table 3.2 (p. 54).

Qualitative Data

Multiple data forms were used for this study. Table 3.4 (p. 58) lists the data collection methods. In-depth interviews are discussed in detail.

Unstructured in-depth interviews. Data for grounded theory research primarily takes the form of participant interview content. Indepth interviews are personal and unique, reflecting the relationship dynamics of the individuals. Situational factors, such as the interview location or timing, also influence the interview. The majority of interviews were conducted within the home environment (22/25). Three of the interviews were conducted in community settings; a private room allowed for confidentiality. Sixty-two interviews were conducted and ranged from one hour to over four hours in length. Breaks were taken for fluids and fatigue.

Although the interview was unstructured, the formatting of questions encouraged reflective sharing through naturalistic spontaneity. Initially, participants were asked to "Tell me" about their life with Parkinson disease. This single request usually sufficed as the major interview question. Follow-up questions and probes enhanced depth. Later, individuals identified through theoretical sampling were asked to "Tell" about a particular phenomenon. Reflective and clarifying statements verified my understanding with the participants during the interviews.

It was important to follow the participant's responses, verbal and nonverbal, as leads for the interview pacing (Charmaz, 2014). This allowed for increasing depth as the person's story unfolded. While people talked about themselves and their experiences, strong emotions were displayed. Most people cried, some softly, others sobbed wrenchingly. Being attentive meant acknowledging people's feelings. It also meant pausing the conversation, giving people opportunities to regain composure (Corbin & Morse, 2003).

Even though this sharing of memories brought intense feelings, participants expressed appreciation for an opportunity to "finally, tell someone" what life had brought. Although some worry about negative repercussions from talking about feelings, this was not the case (Corbin & Morse, 2003). Participants expressed feelings of being understood and accepted.

Table 3.4. Qualitative data forms.

Interviews	Observation	Visual Data	Documents	Researcher Notes	
In-depth interviews	In-home settings	Photographs	Cherished items displayed by participants	Field notes	
Group interview	Support groups	Videos	Notes and emails from participants	Theoretical memos	
	dance class	Drawings	Autobiographies of famous role models		
			Popular movies and documentaries		

Equipment

People with Parkinson disease have monotone low-pitched voices (Holmes, Oates, Phyland, & Hughes, 2000). Equipment was selected which was easily available, moderately priced, and able to record whispered voices. The voice recorder was a digital Sony ICD-UX533 (Sony Electronics, 2014). An Olympus ME52 noise-cancelling mini-microphone (with an optional tie clip) was easily inserted in the audio recorder port (Olympus, 2014). The products produced quality recordings.

Preparation of Data for Analysis

The interviews were audio recorded, transcribed verbatim, and de-identified. A second listening of the audiotapes occurred while reading the completed transcript for accuracy checking and editing as needed. The original transcript was filed. A copy was used for coding. Fields notes and memos were transcribed into an electronic document for coding. Photos and videos were catalogued by participant number and then duplicated for coding. Adobe[®] Photoshop[®] and Adobe[®] Premier[®] Elements were used to remove identifying features such as voice or facial images.

Completion of Data Collection

Interpretative sufficiency. Collection of new data ceased when interpretative sufficiency was achieved. This was determined when categories were developed adequately

to generate a logical substantive theory.

Data saturation. There are differences between interpretative sufficiency and data saturation. Data saturation as defined by Morse (1995) suggests that data collection is completed when no further new information is gathered. One concern, for a novice researcher, is recognizing the difference between new information, the uniqueness of each individual's story, and adequate data for interpretation. For these participants, there was never a lack of new stories, with each unique story contributing to a deeper and richer understanding of the processes of living with the illness. Saturation claims might reflect the researcher's "need" to complete a study versus conceptual adequacy (Charmaz, 2005).

Data Analysis

Analytic Strategies

Constructivist grounded theory uses a systematic interpretative process of analysis (Charmaz, 2014) to examine data through multiple dimensions (Morse, 2007). The product of analysis is an abstract but practical theory. Although the analysis is presented in a stepwise fashion, the actual work is reflexive, continuous, and cyclical. It is an analytic goal to remain close to the data, which deepens a potential understanding of the participant's experience. The phrase "staying close to the data" represents the researcher's analytic relationship with the data. Asking theoretical questions of the data and reflecting on one's own understandings data are techniques of reflexivity that aid in building concepts.

Three hallmark characteristics define grounded theory methods: theoretical sampling, the analytic technique of constant comparison, and a resulting theory (Charmaz, 2014; Glaser, 1978; Morse & Richards, 2002; Strauss, 1987). These strategies are discussed in this section.

General coding descriptions. The interview transcripts, fieldnotes, documents, and photos were broken into smaller bits and examined (Strauss, 1987). Coding summarizes and defines raw data into increasingly abstract category (concept) groups (Charmaz, 2000; 2014; Glaser, 1978). Coding is the link between raw data and emerging theory. Theory is built inductively through this increasing abstraction.

Choosing action terms to represent the categories aid in interpretative closeness. Interpretative closeness has the potential to move the analysis beyond simple description (Charmaz, 2014). The preferred terms used for coding are the participant's own words or gerunds. A gerund is a verb that ends in -ing and functions as a noun. Verbs denote "action or a state of being" (Purdue Owl, 2011). Thereby, while representing the action form of nouns, gerunds provide a descriptive imagery of action. Coding with gerunds allows the researcher to become aware of movement, action, and process within the data (Charmaz, 2014; Glaser, 1978).

Initial coding. The first phase of analysis is initial coding. This phase was the initial breaking raw data into category groupings. The units of analysis are the categories and not the raw narrative data (Charmaz, 2014). Initially, the raw data was examined line-by-line. As the analysis progressed, the raw data was coded either incident-by-incident or word-by-word. How data was examined relied on attentiveness in answering the following questions: What form of initial coding would best enhance understanding? How would narratives be best represented?

Focused coding. A second phase of the constant comparative abstraction is focused coding (Charmaz, 2014). This was accomplished by focusing on the initial codes to determine which of the earlier codes made analytical sense in answering the research question. This form of coding required greater depth of constant comparisons; subsequently leading to more clearly defined, refined, and abstract codes through the synthesis of large amounts of data (Charmaz, 2014). The naming of the focused codes were the most frequent or significant terms from the initial coding phase (Charmaz, 2014; Glaser, 1978; Strauss, 1987).

Constant comparison. The technique of constant comparison builds the dimensions and properties of categories (concepts) through cyclical and iterative comparisons of data-todata, data-to-category, and category-to-category (Charmaz, 1990; 2014). Each level of coding reflects an increasing abstraction for each comparison. The process of constant comparison, through its iteration, has overlapping phases with clarity built on the resulting increasing abstractness.

Theoretical sampling. Constant comparison expands the opportunity to see similarities and differences between the various data forms. Theoretical questions arise and suggest

missing data while conceptual categories are under development. This avenue of directions, questionings, and seeking answers refined needed participant characteristics. It is the emerging concepts that focus the selection of additional data (via additional participants or reexamining current data) for understanding and definition building of the concepts (Charmaz, 2014). Theoretical sampling is a purposeful inductive approach that guides data selection to represent the maximal variety of experiences, including negative cases (Charmaz, 2014; Morse & Richards, 2002).

Examples of theoretical sampling as used in this study are provided. Many of the participants had been diagnosed for several years. The information they provided was helpful but the memories of finding out or beginning medication may fade after time. The sampling direction was based on the theoretical need to find individuals with a diagnosis occurring within a shorter period. Two participants were added who had been diagnosed several months earlier.

Building on this same example, finding the negative case using theoretical sampling consisted of identifying individuals who had been diagnosed for a longer time period than other participants. Would their challenges and strategies be similar? What difference would time have in the maintenance of their identity? One volunteer had Parkinson disease for over 30 years. His perspective of time was compared to other interviews, adding rich dimensions to the data and contributed to theory development. The ability to see the challenges and strategies used by people with Parkinson disease gained conceptual clarity through theoretical sampling.

Theory Generation

Each individual's perspectives are based on unique past and present interactions, involvements, and understandings; providing us with guiding behavioral templates. Theories built through the constructivist grounded theory approach consider the perspectives of participants and the researcher. The goal of a grounded theory is the creation of an explanatory model of human behavior. The theory describes a basic social process (BSP) or a basic social psychological process (BSPP) which explains the transitions through stages of dynamic human actions and interactions (Charmaz, 2014; Glaser, 1978; Strauss, 1987).
The term grounded is used to describe the resultant theories because they are firmly planted, attached, and built upon the data; the theory reflects the experiential process of the studied individuals. Grounded theories are created through the systematic use of constant comparison and theoretical sampling to build, define, refine, and deepen understandings of the emerging concepts (categories). Each phase of coding proceeds through increasing abstraction producing concepts (categories) which represent the stages and phases of the studied phenomenon (Charmaz, 2014; Glaser, 1978; Strauss, 1987). The BSP or BSPP is the core concept that unifies the conceptual categories representing the transitions and stages.

The theory created from this study, *Preserving self*, abstractly, but understandably, explains the behavior, feelings, transitions, and processes for people with parkinsonisim as they face the challenges of maintaining self-identity through the course of their illness.

Rigor

Describing Rigor

Rigor is a general term used to describe the approaches used by science to confirm accuracy, thereby ensuring progress. Representing two separate paradigms, quantitative and qualitative research require separate and specific criteria for determining rigor (Morse, Barrett, Mayan, Olson, & Spiers, 2002). Controversies have surrounded the value and contribution of qualitative research. Issues such as generalizability, evaluation processes, and the unique terms used to describe techniques and outcomes complicate the application of interpretative naturalistic methods of study. In this section, general features of this study which adhered to reliability and validity standards for qualitative research will be discussed.

Methodological adherence. This study has paid particular attention to the hallmark characteristics of grounded theory: constant comparison, theoretical sampling, and theory generation. Recognizing multiple realities is a predominant feature of constructivist grounded theory and has been incorporated (Charmaz, 2014).

Quality of the analysis. Through the iteration of constant comparison, the checking and verifying of concept development occurred naturally through this process. Negative cases and alternate explanations were actively sought to account for the interpretative findings. Through

the phases of concept development and theory generation, multiple data sources were examined to correlate, verify, and achieve findings that reflect and fit the data (Charmaz, 2014; Glaser, 1978, Strauss, 1987). Placing the findings of this study within the context of relevant scientific literature added to the understanding, realism, and applicability of the findings.

Verification. Active clarification of the researcher's understandings during the interview process was sought and obtained from the participants. As the theory developed, it was discussed with individually with approximately 10 participants and in a theoretical group interview (2 participants).

Generalizability. The results of this study most likely are not generalizable. This research was conducted with a unique set of participants, illness experiences, study setting, and researcher skills. However, the findings may be transferable to similar samples and settings.

Ethical Considerations

This study was reviewed and approved by the University of Utah Institutional Review Board (IRB). This study did not use information from or add to medical records, did not involve treatment decisions, and did not use protected personal or health information. Based on the guidelines of the University of Utah IRB (2013), this community based interview study was considered minimal risk.

Potential Risks

The research interview. The in-depth interview may provide an avenue for the expression of feelings, accompanied by a potential risk of distress. The recalling of experiences may elicit anxiety or sadness, the distress of these feelings is similar to the distress of any ordinary risk encountered in daily life (Corbin & Morse, 2003). Participants were provided with explanations about the potential of distressing feelings. The loss of confidentiality was a minimal risk due to the de-identification of data.

The sharing of private information. All information from each participant is considered confidential. Even though we hope for complete and assured privacy, this cannot be guaranteed 100%. Participants were aware of this.

Vulnerability. The participants may be considered vulnerable based on age, illness, or the home setting as the interview site. Preinterview phone contacts began the start of a trusting, respectful relationship. Information was provided regarding duties of the researcher. Therapeutic misconceptions (Lidz & Applebaum, 2002) were not apparent. The consent cover letter was written in plain language, read with the individual, and a copy provided for their records.

Participant Protection

The informed consent. As a minimal risk study, formal documentation of a signed informed consent was not required. A consent cover letter was developed and later amended. Approval from the University of Utah IRB was obtained for videotaping with changes in the consent cover letter. The consent cover letter has check boxes for levels of participation and a signature line; for example: interview alone, interview with photos, or interview with photos and videos. A description of the study purpose, confidentiality practices, and contact names for the study and the IRB are also contained in the consent cover letter. The consent cover letter is found in Appendix G (p. 149-150).

Participant information came in various data forms: Demographic information, audiotaped and transcribed interviews, or photos and videos of the participants performing or demonstrating movements. Permission was obtained from each participant before photos or videos were taken of belongings or of themselves. Written documents (such as field notes) were kept in a secured area within a locked file. The audiotapes were transcribed, digitalized, and maintained on an encrypted computer in the research office. Each data source was de-identified and received a study pseudonym. Each participant was informed of these confidentiality and privacy protection practices. Permission was obtained from the UU IRB to keep the study consents, videos, photographs, and digitalized interviews indefinitely due to potential for secondary analysis.

Benefits

People had opportunities to share their experiences during the interview; most described how relieved they felt. For some people, it was the first time speaking of the impact of the illness.

References

- Anderson, D.G. & Hatton, D.C. (2000). Accessing vulnerable populations for research. Western Journal of Nursing Research, 22(2), 244-251. doi: 10.1177/01939450022044386
- Audulv, Å., Packer, T., & Versnel, J. (2014). Identifying gaps in knowledge: A map of the qualitative literature concerning life with a neurological condition. *Chronic Illness, 10*(3), 192-243. doi:10.1177/1742395313516133
- Charmaz, K. (1990). 'Discovering' chronic illness: Using grounded theory. *Social Science & Medicine, 30*(11), 1161-1172. doi: 10.1016/0277-9536(90)90256-R
- Charmaz, K. (2000). Grounded theory: Objectivist and constructivist methods. In N. K. Denzin & Y. S. Lincoln (Eds.), *The handbook of qualitative research* (2nd ed., pp. 509-535). Thousand Oaks, CA: Sage Publications.
- Charmaz, K. (2005). Grounded theory in the 21st century: Applications for advancing social justice studies. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (3rd ed., pp. 507-535). Thousand Oaks, CA: Sage.
- Charmaz, K. (2009). Shifting the grounds: Constructivist grounded theory methods. In J. M. Morse (Ed.), *Developing grounded theory: The second generation* (pp. 127-191). Walnut Creek, CA: Left Coast Press.
- Charmaz, K. (2014). Constructing grounded theory (2nd ed.). Thousand Oaks, CA: Sage.
- Corbin, J., & Morse, J. M. (2003). The unstructured interactive interview: Issues of reciprocity and risks when dealing with sensitive topics. *Qualitative Inquiry, 9*(3), 335-354. doi: 10.1177/1077800403009003001
- Erbentraut, J. (2014). Chicago just had its coldest winter in history. Here's proof. *The Huffington Post.* Retrieved from http://www.huffingtonpost.com/2014/04/02/chicago-coldest-winter-ever_n_5078201.html
- Glaser, B. G. (1978). *Theoretical Sensitivity*. Mill Valley, California: Sociology Press.
- Goetz, C. G., Poewe, W., Rascol, O., Sampaio, C., Stebbins, G. T., Counsell, C., ... & Seidl, L. (2004). Movement Disorder Society task force report on the Hoehn and Yahr Staging Scale: Status and recommendations. *Movement Disorders, 19*(9),1020-1028. doi: 10.1002/mds.20213
- Grinnon, S. T., Miller, K., Marler, J. R., Lu, Y., Stout, A., Odenkirchen, J., & Kunitz, S. (2012). National Institute of Neurological Disorders and Stroke Common Data Element Project – Approach and Methods. *Clinical Trials*. Retrieved from: <u>http://www.commondataelements.ninds.nih.gov/PD.aspx#tab=Data_Standards</u>
- Hoehn, M., & Yahr, M. D. (1967). Parkinsonism: Onset, progression, and mortality. *Neurology, 17*(5), 427-442. doi:10.1212/wnl.17.5.427
- Holmes, R. J., Oates, J. M., Phyland, D. J., & Hughes, A. J. (2000). Voice characteristics in the progression of Parkinson's disease. *International Journal of Language & Communication Disorders*, 35(3), 407-418. doi:10.1080/136828200410654
- Lidz, C. W. & Appelbaum, P. S. (2002). The therapeutic misconception: Problems and solutions. *Medical Care, 40*(9), V55-V63. doi: 10.2307/3767528

- Michael J. Fox Foundation. (2013). The Fox Trial Finder. Retrieved from https://foxtrialfinder.michaeljfox.org/about-fox-trial-finder/
- Morse, J. M. (1995). The significance of saturation. *Qualitative Health Research, 5*(2), 147-149. doi:10.1177/104973239500500201
- Morse, J. M. (2007). Sampling in grounded theory. In K. Charmaz & A. Bryant (Eds.), *The Sage handbook of grounded theory* (pp. 229-244). Thousand Oaks, CA: Sage.
- Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods*, 1(2). Retrieved from <u>http://www.ualberta.ca/~ijqm/</u>
- Morse, J. M. & Richards, L. (2002). *Readme first: A users guide to qualitative methods.* Thousand Oaks, CA: Sage Publications.
- Olympus. (2014). ME52W mini mono microphone. Retrieved from <u>http://www.olympus.co.uk/site/en/a/audio_accessories/accessories_professional_dictatio</u> n/microphones/me_52w_2/index.html
- Penrod, J., Preston, D. B., Cain, R. E., & Starks, M. T. (2003). A discussion of chain referral as a method of sampling hard-to-reach populations. *Journal of Transcultural Nursing*, 14(2), 100-107. doi: 10.1177/1043659602250614
- Perlmutter, J.S. (2009). Assessment of Parkinson disease manifestations. *Current Protocols in Neuroscience, Chapter 10*, (11). doi: 10.1002/0471142301.ns1001s49
- Purdue Owl. (2011). Gerunds. Retrieved from https://owl.english.purdue.edu/owl/resource/627/01/
- Rathbun, A. & Gottfried, M. H. (2014, June 21). Flooding causes mudslides in St. Paul, Minneapolis. *St. Paul Pioneer Press*. Retrieved from St. Paul Pioneer Press website: <u>http://www.twincities.com/localnews/ci_26003927/flooding-causes-mudslides-st-paul-</u> mendota-heights-minneapolis
- Sony Electronics. (2014). Digital voice recorder ICD-UX533. Retrieved from http://store.sony.com/digital-voice-recorder-zid27-ICDUX533//
- Strauss, A. L. (1987). *Qualitative analysis for social scientists*. NY: Cambridge.
- Strubing, J. (2007). Research as pragmatic problem-solving: The pragmatist roots of empiricallygrounded theorizing. In A. Bryant & K. Charmaz (Eds.), *The Sage handbook of* grounded theory (1st ed., pp. 580-601). Thousand Oaks, CA: Sage Publications.
- Tweed, A. & Charmaz, K. (2012). Grounded theory methods for mental health practitioners. In D. Harper & A. R. Thompson (Eds.), *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners* (pp. 131-146). West Sussex, UK: John Wiley & Sons, Ltd

CHAPTER 4

PRESERVING SELF: THE SOCIAL AND PSYCHOLOGICAL PROCESSES OF PARKINSON DISEASE

This chapter was prepared for future submission to Qualitative Health Research.

Abstract

The purpose of this study was to identify and explore the social and psychological processes of people with Parkinson disease. Constructivist grounded theory was the study method. Participants were 15 men and 10 women (ages 40 to 95), living primarily with their families. Illness descriptions were obtained through the Hoehn and Yahr staging scale, activities of daily living scale, and medication logs. Data included 62 in-depth interviews, photos, videos, and related documents. Analytic procedures generated the theory of *Preserving self* for people with Parkinson disease. This theory has five stages: (1) *Making sense of symptoms*, (2) *Turning points*, (3) *Dilemmas of identity*, (4) *Reconnecting the self*, and (5) *Envisioning a future*. *Dilemmas of identity* brought emotionally painful reminders of former selves and capabilities. Risk-taking occurred as a strategy to function normally. Recommendations discuss methods of *Reconnecting the self* that involve integrating cognitive, emotional, and bodily aspects.

Introduction

Parkinson disease is one of the less well known or understood chronic illnesses. Traditionally, it was considered a disorder of movement, and to this day, a diagnosis is primarily made through clinical observation.

Uniqueness is demonstrated through strong associations with three major public health problems: falls, depression, and dementia. The simultaneous presence of this symptom trilogy influences the daily life of affected individuals and affects health care professional treatment perspectives. Parkinson disease (subtlety and deceptively) changes how people function, interact, and view themselves. Yet they continue striving to maintain roles and identity. Despite the strong behavioral and emotional implications, research on living with Parkinson disease is meager. We do not know how people handle the illness on a daily basis or, because of the chronicity, how this day-to-day management occurs in the privacy of their homes. Thus, this research focused on the profound changes that occur over time and, despite these changes, how people with Parkinson disease retain their identity.

Literature Review

Parkinson Disease

Idiopathic Parkinson disease (without known cause) is the most common form of neurodegenerative parkinsonism,¹ consisting of approximately 80% of all cases (Bartels & Leenders, 2009; Dickson, 2012). This is the condition discussed in this article. People experience a wide range of neurological, cognitive, and psychiatric difficulties. These interrelated features substantiate its position as a quintessential neuro-cognitive psychiatric disorder (Weintraub & Burn, 2011). The core problem of neurodegeneration is the wearing out and functional loss of brain cells responsible for making and secreting dopamine. Dopamine is a neurotransmitter, delivering chemical messages from one nerve ending to another. Without this dopamine-driven connection, signals to other areas of brain functioning are effected. Dopamine is crucial for movement, important in higher cognitive functions, and may have a role with mood (Beaulieu & Gainetdinov, 2011)

A growing epidemic. Parkinson disease is frighteningly common. It affects 1 of 250 people older than age 40, 1 of 100 people older than age 65, and 1 of 10 people older than age 80 (Eidelberg & Pourfar, 2007). Speculations indicate that within 20 years, the number of individuals 65 years or older with this illness will increase minimally by 75% (Dorsey et al., 2007). The probability is high for experiencing Parkinson disease during a person's lifetime. In addition, depression, dementia, and falls seem inevitable. The prevalence for each ranges from 10% to over 90%; the large span reflects various researcher interpretations of the constructs and differing data collection methods (Hiorth, Larsen, Lode, & Pedersen, 2014; Meireles, & Massano, 2012).

Although these problems are growing among all disease categories, these symptoms are considered characteristic for Parkinson disease.

The diagnosis. Diagnosis relies on the clinical presence of characteristic motor symptoms: tremor, stiffness, slowness, and balance changes. Both medical physicians and neurologists frequently have difficulties establishing a diagnosis: people commonly attribute symptoms to aging, subsequently delaying healthcare for several years until symptoms can no longer be controlled or concealed; further, there are no confirmatory laboratory tests or procedures (Joutsa, Gardberg, Röyttä, & Kaasinen, 2014). Autopsy remains the definitive diagnostic standard (Hughes, Daniel, Kilford, & Lees, 1992).

The symptoms. Every body system is effected, although each person uniquely experiences symptom forms, pacing, and severity. Diminishing spontaneity of facial expression is replaced with a "mask-like" appearance and voice softening alters interpersonal communication styles. Swallowing difficulties lead to weight loss, malnutrition, and possibilities of choking. Slowness and stiffness of movement begin as slight problems, gradually altering muscular function, leading to balance impairment, gait disturbances, and subsequently contributing to falls. Involuntary resting tremors increase with deliberate movement, strong emotions, and sleep patterns are disrupted (Chaudhuri, Odin, Antonini, & Martinez-Martin, 2011).

Treatment. Treatments provide limited remedy, gradually cause a worsening of symptoms, and do not slow illness progression. Although there have been pharmacological advances, the reality is that dopamine-replacement medications (for example, levodopa/ carbidopa) improves mobility and functioning only for a limited number of years. Disabling side effects predictably appear and medications eventually become ineffective (Olanow, Stern, & Sethi, 2009).

The prognosis. Parkinson disease is life limiting and life altering; there is no cure. Survival time after the diagnosis has been estimated at 8 to 10 years (Elbaz et al., 2003). Death is commonly (approximately 45%) attributed to aspiration pneumonia (Pennington, Snell, Lee, & Walker, 2010). Regardless of the lifespan reports, remaining life is spent in varied and increasing stages of disability. Based on the lack of cure and the palliative nature of symptom relief,

Parkinson disease has been compared with cancer (Hudson, Toye, & Kristjanson, et al., 2006).

The Concept of Self

Concerns of the self-concept for research. The construct of *self* has been debated for centuries continuing through the present time. Due to the abstract nature of the construct, many definitions and models are used by researchers, providing diverse conceptualizations (Caddell & Clare, 2013). The chronic illness literature, for example, contains many self-concept terms without clear descriptions: self-care, self-management, self-help, or self-efficacy. In light of the complexity and potential confusion about the topic, the construct of *self* will be described as used in this article.

A working definition of the *self*. Here, the concepts of *self* and *identity* are based on principles of symbolic interactionism (Mead, 1934; Blumer, 1969). People are actively involved in constructing their own views of the world that are shaped by relationships with others. Through these interactions, individuals experience, sustain, and transform their sense of self. We use these notions (our concept of self) as a frame of reference for making decisions and guiding our subsequent behaviors. The self is a template of action (Mead, 1934; Blumer, 1969; Charmaz, 1983; 1990; Schwalbe, 1983). Forming a self involves a sense of continuity across time that involves intertwining of the past and an orientation towards a possible future (Giddens, 1991).

Prior Parkinson Disease Research

Parkinson disease research has primarily focused on drugs, genomics, or procedures (T. Li, Ho, & C. Li, 2008). Although the cause(s) remain speculative, much is known about the pathophysiology (Wichmann, Delong, Guridi, & Obeso, 2011). Additionally, various disciplines have examined the psychosocial experience of the person with Parkinson disease using self-report or standardized measures (Abudi, Bar-Tal, & Fish, 1997; Schrag, 2006). In comparison, little is known about the experience of, or how, people face the challenges in living with this progressive degenerative illness.

The contributions of quantitative research. The process of diagnostic reasoning depends largely on quantitatively devised scales for comparing, generalizing, and (subsequently)

identifying the nature of the parkinsonism. Two such scales are the Hoehn and Yahr Disease Staging Scale (HY) (Goetz et al., 2004; Hoehn & Yahr, 1967) and the Schwab and England Activities of Daily Living Scale (ADL) (Perlmutter, 2009). The HY uses observation to rank the presence of motor disability, impairments, and balance. The ADL scale measures functional abilities such as bathing, dressing, and eating.

Although stages of disability can be described with measures of self-care and movement limitations, there are instances when numerical conclusions offer limited insight, for example, depression. Overwhelming sadness, despair, and tremendous loss contribute to personal suffering which is not measureable on a ranking scale. Even with the availability of multiple depression scales, more than 40% of people with Parkinson disease have symptoms of depression not recognized by healthcare providers (Shulman, Taback, Rabinstein, & Weiner, 2002). The depth of human feelings cannot be measured by numbers. The ranking of personal situations and feelings do not measure a person's psychological reality, the depth of feelings, or offer a glimpse into their understanding of the experience (Galasiński, 2008).

The contributions of qualitative research. A major contribution to our understandings of chronic illness and self-concepts was provided by Charmaz (1983, 1990, 1991) through descriptions of the struggles and losses of the chronically ill. Multiple and repeated losses of essential physical, valued social, and psychological functioning potentially results in a loss of self. Charmaz proposed that this loss of personal identity is continuum based with varying levels of vulnerability, sensitivity, and loss. It is demonstrated through passivity, lowered self-worth, and social withdrawal. Parkinson disease, as a chronic illness, has derived benefit from this knowledge. While Charmaz's model of chronicity may be applied to Parkinson disease, from a pragmatic clinical perspective, research has not yet delved into day-to-day illness processes.

The chronic illness literature provides insight into general concerns of long-term conditions but does not encompass the simultaneous multiple complexities occurring with Parkinson disease (Schulman-Green et al., 2012). Qualitative studies provide descriptions of experiences, consistently highlighting symptom difficulties and occasionally providing realistic applicability. A few autobiographies have provided a glimpse of living with the losses of

Parkinson disease (Ronstadt, 2013; Ali, M. & Ali, H., 2004). While qualitative research has begun describing the parkinsonian lifestyle, further questions and deeper concerns have been elicited.

The literature does not sufficiently address how people with Parkinson disease continually strive to maintain daily life. Notable omissions, gaps, and misunderstandings are identified. Generally, disease staging and duration are provided for describing the sample. The disease stages have not been correlated with narrative accounts, life transitions, or addressed in study findings. This omission avoids the complexity of parkinsonisim and complicated lifestyle issues. Changing communication skills are consistently described as problematic, but the depth of research has been minimal. Consequently, we know little of the influence of diminishing expressive abilities on self-identity or closeness with others. The attention to relationships has not been fully examined, leaving behind the importance of belonging, attachment, values, and self-worth. Issues of self-concept, depression, anxiety, and stigma have not been specifically addressed, thereby perpetuating detachment as an optimal researcher position.

We do not know how people handle the devastating changes or effect their self-concept. Thus, we do not understand the experience of Parkinson disease. Appreciating how people face life challenges provides opportunities for healthcare providers to learn, offer guidance, and become fundamentally effective in working with people. Therefore, the purpose of this study was to identify, examine, and explore the challenging and strategic processes for people with Parkinson disease as they endeavor to preserve their prediagnosis self. This inquiry provided detailed insight into life experiences through the progression of parkinsonism. Questions addressed were: What are the challenges faced by people with Parkinson disease? How do people maintain self-identity? The knowledge generated from these insights was used to develop a substantive theory, *Preserving self for people with Parkinson disease*.

Methods

The Sensitizing Concept

Preserving self is an emerging concept, at a descriptive level of development (Johnson, 1991; Charmaz, 1994; Howard, Balneaves, Bottorff, & Rodney, 2011; Irurita & Williams, 2001; King & Jensen, 1994; Morse, 2012). In this article, *Preserving self* describes a way of being that

sustains self-identity through everyday activities, attitudes, and interactions. *Preserving self* represents the struggles, transitions, and strategies undertaken by an affected person who feels they are losing normalcy of familiar roles and interpersonal relationships. It is a social process involving making new meanings and understandings (in this case, for people with Parkinson disease) and taking action based on these meanings and understandings to maintain the former self. Common attributes of this concept are striving, asserting, protecting, and engaging. Failing to *Preserve Self* may lead to the loss of roles, relationships, self-worth, and ultimately, the loss of one's self.

Strategies used to preserve may be identified by examining the behaviors and emotions of people during challenging times, such as managing chronic illness. Here, the concept of *Preserving self* was used as an inductive frame for building interpretative understanding of actions and attitudes reflecting the process of maintaining self-identity by people with Parkinson disease.

Study Design

Constructivist grounded theory shares the theoretical framework of symbolic interactionism, builds on the pragmatic perspective, and develops the constructionist point of view through interpretative understandings of the personal experience of individuals (Charmaz, 1990; 2014). This interactive method uses a problem-solving approach through its pragmatic roots. By focusing "on process, patterns, and meaning of experiences within contexts of daily lives, roles, and relationships" (Tweed & Charmaz, 2012), researchers can view the problems to be solved from the participants perspective.

The Setting

This was a community-based study, taking place in three Midwestern states. This area has a diverse mix of cultural, racial, and socioeconomic groups ranging from the wealthiest in the U.S. to some of the very poorest. Residents of this region live in culturally rich, dense urban concentrations extending to isolated picturesque rural areas. This is a land of contrasts; there are those who have and those that do not have: housing structures are aging, public transportation is limited, grocery stores are a considerable distance, and access to healthcare is difficult.

Hazards were present in the environmental setting. Winter snow and cold were of historic proportions (Erbentraut, 2014) and the spring brought flooding (Rathbun & Gottfried, 2014). Usual distances and access to food, medication, and healthcare became an even greater concern for people during these trying times.

Recruitment Strategies

Recruitment goals of this study were to involve community dwelling individuals who might typically be hard to find: (1) chronically ill older adults, (2) people with mobility problems, (3) people with Parkinson disease, or (4) socially isolated individuals. These goals highlighted social processes of recruitment. A study flyer was distributed to support groups, libraries, grocery stores, and professional colleagues. Later, participants shared the flyer with their friends. Two support group presentations were conducted. Study recruitment Information was posted on the Fox Foundation's Trial Finder website (2013). The initial participant was identified using purposive sampling. The remaining participants were identified through snowball and theoretical sampling.

Data Collection

Data collection took place from September 2013 through December 2014. Multiple sources of data were used: interviews, observations, documents, photographs, videos, and theoretical memos. These activities were seen as opportunities of engagement and commitment to understand the meaning of the participant's world (Blaikie, 2000). The completion of data collection was signaled by interpretative sufficiency.

Demographic and Descriptive Data

Demographic data. This information included contact information, living arrangements, and occupation for each participant.

Medications. A list of all current medications was obtained by examining original containers (whenever possible). Participants more commonly described how and when they actually used the medication. I adapted a medication data tool from The National Institute of

Neurological Disorders and Stroke Common Data Elements for notating the information (Grinnon, Miller, Marler, et al., 2012).

Disease staging. The Hoehn and Yahr (HY) (1967) is the historical parkinsonian staging criteria (Goetz et al., 2004). This 5-point categorical scale describes the clinical presence of motor disability; it does not measure function. Higher numbers indicate a greater stage of impairment. I completed the HY, taking into account other conditions influencing motor function, following the scale instructions to "rate what you see" (Goetz et al., 2004). The stages of the HY are described as follows:

- I. Only one side of body involved, usually with minimal or no functional disability
- II. Both sides of body affected without impairment of balance
- III. Both sides of body involved, mild to moderate disability, impaired balance; generally independent
- IV. Severely disabled, still able to walk or stand, may need assistance
- V. Confinement to bed or wheelchair

Activities of daily living. The Schwab and England Scale for the Capacity for Daily Living is a traditional tool for Parkinson disease. This descriptive 10-item scale ranks, by estimation, an individual's independence in daily self-care. It does not measure motor dysfunction. A score of 100% represents complete independence, while a score of 0% indicates a vegetative state (Perlmutter, 2009). This scale was completed through observation and participant self-report.

Qualitative Data

Unstructured in-depth interviews. Data for grounded theory research primarily takes the form of unstructured interviews; 62 in-depth interviews were conducted. The majority of initial interviews (22/25) were conducted at participant homes. The remaining three were conducted in private community settings. Follow-up interviews (34) included one dyadic interview, 12 home visits, and 22 phone interviews ranging from one hour to over four hours in length. Breaks were taken for fluids and rest.

It was important to follow the participant's verbal and nonverbal responses as leads for interview pacing (Charmaz, 2014). While people talked about what they had been through, strong emotions were displayed. Most people cried, some softly, others sobbed wrenchingly. Being attentive meant acknowledging people's feelings. It also meant pausing the conversation, giving people opportunities to regain composure (Corbin & Morse, 2003).

The interview guide. Although the interview was unstructured, several guided questions were used that encouraged reflection and sharing through naturalistic spontaneity. The initial question asked participants to "Tell me" about their life with Parkinson disease. Guided questions took people through the disease course including their symptoms, medications, and living with the illness. Throughout the interviews, reflective and clarifying statements were used to verify my understandings of the participant's story. In addition to the interviews, other data sources included:

- Observations: In-home settings, two support groups, and a dance class
- Documents: Personal photos and other memorabilia, notes and emails from participants, autobiographies of celebrities, and popular movies
- Visual Data: Photographs of participants and their environments, videos, and selfportraits

Ethics

The Institutional Review Board at the University of Utah approved the study and consenting procedures. Participant consent was obtained prior to interviews, photos, and videos.

The Participants

The sample was comprised of 25 (15 M/10 F) volunteers with self-reported Parkinson disease. Their ages ranged from 40 to 95 years with most people (19) being in their 60's and 70's. The participants came from a variety of backgrounds, occupations, and economic situations. There was a mix of ethnic and racial groups; the sample was predominately Caucasian. Three people lived alone and one person resided in an assisted living home. The remaining 21 participants lived with spouses and family. Four of the 25 participants lived with

children under age 18. Another four participants shared homes with adult children over age 18. Each spouse of three married couples participated (n = 6). Family members wishing to participate completed consenting processes.

The illness duration ranged from 3 months to over 30 years. Disease staging: stage I (n = 0), stage II (n = 0), stage III (n = 14), stage IV (n = 8), and stage V (n = 3). People had a range of self-care abilities. Participants in stage III completed ADL activities at an independence level of 60 to 80%. While people in stage V ranged between independence levels of 20 to 30%. L-dopa was used by 22/25 participants.

Analysis

The audiotapes were transcribed verbatim. Transcripts were read with reference to the corresponding pictures and videos. During the first phase of analysis, data were segmented into broad categories. Categories were microanalytically explored by comparing incident-by-incident. The second phase of analytic abstraction was focused coding (Charmaz, 2014) with the groups of initial codes compared, refined, and synthesized with increasingly abstract labels.

The technique of constant comparison was used throughout analysis; expanding the opportunity to see similarities and differences between the various data forms. Theoretical questions arose which suggested missing data for the concept building. Thus providing an avenue of directions for seeking answers by reexamining data from a new perspective or seeking additional participants. This is theoretical sampling (Glaser, 1978).

Developing the Theory of Preserving Self

One aim of this study was to describe abstractly the experiential process for people with Parkinson disease; *Preserving self* is this clinically derived substantive theory. Decontextualizing participant narratives and grouping segments into broader categories (reflecting experiential phenomena) provided an analytical means of organizing and explaining the relationships between major concepts. Organizing the relationships between the concepts provides a framework for observing, understanding, and making predictions in clinical situations (Charmaz, 1990).

Results

The Basic Social Psychological Process: Preserving Self

Key phenomena were observed as protective behaviors and consistently identified through developing concepts: retaining and taking care of one's own self. Not only did these protective features account for responses in problematic situations, they were also observed in people's daily actions. Additionally, variations and patterns were noted to occur over time and often repeated. The concept of *Preserving self* expanded with continuing analysis, representing an abstract summary for patterns of social life (Glaser, 1978).

Preserving Self: An Overview of the Theory

Preserving self represents the hurdles people encountered and the various means used to counteract the experience intensity and its impact while trying to remain their preillness self. The actions and emotional states of the people with Parkinson disease can be "seen" through the logicalness of this theory. Intensely personal experiences are explicated.

The theory of *Preserving self* is comprised of five interdependent stages: (1) *Making* sense of symptoms, (2) *Turning points*, (3) *Dilemmas of identity*, (4) *Reconnecting the self, and* (5) *Envisioning a future*. Between each stage are transitions that serve a theoretical role of integrating the stages (and their parts) into a unified process. Figure 4.1 (page 79) illustrates the stages and transitions. The following paragraphs descriptively explain *Preserving self*.

Stage 1: Making Sense of Symptoms

Participants struggled to makes sense of troubling inconsistent physical and emotional symptoms by noticing, confirming, interpreting, and taking action. These actions occurred before finding out the diagnosis and continuing through early impairment.

Noticing something is different. Symptomatic changes were often subtle and difficult for people to notice. This was often complicated by other conditions that confounded abilities to decipher new changes. However, a single symptom with increasing intensity or the presence of multiple symptoms brought an awareness of declining health. Family members or friends sometimes noticed developing changes, bringing their concerns to the person's attention.



Figure 4.1. Preserving self for people with Parkinson disease.

Confirming that something is different. As symptoms became more serious, they were monitored and questioned. With jolting awareness, one symptom or several signaled a "wake-up call" indicating a startling confirmation of something being very different. One person had been feeling increasingly fatigued for "a time" and correlated this surge of fatigue to a cross-country driving trip and aging, paying little attention to the symptoms. Priorities changed one morning. "While playing tennis, a friend told me I looked like I had Parkinson's. He said my face had no expression, my walk was stiff, and it looked like I might fall over." The increasing fatigue became "a little bit" more understandable. The disease became a reality. He wanted to find a

solution to this problem, went to his internist promptly, who scheduled an urgent neurology appointment.

Interpreting the symptoms. Symptomatic nuances were studied and developing patterns recognized. These concerns persisted, frequently for several years, before situations were considered serious and needing closer attention. These patterns, however, were typically viewed as normal responses to aging or to increasing use of the computer. Retrospectively, people pointed out symptoms they believed were probably pre-Parkinson changes. One such symptom was scrawled handwriting. This symptom was sufficiently concerning for a participant that he finally sought medical advice: "I said to the doctor, 'You know, I'm having a hard time writing checks.' That tipped him off that I might have Parkinson's."

Taking action. People wondered what caused these physical and emotional symptoms. Specific activities such as excessive exertion or carrying heavy items were blamed for causing tremors and muscular stiffness. People kept trying "this-and-that" with a variety of home remedies and treatments, all without lasting benefit. Muscular discomforts and anxiety were temporarily relieved with exercise. Self-medication practices involved searching home cupboards for pain relievers or muscle relaxants to treat aches and stiffness. For those who worked, a "bad situation" was blamed, resulting in feelings of exasperation while trying to sort through emotional changes, physical discomforts, and available self-medicating products in an effort to find relief.

I was getting really anxious at work; it was ridiculous. My writing was just horrible. My hips started bothering me. I was having issues with sleep. I got really upset about everything. I had all of these medical problems. But I didn't know why these things were happening. Nothing seemed to help.

Sudden acute changes were easily recognized as more serious. Traumatic injuries (especially old injuries to the head) were described as having lingering effects throughout a person's lifetime and were attributed as a possible cause for the present neck, arm, or leg spasms, tremors, and/or pain. For example, one man purchased a walking cane when his right leg began to tremor. He had not considered seeing the doctor. Instead, he believed a home accident (involving a television falling on his head) was the cause of his right leg tremors. Since he had emergency treatment at the time, it was his belief that he should "learn to adjust."

Of the 25 study participants, ten (40%) had emergency room visits. Experiencing a health crisis was alarming for people and their families. A sudden onset of tremors or chest tightness brought concerns about the possibility of seizures or a heart attack. Several people wondered if they "would make it" through. One person was admitted to the intensive care unit and later diagnosed with congestive heart failure. The remaining nine individuals were evaluated, given referrals to neurology or psychiatry, and sent home.

Participants were frustrated at the length of time spent seeking, but not receiving, help. They wondered if their medical doctors could have done something earlier or better. Some people suggested their doctors were also exasperated and described them as stalling or even avoiding conversations about a definitive diagnosis. Doctors were reported as saying, "It could be Parkinson's, but I'm not qualified," or "You might want to think about seeing a neurologist."

Transition: Finding Out

Participants were not surprised to find that something was wrong; after all, most had been living with physical discomforts for several years. It was hearing the diagnosis of Parkinson disease that was unexpected. *Finding out* brought a range of emotions: relief, numbness, or shock. Several people felt relief and thankful this was not something "more serious." Various forms of cancer, multiple sclerosis, and Huntington's disease were considered far more critical because of stereotypical images of continual pain, disfigurement, and dementia.

Everyone had unanswerable questions: "What does this mean?" "What do I do? Succumbing to the darkest of despair, questions were asked of God and of one's self. One woman and her husband spent hours driving through a snowstorm for a long awaited meeting with the "best" doctor. "Finally, the doctor told me, 'It is for sure you have Parkinson's.' That was a very big surprise, a very bad surprise. I didn't believe that it was true. There were questions in my mind. Why me?" Loud sobbing interrupted her words as she talked about recalling and reliving on a daily basis the intensity of finding out.

Several people were not sure what to think. Some recalled driving around aimlessly. While other people remained sitting in their car, finally realizing it was time to go home. The unexpectedness of the diagnosis was not momentary. People younger than age 60 worried

about accomplishing hopes and dreams. "How will I support myself?" Am I supposed to move to a nursing home?" Several participants of childbearing age wondered if having children was "allowed." These questions were silently asked, but not answered. People older than age 60 usually considered ways to keep working. While retired people looked at continuing an active lifestyle. For example, one man was retired for nearly 15 years when finding out the diagnosis. He spoke about his life plans: "We haven't closed up shop. We're going to keep doing what we've been doing"

Stage 2: Turning Points

A *Turning point* is a life-altering event of enormous significance. The emotional force of the diagnosis vibrated, instantly changing their identity and the fundamental aspects of how people knew themselves. People encountered demanding tasks that confronted abilities and continually tested their character. These challenging times highlighted the disruption of life.

Fearing the worst. Living with constant and unpredictable physical, emotional, and social changes, brought fears of the worst possible scenarios: losing body capabilities, memory, and valued roles. The once spontaneous automatic actions of the body now required concentration and determined effort. Holding onto handrails became a requirement, serving as a signal of personal frailties and leading to worries of dependency: "I'm afraid about the Parkinson's advancing because I don't really want to be taken care of."

Losing trusted physical capabilities brought fears of being immobilized in a wheelchair. One person spoke haltingly about his worst fears: "Not being able to move, just being kinda like housebound in a wheelchair, and having to be taken care of. Not being able to talk or swallow. Choking to death...not a good way to go. Yeah" (deep soft laugher and sighing). It was common for people to speak of losing body capabilities, dependency, and death within the same breath. "My biggest fear is keeping the Parkinson's away, keeping the symptoms away. You don't really die from Parkinson's. You die out of the secondary effects ... if you choke to death or aspirate or have a bad infection."

All participants, regardless of the staging severity, expressed concern about dementia. This was the most worrisome fear for most people. Every potential sign was monitored for indications of a memory deterioration. Several people read waiting room brochures, "Has your memory changed?" This question lingered, triggering a new lifestyle: waiting for dementia.

Several people searched for research articles about dementia, but had difficulty understanding the scientific language, subsequently becoming more anxious. When browsing the internet and reading dementia "horror stories", participants feared for their own futures: "The scariest thing is that dementia." One person spoke with great sadness; tears filled his eyes: "My greatest fear is that I lose touch with my loved ones and become a burden. My kids, my wife, I don't want to lose my connection with them. I don't want to miss out on that time." Changing memory abilities resulted in embarrassment and shame:

I'm worried. Sometimes I forgot the names of my nieces. We talk often on Skype. I am so mad because the kids call and I forget their names. I am embarrassed to ask my sister. I don't know if it's like some dementia or ... I'm really worried.

People intentionally developed "just in case" strategies for remembering aspects of themselves and significant relationships. During home visits, common observations were the family photographs lining walls. Pocket-sized albums were often seen placed near a favorite chair.

Changing communication styles became apparent early in the illness and contributed to worries about how to sustain relationships. Everyone reported voice changes beginning even before the diagnosis; symptom intensity was unique for each individual. Decreasing voice strength, increasing monotone qualities, with diminishing speech spontaneity compounded already frustrating and difficult interactions. Spouses were sometimes intolerant while children became impatient. Several people mentioned the difficulties of raising teen-agers, complicated unimaginably with a soft nonprojecting voice.

Spouses were most affected by diminishing facial expressiveness and responsiveness. Stiffened facial movements lose the capacity to smile, laugh, or even display glimmers of affection. "She doesn't think I'm fun anymore." "He wonders if I've lost interest." Participants worried about their abilities to function emotionally and fulfill responsibilities as a spouse, a parent, and friend. The possibility of failure brought worries about disapproval, alienation, or abandonment. For instance, one man could no longer speak above a whisper. He felt his family lost interest in trying to talk with him and were growing distant. They encouraged him to consider a larynx transplant. He was reluctantly thinking about it.²

Seeking knowledge of a new circumstance. Most people were uninformed about the course of Parkinson disease or impending challenges. Important activities were learning about the illness, the role of medications, and making decisions about whom to tell about the diagnosis.

Grasping the situation. To grasp the situation suggests that people have the cognitive and emotional strength to grapple with issues involving living with a chronic illness. Although people were not yet ready to label themselves as parkinsonian; most were passively compliant, taking the prescriptions for medications and therapies.

Although most people received information when they were diagnosed, it was usually "hard to understand." This person described the information he received from his doctor, "He said he would start me on this patch, the Neupro. But, he gave no insight. I had no idea what so ever as to what to expect." People were not given the information they needed for day-to-day living. "I've brought up some issues and the doctor has been helpful on some things. He's a nice guy, but still, he's more clinical." Many participants chose not to discuss relationships, lifestyle problems, or work-related disabilities with the doctor; instead, turning to the internet for answers. This became the primary information source.

Everyone knew about the presence of support groups from brochures or the internet. People had vast ranging and emotionally intense opinions; misunderstandings were common. Several participants attended and spoke of feeling encouraged by meeting people with the same illness. Others described anxiety. One person ominously predicted how her mood might be affected by attending: "I've been avoiding those groups because I'm afraid I'm going to hear things I don't want to hear. I feel like I'm going to see people that are in a worse state, and I don't want to be depressed."

Considering medicine. Participants consistently described surprise at the immediacy of treatment decisions required at the first appointment. Mostly, people accepted the doctor's recommendations, attributing their passivity to feelings of shock and being overwhelmed. People who began taking L-dopa expressed amazement at how much better they felt.

Medication prescriptions were offered but not always filled by the participants. There were people who postponed using medication. Some hoped to participate in clinical trials that required de novo status. Other people were reluctant to take dopamine replacement medication due to eventualities of the writhing involuntary movements of dyskinesia (a permanent and disabling side effect). Still, other people believed that taking L-dopa would be a sign of personal failure. One participant waited years before considering L-dopa, even with her inability to rise from a chair.

Disclosing. People quickly realized the limited knowledge of this illness by others. It was difficult to share this personal information with work colleagues, especially for people who planned on continuing employment. Keeping secrets and keeping private was a tactic used to reduce potentially hurtful situations. One man told his human resources manager (with the intention of protecting his "rights") and requested transfer to a "desk job". He believed working alone would provide fewer opportunities for colleagues to stare or ask questions.

There were people who told their families and received little support. Some family members were not receptive to hearing about the illness or the person's experience. Participants described family responses to the diagnosis: "He (husband) really doesn't want to have much to do with it." "He has never asked me what it's like." "She said, "I don't want to know and I'll never ask." Several participants were told "never mention that again." Many people did not speak with family members because of worries over their reactions. One participant described her decision in not telling her father (both were older adults). "My dad doesn't know that I have Parkinson's disease. I just as soon keep it that way. I think that he would get upset. So, I hope he passes away before I have to say..."

Transition: Unsettling Reminders

People tried to do for themselves, but sometimes the old familiar ways no longer worked. For example, a person's mouth could not form words easily or tremors meant holding a martini with two hands. Knowing other people saw these changes was embarrassing. Feelings of interpersonal inadequacy and increasingly obvious physical limitations served as jolting bolts of

awareness that life had changed. Self-defining characteristics were no longer clear. People were perpetually reminded that they were no longer the same.

Communicating the meaning of unsettling reminders was difficult. Most every person, male or female, cried and sobbed heavily. Some people rubbed their faces, others held their heads in their hands, eyes brimmed with wetness, or hands were grasped and wringing. Emotional expressions were intense, causing each person to question their sanity.

Stage 3: Dilemmas of Identity

Living in a blur after the diagnosis, people searched for continuity and predictability in the midst of unanticipated changes. Every participant described frequently returning to *Dilemmas of identity,* most considered this stage to be a prevailing way of life. Sometimes these dilemmas occurred several times daily, often lasting for days or weeks. Relinquishing comfortable and familiar self-attributes while making room for a new set of identities was unimaginably difficult. This perplexing time involved personalizing new information in useful and understandable ways.

Desperately holding onto former selves. People were fiercely determined to be themselves as before. Behaviors continued, without recognizing or taking into account illness changes. Sensations of numbness, emotional disconnectedness, and reliving of diagnosis events were frequent. Being unable to respond or function predictably led to frustration, confusion, and questions about one's capabilities. Each person described overpowering feelings of doubt and disbelief surrounding the validity of a Parkinson diagnosis. "The neurologist told me there is no test, no way to diagnose for sure. If I could have a blood test, then I would know. I still don't want to believe it. It's hard."

Taking risks. Between the former and new attributes of the self, was a grey area of personal negotiation in which people took risks. Compromising chances were taken as people fiercely tried determining their self-boundaries by retaining old familiar ways. People had tremors while working with sharp power tools. Some described hiking a usual route, but then found themselves unable to return home because of "getting stuck." Having a recent fall or constant tremors did not stop people from climbing ladders or wearing high heels.

Driving a car was important for participants to work, purchase household necessities, or obtain medical care. Most people tried to drive less during heavy traffic or winter weather. Participants considered driving with tremors or possibilities of freezing episodes as less than ideal; but not considered risk-taking. One participant routinely drove hundreds of miles weekly for volunteer work. He described his experience of tremors while driving:

The shaking is always there. It wants to get out but you hold it in as much as you can. It starts with the arms, goes into the legs, and then the feet. I'll be driving along and start shaking and say to myself, 'Well, this isn't supposed to be.' This isn't fun when you're driving. You take your meds, sit there, and then go.

His confidence is boosted by the L-dopa medication containers within reach on the passenger seat and above the sunshade. For each participant, choosing risky situations supported some aspect of former identities, but also pointed to *overwhelming* new limitations. People tried avoiding risks, but since circumstances had changed, determining what defined a risk was difficult.

The vulnerable self. Emotional pain and continuing physical changes gave reason for concerns that future circumstances might worsen, thereby perpetuating a sense of helplessness. People tried but sometimes the "best strategy" contributes to the difficulty. Feelings of disconnection may lead to isolation. As a temporary solution, isolation could be helpful, but may lead to paralyzing anxiety and eroding self-worth.

Feeling detached and disconnected. People described feeling disconnected from their lives. Increasing involvement with activities prevented face-to-face confrontation with changing circumstances. They tried, but failed to maintain their former busy activities: babysitting grandchildren, traveling, community activism, cultural events, movies, and exercise. Participants reported feeling like "the same old self" after successfully completing even one familiar routine.

Eroding self-worth. This is depression. People described their outlook on life with phrases such as, "No future", "Every day is overwhelming", or "Going through this on my own." Depression was not a commonly used word. Only one participant reported depressive feelings while another person reported feelings of "chronic gloominess", but not depression.

Paralyzing anxiety. Intense fears and constant worrying about an unknown impending doom were common. Anxiety becomes paralyzing when it dominates feelings, thoughts, and

actions. For some people, paralyzing worries developed when encountering situations challenging former skills or requiring decisions. Instances of anxiety producing decisions include driving alone through snow for needed supplies, dinner meal planning, or morning clothes selection.

Suddenly being unable to move (freezing of gait) caused enormous anxiety. During a home visit, a woman stood up to obtain something. She stood up and could not turn, her face becoming a sheet of fear. Swaying from side to side did not help complete the turn; her lower body just would not move. My arm was extended, the woman held onto it with both hands, and was able to walk into the next room. We talked about what happened to cause the inability to move:

Interviewer: Do you freeze up very often? Participant: No, I never freeze. Interviewer: Tell me about what happened. Participant: Oh, that. That's nothing. I get stuck like that all the time.

She went on to describe not knowing what to do when being stuck. Feeling afraid prevented her from planning her next actions. "What happens if I fall? What do I do if I have to go to the bathroom?" The term "freezing of gait" was not used or understood by most participants. Each individual had personal definitions, explanations, and actions for being "stuck" and becoming unstuck.

Facing hurdles. Formerly mundane tasks became obstacles that complicated the integration of a past and present self, leaving a person without well-rehearsed defense strategies. Enormous energy and effort were used to remain self-reliant, yet, dependencies occurred with frightening frequency.

Physical dependencies. Parkinson disease gradually diminishes ADL capabilities. Personal hygiene, feeding one's self, or remaining diaper-free were important to participants, however, how these concerns were appreciated changed with increasing disability and personal views. This person (midstage) described the efforts of getting dressed: "I do everything myself. It takes a lot of time and I fall all the time when putting on my pants. Why can't I remember that I can't stand up anymore and put one leg in at a time?" Regardless of the stage of illness, every person worked diligently at doing all they could for themselves, even if it was a risk for discomfort or injury. Even when they could no longer feed themselves or walk, participants struggled to continue caring for themselves. One person (stage V), relying on daily nursing care, described his determined attempt to shower on his own. "It was tough, but I did it. I didn't finish the shower because I was afraid of falling. I held onto the walls until someone came to help. It is an insult to my manhood needing someone to clean me."

Conflicting images of past and present identities compounded with the fears and realities of physical dependence brought strong emotional responses. This participant exclaimed, "I don't want to give up. I work, exercise. I don't want to be taken care of." Although admitting to using folding canes with seats, relying on or needing assistive devices was denied, even while a cane rested within reach. One person adamantly refused to consider using a mobility aid, "I would rather crawl on the ground. That is not me...I don't want anyone to see me like that because that is not who I am."

Falls were concerning, before they started routinely. Participants with one or two past fall incidents (HY stage II to early stage III), were quick to say, "It was just a stumble" or "I wasn't watching where I was going." Promises were made to themselves and family members to standup straight, use the handrail, and be more careful. People who reported falling "over 100 times" or having had numerous breaks and fractures (HY stages III to V), recognized their susceptibility, but acknowledged falling as to be expected with illness and aging. Naturally, no one wants want to fall down and get hurt; but attention to safety concerns diminished as falls increased. This participant (stage V) spoke about nursing aides interfering with his mobility:

What really bothers me is that damn buzzer on the seat cushion. Every time I move, they (nursing aides) run here and tell me to stop and sit still. This is my apartment; I should be able to get up when I want to. If I fall, then they can help by picking me up.

For this man, self-determined independence was a higher priority than preventing a potential fall. Another participant (stage IV), every Sunday, carried his wife (stage V) down the front stairs, placed her into the car, returned to carry a wheelchair down the stairs, and went out for dinner. He considered himself capable to complete this routine. This situation predicts a fall incident. **Relationship dependencies.** Participants expressed worries of being abandoned by spouses or children when the illness diminished mental and physical abilities. Some people felt marrying a dating partner would ensure permanency. At least the doctor knew about the changing abilities, but "needing" the doctor became an emotional ache. It was difficult to form a relationship with someone who did not share the same need for connectedness.

People encountered embarrassing, humiliating, or demoralizing situations on a routine basis. Work-related problems related to misunderstandings of Parkinson disease were reported by all employed participants. Many were asked to resign because of the observable symptoms. They said, "Here's the deal. I was asked to not come back to my job by my boss," "Well, I just couldn't keep up anymore," and "They don't know it has to do with memory-but once they find out, I'm gone."

Sometimes family members, without meaning to, used hurtful words or actions. For example, one end-of-life participant had become primarily bedridden. She spoke, her voice filled great sadness, about her grandchildren (under age 6 years) and their responses to her physical disabilities. "One of the big kids said to the youngest, "Why don't you go play with Grandma?" and he said, "No, she's broke." With young children, it is a little easier to understand why some things are said. However, adult family members believed (according to participants) symptoms of this progressive chronic illness could be overcome and were frequently the ones who made disparaging comments. One spouse said:

I think he fades more than he used to. Sometimes it just pisses you off. That apathy! I mean he just puts his little butt down in the chair and watches sports until the end of the creation. Stop it! I work hard to combat that. We try to be active. Usually I bully him into going out and doing something, which snaps him out of it. We're signed up for a zillion things.

The watchful self. Situations of adversity came to be anticipated. During this time of *vigilance*, participants were learning skills of self-observation, trying to predict situations in which their symptoms would be manifest, and *developing protective actions*. People became attentive to subtle nuances of expression, sidelong glances, and even well-meaning efforts of friends. Because of speech changes or stiffened facial muscles, people made sure they had a "code book" of phrases to use when their voice was especially soft. For example, "I've had a cold" or

"It's loud in here" helped discretely explain this innocent symptom.

Finding direction. By paying attention to symptoms and evaluating their responses to situations, activities, and medications, new understandings of Parkinson disease developed. This participant explained, "Parkinson's is not just in one place. It's everywhere." *Finding direction* relied on observations and actions of *the Watchful self*. Exercise became a part of daily routines. Dietary intake was monitored to avoid interference with medication absorption. Some participants hired a food delivery service to avoid driving due to unpredictable freezing episodes during hazardous winter weather.

Learning practicalities. People realized how important others were in their lives and the importance of trying to maintain prior approaches to relationships. This usually involved degrees of silent compliance in order to achieve personal goals. People took over household chores for which they had little previous experience, such as cooking, cleaning, or managing the finances. One married couple (both with Parkinson disease) had recently moved to be closer to their only child and soon after became full-time babysitters for their two-year-old grandchild. This cherished experience was challenging. The wife had midstage disabilities while the husband was in the most advanced stages. The toddler and grandfather were outside while the grandmother was grocery shopping. The child ran into the street, the grandfather could not speak loud, walk fast, or run. He took action by intentionally falling on top of the toddler. They were both bruised, but otherwise unharmed. Learning practicalities did not always involve planning for untoward events.

In particular, L-dopa was an important means to hide symptoms, gain a sense of control, and feel "normal". People gained firsthand practical knowledge of how to use the L-dopa by "experimenting" with self-adjusted doses to improve functioning before activities or interactions. Information on how to dose did not come from the doctor nor was self-administration discussed: instead, participants learned through trial-and-error.

Because L-dopa has a short half-life, the timing of medication wearing-off was not predictable. People described being away from home when suddenly (without extra L-dopa); they were not able to move. This became problematic in situations such as bicycling alone for 50 miles, standing in a busy parking lot, or reaching for money to pay the grocery clerk. Humiliation and embarrassment were the emotional responses. Participants addressed safety issues by vowing to bring along extra medication and a cell phone.

The very presence of a filled medication bottle seemed to offer comfort. Medication containers were placed in every household room, the car, and coat pockets. This person spoke of her reliance on L-dopa:

I carry my pills wherever I go. In case something happens to me, I don't want to be without them: If I get in a traffic accident or get run over or fall off my bicycle and end up in the emergency room.

Transition: Sifting and Sorting

Sifting and sorting is a time of self-evaluation: abilities, successes, hopes, and dreams. People hold on to the most defining and valued characteristics while letting go of those that are no longer purposeful or relevant. Grieving for the past self occurred during this time. People demonstrated sifting and sorting by putting away former interests and considering new activities.

Stage 4: Reconnecting the Self

This stage synthesizes the significant and defining characteristics of former and current identities. People are *evolving with the illness* and, as a result, new identities form. With this synthesis, comes a sense of continuity as highlighted by this participant, "I think that knowing that this is a symptom of things that change in my brain because of the Parkinson's, makes everything less scary." Values and convictions are refined.

Forming new identities. Although a multitude of identities are possible, resentful, resolute, and reformulated described predominant data patterns. These identities reflect development through *Preserving self*-processes, subsequently evolving with a person's experience.

Resentful. Some people expressed animosity for their lot in life. Statements of anger were directed towards neurological research, doctors, employers, and family members. People described exasperation with continuing brain research efforts that still had not clearly identified a cause or cure. Doctors were blamed for medication side effects. Family members were begrudged for not providing desired levels of attentiveness, while the capabilities of colleagues

and friends were coveted. "Without Parkinson's, I would still be young. It's very discouraging." People expressed stigmatizing statements at themselves and other people, "I'm such a clod," or "That person looks too good to have Parkinson's."

Resolute. People were relentlessly determined and creative in efforts to maintain their identities and fulfill responsibilities. For instance, one person (stage IV) worked full-time and was the primary care partner for his wife (stage V). He woke daily at 3:00 am to care for his wife and complete daily tasks before 8:00 am work. Because the last dose of L-dopa was the evening before, the effects had worn off, and he was unable to walk or move his legs. Every night, kneepads were applied. The following morning, after taking a bedside dose of medication, he slid to the floor and crawled by pushing and pulling his lower body to the kitchen. After his knees developed blisters, he began using a boogie board to slide down the hallway. Other people described walking on their knees after the wearing-off of L-dopa. Knee walking became routinized for participants of this study.

Reformulated.³ People redefined themselves as accommodating the parkinsonian symptoms. Acknowledging losses of past identities was a means of coming to terms with their circumstances. Living with Parkinson disease became a reality. People became more tolerant of themselves, recognizing differences between the disease and themselves. This participant spoke of his frustrations of being a grandparent, "When my granddaughter insists on watching cartoons on television and I'm going slowly mad. At least I have a defense for that. But that's not really Parkinson's, that's every grandparent (chuckling)."

Disease symptoms were acknowledged and preconceptions gradually set aside. Several participants explained, "I always thought Parkinson's was just about having a shake, but it's not," and "It's not just your body, Parkinson's affects your mind and your relationships. It's everywhere." Strategies became refined, "I found solutions for most of the devils that harass me; anxiety and claustrophobia."

People devoted efforts in maximizing their abilities. Some participants "knew" they should exercise or practice voice techniques more often. Another person (advanced stages) developed a ritual of taking lettuce leaves with medication to aid in preventing vision loss. This

participant explained his approach to life, "If I do things I can do, that's all I need to worry about. If I get worse, I get worse; if I get better, I get better. But I will do what I can do in the meantime." Former interests were examined and adjusted while new interests developed. Some people became avid bicyclists, others developed skills in wood sculpting or painting, while others became community volunteers.

Priorities became reorganized, "coming down with a disease" placed valued roles and relationships "where they should be." One person, with hand contractures, devoted time daily for exercising her index fingers to ensure capabilities for sending emails to distant family members. One person put away a life-long hobby of crocheting without remorse, the diminished dexterity of her hands was acknowledged, and felt sitting with her husband every night was more rewarding. Some relationships were relinquished, significant ones nurtured, while new relationships were formed providing companionship, offering acceptance, resulting in feelings of closeness. One participant spoke about feeling close with his grandchildren, "I feel happy when I see my grandchildren or their pictures, I look at them and say, 'God! They're so beautiful!' Having family, that's what counts in life." Many people attended Parkinson disease dance groups and consistently described renewed energy and motivation. This participant explained the importance of the dance group: "The highlight of my life now is this dance for Parkinson's."

Becoming reformulated is a process and not a milestone of achievement. Coming to terms with the illness does not imply that people accept their illness; instead, becoming a *reformulated self* represents increasing connectedness to newly forming identities and relationships.

Transition: Balancing Risks and Rewards

During prior stages, the individual's sense of continuity became disrupted; people could not see themselves as they previously envisioned before the diagnosis. Plans and dreams created for their future were reshaped. While *Sifting and sorting* was a method of reduction, *Balancing risks and rewards* is a strategy of comparison. People looked at their current abilities and circumstances, imagining what life might be like in the future, while seeking to establish a base of equilibrium. However, participants frequently miscalculated the extent of their impairments resulting in an overestimation of abilities.

Stage 5: Envisioning a Future

"With Parkinson's, today is the best day you will ever be. Today is tomorrow." Becoming a connected self and having a place in the world, relies on experiencing time as a continuous flow. Diminishing movement abilities causes people to become firmly anchored to the moment, subsequently changing sensations of continuity; the past was compressed, the present became expanded, and the future was shortened. Recognizing the inevitable and moving forward were difficult.

Recognizing the inevitable. Initially, people did not realize the major impact Parkinson disease would have in their lives. This participant found out the diagnosis after age 70. He described what he was told about the course and prognosis, "I remember the doctor told me it wasn't a death certificate, I have 20 more years to live. Then, when I got more into it, they said there were medicines that would help." Hope for permanent symptom relief or the possibility of a cure was common. Deep Brain Stimulation (DBS) was being considered by several advanced stage participants. One person wanted a third procedure; another was considering it for the first time, while a third person wanted DBS, but was told by his doctor that he would probably "become a vegetable." So, hope was given and hope was taken away.

None of the participants had an understanding for the severity or stage of their illness. Most had heard of the Hoehn and Yahr scale from the Internet. They did not speak with their families or doctor about driving difficulties, memory and mood changes, or increasing movement problems. They recognized Parkinson disease had early, middle, and late stages; but did not know what this meant. For instance, a participant (nearing the end of the middle stage) considered himself as being in the early stages:

I guess I still think I'm in the early stages. Probably because I see this as something that's going to last a long time, 20 to 30 years of this stuff. So, I better be in the early stages now. I'm trapped enough without getting to that stage. But, I am hopeful that I'm still in the early stages of it. It would be nice if this was as bad as it gets. But it probably gets worse (deep sighing).

Peer groups (support or dance) provided opportunities to make friends, while observing people who were at different disease severity stages. Some group members (nonstudy

participants) even attended on a "reclining wheelchair" accompanied by nursing aides. Several people described becoming more understanding of others less fortunate than themselves and developed greater self-tolerance. This participant described the dance group atmosphere, "There's no judgment, it's all very accepting and easy. You go and do what you can. It's liberating."

Social comparisons provided first-hand knowledge of the unique debilitating decline occurring with Parkinson disease; it became easier for people to recognize future disabilities. However, seeing other people did not provide information on how to live with the condition on a day-to-day basis: organizing medications, managing incontinence, or determining home safety hazards.

Planning pragmatically with tunnel vision. As a result, people felt it was their duty for monitoring their health, evaluating changes, and becoming treatment proactive in the belief that their efforts would maintain a sense of self-responsibility, delay symptoms, and improve their condition. Twenty-two participants (88%) were responsible for administering their own medications; one of these people was in the advanced stages of illness. Three advanced stage participants (12%) had medication administered by spouses or by nursing personnel. No one felt assistance was necessary. Medication organization and storage varied from bottles tossed into larger bins to personalized portable containers. People made independent decisions regarding how and when to take prescribed and nonprescribed medications. Since medication taking is a private event (unmonitored), it must be acknowledged that most of the serious problems were not reported to providers.

Common sense and feedback from family members aided people as they strived to make daily life simpler. Several participants moved within the year before the diagnosis. Other people moved within three to five years after *Finding out*. Smaller homes and being closer to resources were important. All but one participant remained in the communities where they spent most of their adult lives. For the people who had not yet moved, they were considering factors on which to base this decision. These factors included not being able to climb stairs, difficulties caring for their homes, or being closer to medical care. However, selecting a new home was based on

current situations; the ramifications of future disabilities were not usually considered. It was the goal of one family to walk through their neighborhood for services; they selected a home with a grocery store across the street. Unfortunately, a four-lane highway made crossing the street difficult for a person with a stooped posture, shuffling slow gait, and a cane.

Independence was important. People imagined they would take public transportation when no longer able to drive, but did not account for walking distances to the bus stop. Taking the elevated train into the city for specialized medical care meant going to a station without an elevator and walking up two steep flights of stairs. The participant (stage IV with dyskinesias) walked sideways, facing the handrails, and would slowly climb one-step at a time while leaning forward and hugging the handrail with his upper body. His wife followed behind to prevent him from being bumped by rushed commuters. Community services do not consistently meet the needs of older adults or people with mobility problems.

Several people described having space in their homes for a nursing aide, "if it should come to that." One person (late midstage) lived alone in her "dream home", but realized she was essentially living in the basement because stair climbing was difficult. She hasn't thought about the future possibilities of home services, but has considered a rental arrangement. Other people made decisions to move into nursing homes if situations such as urinary incontinence required assistance. One man adamantly stated, "I will never have my wife clean me up. That's when I'm signing myself into a home." People hold strong views of themselves as always being capable and using care services was considered a "last resort." Information about the variety of home services and community resources is not easily accessible.

Fewer than four people had completed advanced directives. People explained, "I still have time" or "I thought that was just for heart attacks or comas." One participant had considered asking her neurologist to serve as her power of attorney over healthcare. She lived alone, family members lived a great distance, and felt the doctor would make the wisest decisions. But she was worried that her request would be denied and planned for the medical doctor to speak for her with the neurologist. Participants, generally, did not know or have information about advanced planning. For the people who had this information, they needed to become their own advocates
for ensuring their advanced directive goals.

Moving forward. Every participant was aware Parkinson disease was a permanent condition with no cure. People realized they would become increasingly disabled, but it was difficult for them to imagine what this might mean. Some described feeling overwhelmed by the larger than life qualities of the illness. This person spoke of what her world was like:

You start out with a little bit of symptoms, then you've got more symptoms, then they compound on each other. You feel like you're just going to keep rolling downhill on a slippery slope; and you can't control it. It's kind of like that (crying loudly, tears are falling down cheeks).

People described needing to change their views of the illness before being able to think of a future. Some spoke of changing their frame of mind, "This is not going to take me over. I'm going to be the boss of my body. I started getting my frame of mind, where you are what you think you are." One participant "put Parkinson's into the passenger seat. I'm the only one driving this car." However, there were occasions when aches, pains, and immobility episodes became consuming, leaving a person to lay in bed until the next day. Hope and optimism were desired traits but required continual efforts as this person pointed out: "I'm really conscious of and working hard at not being consumed by the illness. It hasn't miraculously opened up my heart to people who I wouldn't have otherwise liked or wanted to have anything to do with (chuckling)."

People strived to be engaged in daily life. Most of the participants became involved with volunteer activities; it was a shared sentiment to "give back" to the Parkinson community. They started support groups, actively sought opportunities to participate in research, and offered guiding friendship for others who recently found out the diagnosis. The advanced stage participant living in an assisted living home attended community meetings, voiced his opinions, and read internet material about current trends in Parkinson treatment or research. Physically assisted by two nursing aides, using a walker, then being placed onto a piano bench, he continued his long-time love of music by playing the piano in the home's foyer. Another participant had continued bicycling, feeling a sense of normalcy with little interference from the movement disabilities. She started a cycling group for people with Parkinson disease.

Apathy frequently accompanies Parkinson disease. Family members often mentioned the participant's lack of interest or enthusiasm; this was disheartening when this was pointed

out since relationships were vital. One person clarified his experience of apathy:

Apathy ... It's something that I don't feel, it's not caring. Apatheia is from Greek origins. It means without passion, without emotion, without feeling. One of the major results of (this illness) is the inability to get up very much energy and interest in your work. You kind of dismiss your whole life before the disease. I have enthusiasm, but most of it is taken up with ... my grandchildren.

Every participant described having feelings (often intense) but their bodily expressions were not congruent with their emotions. This was frustrating and often brought feelings of being trapped within their body, followed by sadness regarding losses of their relational abilities.

Discussion

How people responded to daily life challenges was clear; routines and evolving strategies functioned as a means to preserve favored prediagnosis identities, roles, and relationships. People faced their challenges based on past roles and identities while functioning based on the present moment. This affected their relationships, daily activities, their decisions, and ultimately the course of their illness. Over time, strategies emerged by trial and error (regardless of age or disability), based on the immediate and ever changing nature of problems. Responding successfully meant participants endured hardships and developed creative methods for sustaining the continuity and normalcy of themselves. This theory of *Preserving self* describes how people with Parkinson disease endeavored to maintain their identities through everyday activities, attitudes, and interactions.

Preserving Self-Strategies

Interacting with other people. Data highlighted two *Preserving self*-strategies for maintaining self-identity: (1) interacting and (2) taking action. These processes are distinct, identifiable, yet, blend during daily life. Interacting represents the contexts of a person's relationships and roles. Individuals experience, sustain, and transform their sense of self through relationships with others.

The inner striving for normalcy directed people's feelings, ways of relating with others, and subsequently their actions. Images of one's self as standing tall, strong, and independent reinforced a person's adamant refusal to consider a mobility device, "That is not me...I don't want anyone to see me like that because that is not who I am." In the case of falling, the man (stage IV) who carried his wife (stage V) down the stairs every Sunday saw himself as capable. This self-view was reinforced by his wife, adult children, and his employer. Neither of these individuals wanted to get hurt, but past self-images warranted their actions. Their present disabilities were set aside (bracketed) as though not applicable to themselves.

Taking action. The second *Preserving self*-strategy was taking action. The self becomes a frame of reference for making decisions and taking action. Insight regarding a person's template of action (self-identity) must take into consideration relationships with family, community, and healthcare that provide the meaningful basis for how people feel, think, and act.

Participants were determined to retain their former self. However, by continually facing *Dilemmas of identity* (stage 3), feelings of detachment or disconnectedness became states of vulnerability for ongoing isolation, depression, anxiety, and dependencies (physical and emotional). They searched desperately for comforting and familiar routines, activities, and ways of relating. Subsequently, taking risks became a method of trying to reestablish former identities.

Taking risks. It became evident that participants of this study had a global knowledge of Parkinson disease, but did not consider the illness as part of a new identity, did not ascribe it as influencing their lifestyles, and did not always correlate their actions with risk taking. Their selfperceptions remained as before the illness. Consequently, decisions and actions were effected. Driving with the possibility of a freezing episode brings a potential for hazardous situations. Selfadjusting L-dopa without knowing side effects or consequences poses potential risk. In both of these examples, people become susceptible to vulnerabilities (such as depression or anxiety) when they cannot perform as previously, incur relationship disappointments, or fail societal standards and expectations.

Patterning of successful strategies. People who were able to reconnect and reformulate themselves demonstrated using strategies involving bodily movement, cognition, and emotions. Engagement with important relationships provided respected and on-going feedback. Involvement in activities such as bicycling, music, or playing with children required planning, coordination, and activated feelings.

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Generalizability

This research was conducted with a unique combination of participants, their illness experiences, hazardous and diverse settings, and researcher skills. The study design may be difficult to replicate. However, these findings may be generalizable to people with a variety of chronic conditions who have memory changes, depression, or fall while living in the community.

Strengths and Limitations

Strengths. A variety data collection methods were used which built engagement and commitment with people. Home observations provided glimpses into previously private worlds and instances of intimacy. Knowing participants took time but opened up windows of opportunity for depths of perspective. Additionally, the unique variety of people during different stages of the illness progression contributed to understanding the experiential processes of this unique chronic illness.

Limitations. Recruitment strategies of group presentations, distribution of flyers, and a website posting were simple, yet effective. A very large number of potential participants could not be consented due to the intensive nature of the study design and time constraints. This limitation points to how little attention has been given to psychosocial issues. When an empathetic listener offers time, people with Parkinson disease seek the opportunity to share.

Recommendations for Supporting Processes of Preserving Self

Although finding out the diagnosis was shocking, this was time limited and surpassed by conflicting images of past and former selves. Every participants experienced great difficulty from the unsettling reminders of former selves preceding *Dilemmas of identity*. People reexperienced these dilemmas (of varying duration and intensity) throughout the illness. However, people who had strong relationships and became involved with particular activities, demonstrated forms of reconnecting and reformulating. This does not mean that people accepted the illness; instead, the illness was accommodated.

Interventions designed for reducing the impact of unsettling reminders and *Dilemmas* of identity would enhance *Preserving self* and potentially reduce the loss of self. These

recommendations are for healthcare professionals, families, and people with the illness.

Develop relationships. People seek familiarity and closeness with family members, friends, and their health providers. Nurse practitioners could provide continuity and linkage between specialty and general medical providers.

Teach expected and unexpected feelings and behaviors. Sustaining trusted relationships become the basis for asking questions, communicating concerns, and providing "bad news," especially surrounding risk-taking behaviors.

Involvement with sensory integrating activities. Loss of self essentially means not being a whole person. Parkinson disease effects every sensory organ and experience, alters understanding of a person's position in the world due to mobility and movement symptoms, and fundamentally reshapes relationships. Integrating emotions, cognitions, and the body through activities such as dance or bicycling provided benefit to many participants (Alberts, Linder, Penko, Lowe, & Phillips, 2011; Heiberger, Maurer, Amtage, et. al., 2011; Lewis, Annett, Davenport, Hall, & Lovatt, 2014; Snijders, Toni, Ružička, & Bloem, 2011). Even though people in the later stages participated in dance, this may not always be practical. Integrating activities include preparing vegetables for dinner, folding clothes, humming, or singing.

Conclusion

The lifestyles of people with Parkinson disease portray a desire to complete responsibilities, satisfy obligations, and share fulfilling relationships. Meaningful explanations of their situations were sought, relying on family, friends, and healthcare providers, as they struggled through day-to-day living. Substantiating these statements is this fact: over 95% of people with Parkinson disease remain living at home. Without thoughtful explanations or guidance, people are left on their own to devise ways of making sense of dilemmas, while creating new forms of identities, relationships, and futures.

Endnotes

¹ Parkinson disease is one of several progressive neurodegenerative parkinsonian disorders. These disorders may be difficult to distinguish from nonprogressive forms of parkinsonism (such as drug induced). Diagnostic accuracy is low for all forms of parkinsonism because people without obvious drug induced or vascular causes may eventually be determined to have other atypical forms of neurodegenerative parkinsonism as the disease progresses. Examples of more serious forms of atypical neurodegenerative parkinsonism include multiple system atrophy, progressive supranuclear palsy, or corticobasal degeneration. Diagnosis can only be confirmed with autopsy (Dickson, 2012; Wenning, Krismer, & Poewe, 2011).

² At the time of data collection (2013-2014), larynx transplantation was a novel and extraordinarily complex procedure. Two larynx transplants have been documented: The Cleveland Clinic in 1998 and UC Davis Medical Center in 2010 (UC Davis Health System, 2014).

³ Mayan, Morse, & Eldershaw (2006) expanded the concept of self-reformulation from interviews with people who had faced death, but recovered. They considered self-reformulation as a desired outcome from suffering and a goal of rehabilitation.

References

- Abudi, S., Bar-Tal, Y., Ziv, L., & Fish, M. (1997). Parkinson's disease symptoms patients' perceptions. *Journal of Advanced Nursing*, *25*(1), 54-59. doi: 10.1046/j.1365-2648.1997.1997025054.x
- Alberts, J. L., Linder, S. M., Penko, A. L., Lowe, M. J., & Phillips, M. (2011). It is not about the bike, it is about the pedaling: Forced exercise and Parkinson's disease. *Exercise and Sport Sciences Reviews*, 39(4), 177-186. doi:10.1097/JES.0b013e31822cc71a
- Ali, M., & Ali, H. Y. (2004). The soul of a butterfly: Reflections on life's journey. NY: Simon and Schuster.
- Bartels, A. L. & Leenders, K. L. (2009). Parkinson's disease: The syndrome, the pathogenesis and pathophysiology. *Cortex*, *45*(8), 915-921. doi:10.1016/j.cortex.2008.11.010
- Beaulieu, J.-M. & Gainetdinov, R. R. (2011). The physiology, signaling, and pharmacology of dopamine receptors. *Pharmacological Reviews*, 63(1), 182-217. doi: 10.1124/pr.110.002642
- Blaikie, N. (2000). Designing social research. Malde, MA: Blackwell Publishers.
- Blumer, H. (1969). *Symbolic interactionism: Perspective and method*. Berkeley, CA: University of California Press.
- Caddell, L. S., & Clare, L. (2013). Studying the self in people with dementia: How might we proceed? *Dementia*, *12*(2), 192-209. doi:10.1177/1471301211418486
- Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. Sociology of Health & Illness, 5(2), 168-195. doi:10.1111/1467-9566.ep10491512
- Charmaz, K. (1990). 'Discovering' chronic illness: Using grounded theory. Social Science & Medicine, 30(11), 1161-1172. doi:10.1016/0277-9536(90)90256-R
- Charmaz, K. (1991). *Good days and bad days: The self in chronic illness*. New Brunswick, NJ: Rutgers University Press.
- Charmaz, K. (1994). Identity dilemmas of chronically ill men. Sociological Quarterly, 35(2), 269-288. doi: 10.1111/j.1533-8525.1994.tb00410.x
- Charmaz, K. (2014). Constructing grounded theory (2nd ed.). Thousand Oaks, CA: Sage.
- Chaudhuri, K. R., Odin, P., Antonini, A., & Martinez-Martin, P. (2011). Parkinson's disease: The non-motor issues. *Parkinsonism & Related Disorders, 17*(10), 717-723. doi: 10.1016/j.parkreldis.2011.02.018
- Corbin, J., & Morse, J. M. (2003). The unstructured interactive interview: Issues of reciprocity and risks when dealing with sensitive topics. *Qualitative Inquiry, 9*(3), 335-354. doi:10.1177/1077800403009003001
- Dickson, D. W. (2012). Parkinson's disease and parkinsonism: Neuropathology. *Cold Spring Harbor Perspectives in Medicine, 2*(8). doi:10.1101/cshperspect.a009258

- Dorsey, E. R., Constantinescu, R., Thompson, J. P., Biglan, K. M., Holloway, R. G., Kieburtz, K., . . Tanner, C. M. (2007). Projected number of people with Parkinson disease in the most populous nations, 2005 through 2030. *Neurology, 68*(5), 384-386. doi: 10.1212/01.wnl.0000247740.47667.03
- Eidelberg, D., & Pourfar, M. (2007). Parkinson's disease. In R. S. Porter & J. L. Kaplan (Eds.), *The Merck manual: Home health handbook.* Whitehouse, NJ: Merck, Sharp, & Dohme
- Elbaz, A., Bower, J. H., Peterson, B. J., & et al. (2003). Survival study of Parkinson disease in Olmsted County, Minnesota. *Archives of Neurology*, 60(1), 91-96. doi: 10.1001/archneur.60.1.91
- Erbentraut, J. (2014). Chicago just had its coldest winter in history. Here's proof. *The Huffington Post.* Retrieved from http://www.huffingtonpost.com/2014/04/02/chicago-coldest-winterever_n_5078201.html
- Fox Foundation. (2013). The Fox Trial Finder. Retrieved from https://foxtrialfinder.michaeljfox.org/about-fox-trial-finder/
- Galasiński, D. (2008). Constructions of the self in interaction with the Beck Depression Inventory. *Health:*, *12*(4), 515-533. doi: 10.1177/1363459308094423
- Giddens, A. (1991). *Modernity and self-identity: Self and society in the late modern age*. Stanford, CA: Stanford University Press.
- Glaser, B. G. (1978). Theoretical sensitivity. Mill Valley, CA: Sociology Press.
- Goetz, C. G., Poewe, W., Rascol, O., Sampaio, C., Stebbins, G. T., Counsell, C., . . . & Seidl, L. (2004). Movement Disorder Society task force report on the Hoehn and Yahr Staging Scale: Status and recommendations. *Movement Disorders, 19*(9),1020-1028. doi: 10.1002/mds.20213
- Grinnon, S. T., Miller, K., Marler, J. R., Lu, Y., Stout, A., Odenkirchen, J., & Kunitz, S. (2012). National Institute of Neurological Disorders and Stroke Common Data Element Project – approach and methods. *Clinical Trials*. Retrieved from http://www.commondataelements.ninds.nih.gov/PD.aspx#tab=Data_Standards
- Heiberger, L., Maurer, C., Amtage, F., Mendez-Balbuena, I., Schulte-Monting, J., Hepp-Reymond, M. C., & Kristeva, R. (2011). Impact of a weekly dance class on the functional mobility and on the quality of life of individuals with Parkinson's disease. *Frontiers in Aging Neuroscience, 3*, 14. doi:10.3389/fnagi.2011.00014
- Hiorth, Y.H., Larsen, J.P., Lode, K., & Pedersen, K.F. (2014). Natural history of falls in a population-based cohort of patients with Parkinson's disease: An 8-year prospective study. *Parkinsonism & Related Disorders, 20*(10), 1059-1064. doi: 10.1016/j.parkreldis.2014.06.023
- Hoehn, M., & Yahr, M. D. (1967). Parkinsonism: Onset, progression, and mortality. *Neurology, 17*(5), 427-442. doi:10.1212/wnl.17.5.427
- Howard, A. F., Balneaves, L. G., Bottorff, J. L., & Rodney, P. (2011). Preserving the self: The process of decision making about hereditary breast cancer and ovarian cancer risk reduction. *Qualitative Health Research*, 21(4), 502-519. doi:10.1177/1049732310387798

- Hudson, P. L., Toye, C., & Kristjanson, L. J. (2006). Would people with Parkinson's disease benefit from palliative care? *Palliative Medicine*, 20(2), 87-94. doi: 10.1191/0269216306pm1108oa
- Hughes, A. J., Daniel, S. E., Kilford, L., & Lees, A. J. (1992). Accuracy of clinical diagnosis of idiopathic Parkinson's disease: A clinico-pathological study of 100 cases. *Journal of Neurology, Neurosurgery & Psychiatry, 55*(3), 181-184. doi: 10.1136/jnnp.55.3.181
- Irurita, V. F., & Williams, A. M. (2001). Balancing and compromising: nurses and patients preserving integrity of self and each other. *International Journal of Nursing Studies, 38*(5), 579-589. doi:10.1016/S0020-7489(00)00105-X
- Joutsa, J., Gardberg, M., Röyttä, M., & Kaasinen, V. (2014). Diagnostic accuracy of parkinsonism syndromes by general neurologists. *Parkinsonism & Related Disorders*, 20(8), 840-844. doi: 10.1016/j.parkreldis.2014.04.019
- King, K. M., & Jensen, L. (1994). Preserving the self: Women having cardiac surgery. *Heart & Lung*, 23(2), 99-105. Retrieved from <u>http://www.ncbi.nlm.nih.gov/pubmed/8206780</u>
- Lewis, C., Annett, L. E., Davenport, S., Hall, A. A., & Lovatt, P. (2014). Mood changes following social dance sessions in people with Parkinson's disease. *Journal of Health Psychology*. doi:10.1177/1359105314529681
- Li, T., Ho, Y.-S., & Li, C.-Y. (2008). Bibliometric analysis on global Parkinson's disease research trends during 1991–2006. *Neuroscience Letters*, 441(3), 248-252. doi: 10.1016/j.neulet.2008.06.044
- Mayan, M. J., Morse, J. M., & Eldershaw, L. P. (2006). Developing the concept of selfreformulation. *International Journal of Qualitative Studies on Health and Well-being*, 1(1), 20-26. doi:10.1080/17452620500534587
- Mead, G. H. (1934). *Mind, self, and society: From the standpoint of a social behaviorist* (C. W. Morris Ed. reprint ed.). Chicago, IL: University of Chicago Press.
- Meireles, J. & Massano, J. (2012). Cognitive impairment and dementia in Parkinson's disease: Clinical features, diagnosis, and management. *Frontiers in Neurology, 3*, 88. doi: 10.3389/fneur.2012.00088
- Morse, J. M. & Johnson, J. (1991). Toward a theory of illness: The illness constellation model. In J. M. Morse & J. Johnson (Eds.), *The illness experience: Dimensions of suffering* (pp. 315-342). Newbury Park, CA: Sage.
- Morse, J. M., & O'Brien, B. (1995). Preserving self: From victim, to patient, to disabled person. Journal of Advanced Nursing, 21(5), 886-896. doi: 10.1046/j.1365-2648.1995.21050886.x
- Morse, J. M. (2012). Qualitative health research: Creating a new discipline. Walnut Creek, CA: Left Coast Press.
- Olanow, C. W., Stern, M. B., & Sethi, K. (2009). The scientific and clinical basis for the treatment of Parkinson disease (2009). *Neurology*, 72(21 Supplement 4), S1-S136. doi: 10.1212/WNL.0b013e3181a1d44c
- Pennington, S., Snell, K., Lee, M., & Walker, R. (2010). The cause of death in idiopathic Parkinson's disease. *Parkinsonism & Related Disorders, 16*(7), 434-437. doi: 10.1016/j.parkreldis.2010.04.010

- Perlmutter, J.S. (2009). Assessment of Parkinson disease manifestations. *Current Protocols in Neuroscience, Chapter 10*, (11). doi: 10.1002/0471142301.ns1001s49
- Rathbun, A. & Gottfried, M. H. (2014, June 21). Flooding causes mudslides in St. Paul, Minneapolis. *St. Paul Pioneer Press*. Retrieved from <u>http://www.twincities.com/localnews/ci_26003927/flooding-causes-mudslides-st-paul-mendota-heights-minneapolis</u>

Ronstadt, L. (2013). Simple dreams: A musical memoir. NY: Simon & Schuster.

- Schulman-Green, D., Jaser, S., Martin, F., Alonzo, A., Grey, M., McCorkle, R., . . . Whittemore, R. (2012). Processes of self-management in chronic illness. *Journal of Nursing Scholarship*, 44(2), 136-144. doi:10.1111/j.1547-5069.2012.01444.x
- Shulman, L. M., Taback, R. L., Rabinstein, A. A., & Weiner, W. J. (2002). Non-recognition of depression and other non-motor symptoms in Parkinson's disease. *Parkinsonism & Related Disorders, 8*(3), 193-197. doi:10.1016/S1353-8020(01)00015-3
- Schrag, A. (2006). Quality of life and depression in Parkinson's disease. *Journal of the Neurological Sciences, 248*(1–2), 151-157. doi: 10.1016/j.jns.2006.05.030
- Schwalbe, M. L. (1983). Language and the self: An expanded view from a symbolic interactionist perspective. *Symbolic Interaction, 6*(2), 291-306. doi: 10.1525/si.1983.6.2.291
- Snijders, A. H., Toni, I., Ružička, E., & Bloem, B. R. (2011). Bicycling breaks the ice for freezers of gait. *Movement Disorders*, 26(3), 367-371. doi:10.1002/mds.23530
- Tweed, A., & Charmaz, K. (2012). Grounded theory methods for mental health practitioners. In D. Harper & A. R. Thompson (Eds.), *Qualitative research methods in mental health* and psychotherapy: A guide for students and practitioners (pp. 131-146). West Sussex, UK: John Wiley & Sons, Ltd.
- UC Davis Health System. (2014). Extraordinary larynx transplant restores voice, sense of taste, smell to California woman: World's second documented voice box transplant. *UC Davis Newsroom.* Retrieved from https://www.ucdmc.ucdavis.edu/publish/news/newsroom/4949
- Weintraub, D., & Burn, D. J. (2011). Parkinson's disease: The quintessential neuropsychiatric disorder. *Movement Disorders*, 26(6), 1022-1031. doi: 10.1002/mds.23664
- Wenning, G. K., Krismer, F., & Poewe, W. (2011). New insights into atypical parkinsonism. *Current Opinion in Neurology, 24*(4), 331-338. doi:10.1097/WCO.0b013e3283480569
- Wichmann, T., DeLong, M. R., Guridi, J., & Obeso, J. A. (2011). Milestones in research on the pathophysiology of Parkinson's disease. *Movement Disorders, 26*(6), 1032-1041. doi: 10.1002/mds.23695

CHAPTER 5

MEDICATION AS A SOCIAL PROSTHESIS

This chapter was prepared for future submission to Qualitative Health Research.

Abstract

The purpose of this study was to identify the emotions and actions of embodied medication use for people with Parkinson disease. Constructivist grounded theory was the study method. Participants were 15 men and 10 women (ages 40 to 95 years), living primarily with their families. Illness descriptions were obtained through Hoehn and Yahr staging, activities of daily living, and medication logs. Data included 62 in-depth interviews, photos, videos, and related documents. Analytic procedures generated the theory of *Medication as a Social Prosthesis*. This theory has three stages: (1) *Sifting and sorting*, (2) *Establishing expertise* and (3) *Embodying medication*. In this way, medications, both the frequency and dose, are under the control of the person and not the prescriber. Medications were embodied into the parkinsonian self. In order to feel and function normally, people learned how to take and when to use supplemental L-dopa. Extra dosing was beneficial in controlling symptoms and living normally.

Introduction

Parkinson disease is unique: it can be difficult to diagnose, challenging to treat, and is considered life altering and life limiting (Joutsa, Gardberg, Röyttä, & Kaasinen, 2014). It is characterized by three major public health problems: falls, depression, and dementia. While these symptom patterns may occur with other neurological and chronic illnesses, they are now considered part of the parkinsonian symptomology. The ambiguous and insidious onset of symptoms occurs over many years, leading to an irregular and inconsistent loss of abilities. Chronicity and gradual decline influences every aspect of a person's life. Mobility slows,

movements stiffen, and activities of daily living gradually fail, along with diminishment of valued relationships, roles, and identity. Individuals respond to these challenges by developing strategies for *Preserving self* (discussed in Chapter 4).

Initially, people were surprised and dismayed at their bodily changes. Not wanting to look or feel differently from their usual self, people developed ways to maintain capabilities and conceal symptoms. One of these strategies was the self-adjustment of prescription medication, specifically, dopamine replacement (L-dopa). People quickly learned medication use practicalities for reducing symptom onslaughts to achieve their goal of maintaining familiar lifestyles. They learned that L-dopa softens facial masking, diminishes tremors, and enhances gait stability. As symptoms increase with continuing illness, the strength of impact was felt on a person's identity. Subsequently, the use of L-dopa also increased.

In this article, I will identify the emotions and actions of embodied medication use in Parkinson disease, develop the theory of *Medication as a Social Prosthesis*, define and identify the characteristics of the concept, and discuss implications for care.

Background to the Study

During my study examining the challenges and strategies of maintaining identity for people with Parkinson disease, the core variable was identified as *Preserving self* (previously discussed in Chapter 4). The resulting theory descriptively explained the social psychological processes beginning from before the diagnosis and continuing through advanced illness stages. *Preserving self* describes a way of being that sustains self-identity through everyday activities, attitudes, and interactions. Maintaining preillness self-identity was the goal of actions taken. Failing to *Preserve self* may lead to the loss of relationships, roles, self-worth, and ultimately, the loss of one's self. This theory has five stages: (1) *Making sense of symptoms*, (2) *Turning points*, (3) *Dilemmas of Identity*, (4) *Reconnecting the self*, and (5) *Envisioning a future*. Between each stage are transitions, representing decisions involving emotional and cognitive responses. Strategies used to preserve may be identified by examining the behaviors and emotions of people during challenging times, such as managing chronic illness. An extraordinary relationship was observed between people with Parkinson disease and their medications beginning after finding out the diagnosis (*Turning points*) with momentum building during the transition of *Sifting and sorting* continuing through an accommodation of the illness (*Reconnecting the self*). They constantly monitored their bodies, recognizing when movements became slower and stiffened. Difficult situations dictated the inventing of a new lifestyle. Slowing and tremulous hand movements made eating difficult while motionless facial expressions worried family members. Uncontrollable distortions of movements while in public brought shame and humiliation. Possibilities of being unable to move (freezing) brought intense anxiety. Participants relied upon these medications in order to perform everyday living activities: eating, dressing, talking, smiling, walking, standing, sitting, and driving. Ways were devised to have medications immediately available; eventually people became embodied with the medication and its containers. This concept, I have labeled *Medication as a Social Prosthesis*.

Methods

The *Preserving self* study used constructivist grounded theory (Charmaz, 2014); it was conducted in three Midwestern states. IRB permission was obtained from the University of Utah. Individuals responded to fliers placed in community centers and a notice on the Fox Trial Finder website (2012). All participants consented for interviews and signed for the release of videos and photographs. Twenty-five persons volunteered to be interviewed in their homes and were observed as they went about their daily lives.

A total of 15 males and 10 females participated, aged between 40 and 95 years. The diagnosis of Parkinson disease was self-reported. The illness duration ranged from 3 months to over 30 years. Participants varied in the stage of disease progression based on the five Hoehn and Yahr (HY) stages (1967), with the majority (n = 14) having mild to moderate disability. HY stages for all participants were stage I (n = 0), stage II (n = 0), stage III (n = 14), stage IV (n = 8), and stage V (n = 3). People had a range of self-care abilities based on The Schwab and England Scale (Perlmutter, 2009); stage III completed ADL activities at an independence level of 60 to 80%. While participants in stage V ranged between independence levels of 20 to 30%. A variety of OTC and prescription medications were used with the most common being L-dopa (n = 21).

The duration of L-dopa use ranged from 3 years through 30 years. Five people had dyskinesias due to long-term use of L-dopa. Data consisted of 62 formal unstructured interviews, photographs, videos, and other materials shared by participants. Details were provided in Chapter 4.

Data Analysis

In my first study (Chapter 4), I described the strategies participants used to maintain identity while living with an insidiously progressive chronic condition. Of particular interest was the role of L-dopa that enabled participants to move, talk, express themselves, and maintain independent living despite the disease. The results section of this article contains two parts. First, the strategic role of medication was explored further, again using constructivist grounded theory, resulting in the theory of *Medication as a Social Prosthesis*. Next, qualitative content analysis (Morse, In press), was a second method used for concept development. Identifying the anatomy of a concept is a formal analytic process, beyond the theoretical development (Morse, In press; Morse, Mitcham, Hupcey, & Cerdas Tason, 1996), used in grounded theory. A definition of the scientific concept for *Medication as a Social Prosthesis* was developed and characteristics (i.e., attributes) identified. Finally, the boundaries of the concept were located by comparing the attributes with concepts of drug dependencies, lifestyle drugs, and the meaning of medications. This technique has been used in previous concept analyses (Morse & Mitcham, 1998).

Results

Part 1. Developing the Theory of Medication as a Social Prosthesis

Overview

Medication as a Social Prosthesis represents a self-preserving strategy (used by people with Parkinson disease) serving to extend or build upon diminishing abilities for sustaining vital relationships and valued identities. Participants passed through three stages: (1) *Sifting and sorting*, (2) *Establishing expertise* and (3) *Embodying medication*. Figure 5.1 (p. 112) illustrates the stages. Marking these stages are the decisions made to deal with identity and relationship challenges by self-adjusting medication accompanied by expertise and reliance. Medication



Figure 5.1. The stages and transitions of *Medication as a Social Prosthesis*.

functioned as a prosthesis for maintaining a balanced and normal connection with one's selfidentity and essential relationships.

Stage 1: Sifting and Sorting

People were so involved with routine daily activities that their bodily changes usually stayed in the background of awareness. However, with multiple symptoms and increasing disability, the body was thrust into the foreground. The loss of capabilities created a sense of not being an integrated whole and altered the understanding of one's place in the world. The trustworthiness of the body became diminished. This was a time of grieving for lost hopes, abandoned dreams, and worry about future losses. To accomplish tasks of *Sifting and sorting*,

participants had to think differently about themselves. Since we relate to the world through our bodies, constant unpredictable physical changes shaped and directed their participation. People began reading their bodies more closely.

Reading the body. Participants endured hardships and suffered from wide-ranging physical and emotional symptoms. This distressing lifestyle has been compared to the experience of people with cancer; parallel needs extend from diagnosis to end stage illness. As one participant described, "(People) don't see the devastating things that it does to your body and possibly your mind. It really affects every part of you." One task of *Sifting and sorting* was to set aside dichotomous views of Parkinson disease.

The deceiving body. People expected declining function to be part of the illness experience, but did not anticipate that it would happen "so quickly." Each additional loss brought a sense of anxiety and sometimes near panic. Getting ready for work frequently took hours because of movement slowness. One person described how fatiguing it had become to devote such concentrated effort in lifting her hand for hair brushing. However, try as she might, she could not lift her hand above her elbow.

Accomplishing tasks such as feeding one's self or personal hygiene became daily priorities. Declining abilities brought frightening images of being in a wheelchair and depending on others for care, details formerly managed independently. This person described her fear of advancing illness:

Well, I'm a little afraid ... because I don't really want to be taken care of (speaking loudly with a mixture of shrieking, crying, and laughing). I guess we'll get to that point at some point. I don't want to give up. I work, exercise. I'm not ready to give up.

How people viewed concerns of physical dependency changed over time and with the degree of disability. Personal experience over the passage of time contributed to greater understanding of the self in illness. Subsequently, people who were in later illness stages and older grew less fearful. Regardless of age, illness stage, or fear, everyone continued to spend enormous physical and mental energy trying to remain independent.

Sometimes people's worst fears of dependency came to be a reality. One man had lost weight, explaining he was not often hungry, but felt he was eating "pretty much ok." This

participant described how his daughter helps him with dinner.

When my daughter and her friend are over, they cut my meat up for me at night. I don't ask or nothing. They'll just say, "I'll fix your plate and cut your meat up for you." They cut the carrots and everything. When they first started doing it, I started arguing with them. I said, "No, no, no." But if they want to and they're happy doing it, it's okay with me. They say, "You're not going to choke on me (laughter)!"

His wife reported he was having a hard time chewing and swallowing. The man added, with embarrassment, that his daughter recently began placing the food-filled fork up to his mouth. These situations of being done to or done for occurred with increasing frequency. Formerly mundane tasks became obstacles, complicating views of one's self as a capable and responsible adult. These obstacles also complicated how other people viewed each of the participants.

Falls became a routine event and were concerning for participants. Those who reported falling "too many times too count," "over 100 times", or having had "numerous breaks and fractures", recognized their vulnerability, but seemed to accept falling as something to be expected with illness and aging. People with one or two falls behind them, were quick to say, "It was just once." "I stumbled over my feet. I wasn't watching where I was going." No one wanted to fall down and risk getting hurt; but falls soon came to be considered a new normal.

It was common for people to own a cane, walker, or wheelchair. However, they emphasized, "I don't use a cane. It's only for sitting when I have back pain at the Museum." These dependencies were frightening to acknowledge and resulted in people denying that they relied upon assistive devices.

Encountering the vulnerable self. Being vulnerable represents susceptibilities to depression, anxiety, or social isolation resulting from misreading the body, available knowledge, and available support.

Eroding self-worth. The new bodily changes forced reality onto images of the past self. These observations were sometimes alarming, humiliating, or shaming. Repetitious and conflicting images eroded the integrity of one's self-worth; setting a foundation for the emotional pains of helplessness and hopelessness. This is depression. Depression is a highly stigmatized illness, subsequently difficult to acknowledge. Participants used terms such as "stress" or "feeling pressured" and most described periods of loneliness and crying. This participant explained depression: "I know one of the symptoms of Parkinson's is clinical depression. Your brain is physically sick that way. Fear is always in the background about this stuff."

Paralyzing anxiety. Intense fears with constant worrying about imagined incidents of impending doom were common. For many people, paralyzing thoughts developed when encountering situations requiring decisions or challenging former skills. These situations were usually former routines; for example, driving alone through snow for needed supplies, meal planning and preparation, or predicting their capabilities in maintaining scheduled medical appointments. Participants tried to avoid taking risks, but since circumstances seemed to change constantly, determining what defined a risk was difficult. People doubted their thoughts, questioned their feelings, and hesitated before acting.

Freezing of gait caused enormous anxiety. "What if I fall?" "How long would I have to lay on the floor?" "What if I have to go to the bathroom?" The anxiety often became so large and encompassing, that people had difficulties thinking of their next possible actions. The unexpected suddenness of the freezing caused the anxiety, not the actual event itself.

Demoralizing situations. People encountered embarrassing situations on a routine basis (felt stigma). Sometimes it happened when and where it was least expected. Family members were sometimes the ones who made minimizing comments, such as, "I've tried to explain to my wife ... that you can't help the things to do with Parkinson's. She still has this idea, that you could just overcome it. I don't think she really gets it."

Concealing. Roles developed at work are integral to an adult's self-image. Working brings opportunities for experiences of achievement with rewards of income, health insurance, and friends. However, to continue with this satisfying role, it became increasingly important to maintain control over levels of self-disclosure and conceal symptoms. People voiced concerns about the possibilities of being judged, laughed at, or fired, if the illness was discovered. At least half of the participants described work-related problems related to misunderstandings of Parkinson disease despite antidiscrimination laws. Most were asked to leave their employment because of the observable symptoms.

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Recurring evidence undermined a person's understanding of their place in the world. Emotional vulnerabilities and a deceiving body brought an awareness of the incessant unrelenting nature of personal suffering. "I would say I'm suffering; because of a loss of mobility and sense of stability in my life. I think I suffer from that. I suffer because I'm worried about the future." Being unable to respond or function predictably in the old familiar ways led to frustration, confusion, and never ending concerns about one's capabilities and relationships. All of which lead to emotional suffering, physical distress, and social isolation.

During this first stage, people engaged in emotional and cognitive processes of selfevaluation. *Sifting and sorting* through activities, relationships, and various self-identities assisted in focusing efforts of maintaining the most valuable connections. The least important features for their present circumstances were set aside. While at the same time, holding on to the most valued characteristics that might provide meaning to an evolving but yet unknown self. People synthesized the sifted and sorted aspects with newer attributes in an effort to be as they were before the illness. Values and convictions were perpetually redefined, while reformulating tentative boundaries of a changing self. Goals of maintaining valued relationships and familiar identities became a priority. Knowing this provides a basis for understanding how participants made medication treatment decisions.

Transition: Making Treatment Decisions

Receiving the first prescription. Everyone received some type of prescription at the time of diagnosis, whether it was for emotional concerns, sleep problems, or movement difficulties. Approximately half of the participants received L-dopa at the time of diagnosis. A few people mentioned receiving medication options and, in these situations, declined dopamine replacement. Even though receiving medication was described as taking up a major portion of each office visit, nearly every participant reported receiving little information about prescriptions or the illness. Instead, relying on family, friends, or the internet for information. Complicating the situation was the simultaneous presence of other chronic conditions (and their medications) that people needed to understand and organize. Feelings of bitterness, anger, and worry were present when describing the lack of information provided.

Feeling all alone. Neurology follow-up visits were usually scheduled every six months with advisement to call with problems. Medical appointments were generally every one to three months, but asking about any new symptom that might be related to Parkinson disease, resulted in the doctor's referral of care back to the neurologist.

People felt alone in their responsibilities for handling this illness. Without knowing the cause of the illness and without consistent health provider contact, most participants felt compelled to try various treatments with the hopeful intent of reducing or eliminating symptoms. "If I knew what caused it, I could do something." However, for others, knowing the cause was not essential; having an official diagnosis helped clarify their course of action. Somehow knowing, or even being able to attribute, a particular sign as being related to Parkinson disease made treatment decisions less frightening.

I think knowing this is a symptom of things that changed in my brain because of Parkinson's, makes everything less scary. So, if I'm feeling this way, I know why. I either take the medicine or I get past it.

Life experience and "basic common sense" was applied to their symptoms. By doing this, people gained skills in reading their bodies and making independent treatment decisions.

Expecting medical care to improve life. People were used to taking responsibility for accommodating daily life nuances, including other illnesses and medications. It was a commonly expressed expectation that medical care enhance a person's capabilities in accomplishing life goals. Consequently, relationships with health providers became frustrating disappointments. One participant reported that the neurologist, a year earlier, had "wanted to make some medication adjustments" and discontinued her prescribed antidepressant, Wellbutrin. She accepted his decision until her symptoms became unbearable.

I just couldn't deal with it anymore. I just wasn't myself. It was like, "Oh, it's a sunny day. Yeah" (using a dull, flat, unenthusiastic voice). Most the time I'm out there doing something with my flowers or something. It's like I didn't care. I thought, "Ok, something's wrong". I started crying at times that I know I shouldn't have.

She made a doctor's appointment, wrote out what she wanted to say, brought her husband, and asked for the antidepressant to be restarted. The prescription was provided. The participant knew she had the "right" to ask for this medication, but felt she needed to express the request in a manner that "respected and protected" the doctor's position of authority. She knew she would

need the prescription writing capabilities of the doctor. It was essential for people to learn about their symptoms and available treatments in order to care for themselves.

Taking extra dopamine replacement medication. It was essential for people to learn about their symptoms and available treatments in order to care for themselves. Influencing each person's decision to self-adjust L-dopa was the immediate benefit from the drug, the number of bothersome symptoms, severity of functional disability, degree of life impact, and the involvement of other people.

Discovering the benefits of L-dopa. People noticed an immediate difference, even with the first doses. Using L-dopa was described as being miraculous. A return of smiling to a previously motionless facial expression brought relief, "I am so grateful. I can smile again. It bothered me that I couldn't smile." Improved functioning at work and with relationships brought feelings of being normal; it was as though their bodies were free of parkinsonian symptoms.

Making accommodations to live a normal life. People were generally aware of the adverse effects of dopamine replacement; some had seen people with dyskinesias, while others had heard of this eventual disabling side effect. This participant described his knowledge of dyskinesias, "The treatment, as I understand it, would create more unwieldy body movements after a while. This was something I would have to look forward to, and ultimately it would worsen my coordination and ability to do for myself." The consensus of the participants was summarized by this person: "I'm willing to take this (medication) to live a normal life."

Wanting to control the disobedient body. It was a goal of every person to feel, act, and participate in ways that they had done before the illness. The meaning of life goals changed, "I think when you come down and have a disease ... it makes such a priority. It should put your priorities where they should be." Medications became increasingly important to sustain normal functioning at home, work, and in public. Children did not see distorting movements, spouses responded with previous levels of closeness, and friends offered the respect of an equal. L-dopa was the only method that immediately concealed symptoms, provided a sense of control over the illness, and contributed to feeling like a whole person. One person was considering retirement due to his "reluctance to move." He saw the long hall ahead of him and imagined his slowness and discomforts while trying to maneuver his body. Compounding the physical demands of work, were enormous financial pressures for maintaining his role of being the family's primary wage earner. Taking extra doses of L-dopa sufficiently reduced his body's "reluctance to move", allowing him to continue working.

Receiving encouragement from family and friends. One woman described crying for days because of her "failures" and hopeless future. She told her husband that she "didn't want to go through this anymore." He told her there were no other options, she had no choice, and he would be there "every step of the way." The woman continued with her story, "Then I got to thinking, 'Ok, what am I going to do about this now? How am I going to handle this?" She confided in her support group friends who shared experiences and practical techniques for self-adjusting L-dopa with the admonishment, "Take care of yourself." People did not decide to self-adjust L-dopa on independent whims; advice was sought from many sources, but not from healthcare providers.

Postponing or discontinuing dopamine replacement. Slowness, stiffness, and balance instability have progressed sufficiently within two to three years after diagnosis to warrant initiating treatment with L-dopa (if not already started). However, in my study, medications were not always accepted. Even after eight years or more of increasing disability, several people declined L-dopa. Some had received but were holding onto prescriptions while they decided whether to begin using it. Several reasons were described for these actions; all were social or psychological in nature.

Living in fear of the side effects. I had one participant who began taking L-dopa when diagnosed, subsequently discontinuing the medication after eight years because she "knew that dyskinesias start after eight years." Gradually and permanently, she has become as "stiff as a board." She can no longer feed herself, perform any personal care, and is primarily restricted to bed. We spoke at length about her very personal decision: choosing between the physical vibrancy of movement or living her life "housed" in a body. She considered the dyskinesia side effects of L-dopa to be far worse than her current condition. "I'd just as soon finish up my life the

same way I'm living now. Not have debates, new techniques, or any drugs, because I'm just plain tired."

Misunderstanding the illness and its treatment. Having more than one chronic illness usually meant taking multiple daily medications. There was a reluctance to take "so many pills," especially if a medication could not be correlated with noticeable improvement, "I don't know how much of this is really going to help me." Some people postponed the medication based on beliefs that prolonged use would cause an immunity to future benefit. While others clung to hopes of permanent improvement if dopamine replacement was started with small doses later in the illness.

Taking responsibility. Several people described their definitions of adulthood that included successful accomplishment of responsibilities. Maintaining daily exercise schedules, going to work, and continuing an active social life meant that people were "doing something" about their condition. By not attending to these routines, not seeing improvement, or relying on a pill (and not one's self), represented failure. One participant said, "Taking medication would mean I didn't do something right." By failing to live up to personal expectations of adulthood, implied other people might treat them as being passive dependent children.

Stage 2. Establishing Expertise

Experimenting. People learned how to use and self-adjust L-dopa by experimenting with dosage and timing for improved functioning. Information on how to dose did not come from the doctor nor was self-administration discussed; instead, participants learned through trial-and-error.

Studying personal responses to the medication. Experimenting with dopamine replacement meant understanding what the drug did to one's mind, body, and interaction skills. Before committing to taking extra doses of medication, one person decided to stop L-dopa, "A couple of weeks ago, I just wanted to see what would happen, so I went off. I could feel walking was stiffer. I had to concentrate on moving that leg." Stopping the medication provided an opportunity for this participant to compare and evaluate the responses of her individually defined target symptoms.

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People felt it was their responsibility for monitoring symptom changes. "No swallowing difficulty. I take about an entire shelf worth of pills every morning and every evening. So, the swallowing is important. If that goes…" Learning personal boundaries of safety and comfort was important when self-adjusting L-dopa.

Learning practicalities. People learned to balance the medication with their daily routines. An extra dose was taken before important events while dietary protein was avoided surrounding administration times for enhanced absorption.

Organizing medications. Nearly all individuals were responsible for purchasing, setting up, and administering their daily medications. Medication set up and storage varied from pill bottles tossed into plastic storage boxes to personalized portable containers. Pill bottles were stacked at the bedside or kitchen cupboard for daily use. Small unit dose devices were also frequently observed, but were usually empty. Many people received several months of medication at one time through health insurance mail order systems. This bulk delivery of pills added complexity to routine drug storage, especially if instructions were not clear or if children were in the home. People reported difficulties keeping track of medication changes and organizing the medications for safe practical use. Even with self-reported concerns about memory changes, participants did not feel assistance was necessary with medications. Whether this was said from pride or confidence, it was clear people felt their medication was their duty.

The majority of participants made efforts to have a written list of their medications. Difficulty with handwriting made the homemade list indiscernible to all, including the writer. A typed list was reported as being very helpful, due to forgetting medication names, times, or instructions. However, only one person used a medication list printed by the doctor's office. Several people were not sure if their list was up to date, while others described difficulties keeping up with prescription changes sufficiently to make a medication list.

While looking at the containers, the directions for self-administration were not clearly stated. For example, one container of L-dopa listed instructions as "Take one tablet 11 times daily." The participant explained how he took the pills:

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It's 11 because if I take three doses in the morning (two tablets for each dose), there's six tablets; and I take them like every two and a half hours. In the afternoon, I take one and a half each time. So, if I take four of those, that's six. Plus, the six in the morning.

He felt it was easier to calculate his daily dose based on an even number, therefore taking 12 tablets per day and not 11.

Learning side effects. A practicality of self-adjusting L-dopa was learning side effects and warning signs. Participants considered this an essential skill. One woman recalled how she had been "popping dopamine" whenever effects of prior doses wore off. She became "very ill" with walking and talking difficulties because of "taking too many pills" and was briefly hospitalized. This participant later worked with her neurologist to develop a plan for safely taking extra L-dopa.

Bridging. Bridging was a clinical method of adjusting medication dosing. Taking an extra dose of dopamine replacement aided independent living. Several people calculated dosing schedules based on their daily activities. One participant described taking an extra dose whenever he needed to wake-up early, "If I don't take something, I don't move." Other people considered feedback from family members or coworkers in determining when supplemental L-dopa was needed. For example, one man noticed he consistently became quiet when the medication started wearing off. His wife worried about his quietness, believing he had lost interest in her and with life. Subsequently, for this participant, calculating an extra dose included his levels of quietness to avoid appearing detached.

However, this method was not always effective; people have unpredictable variations in their own responses to L-dopa. Learning how to differentiate emotional and physical symptoms was important in using the technique of bridging for self-adjusting L-dopa.

Transition: Becoming Reliant

Self-adjusted doses of L-dopa brought improved physical capabilities, enhanced social functioning, and emotional comfort. "Sometimes just thinking that 'Well, I've got this in my pocket. I don't need to worry about this anymore.' It's right here, just taking care of it for me, and I was ok." Eventually, however, difficulties were encountered.

Needing more and more medication. Often times there were unrealistic expectations for longer lasting (or even permanent) symptom relief. Because each dose of L-dopa initially

provides benefit for approximately two to three hours, more medication is needed to prevent the wearing off effect or "off-time." In addition, off-times become unpredictable with greater frequency of freezing episodes with a longer duration of dopamine replacement use. [ref]. After an early morning church service, a participant was waiting to greet the minister when, suddenly, she found herself unable to move. She had forgotten to bring extra medication with her. "I was so embarrassed. It was terrible. I felt so ashamed to ask strangers for help." A married couple drove her home.

Developing clouded self-judgements. Overreliance on L-dopa might cloud a person's abilities to determine typical feelings, personal assessments, or situations. Frequently, people thought their overall condition was improving because they felt improved social and physical functioning. One person had psychological testing done when diagnosed with Parkinson disease. Ten years later, the testing was repeated. "When I got done, he told me that I was the first patient he had that had improved his score from when he had come in initially." He attributed this improvement to the mental efforts required by employment, dedication to routine exercise, and extra doses of L-dopa.

Taking risks. Several people mentioned that they were becoming "a little bit uncomfortable" with driving and viewed this as a hardship. Driving is important to obtain groceries, access medical care, and maintain a social network. A sense of driving confidence was regained with self-adjusted L-dopa. It was mentioned (jokingly) that although participants felt more confident, their driving skills had "changed," and others didn't feel comfortable riding with them.

Stage 3. Embodying Medication

Each of the prior stages and transitions was a negotiation process between the persons mind, body, and world. The addition of dopamine replacement medication provided opportunities for reconnecting and reformulating identities. People were redefining themselves through a sense of oneness with the L-dopa.

Knowing one has a chronic illness (in this case, Parkinson disease) specifies a lifestyle requiring an almost forcible awareness of one's body. "I know I have it every minute of every day

because I feel it every minute of every day ..." At some point, the illness influences how people view themselves; changing sensations and bodily awareness become part of a person's self-concept. L-dopa temporarily supplements physical, cognitive, and emotional functioning. Subsequently, enhancing social performance and strengthening waning self-confidence.

Needing perpetual presence of L-dopa. Close proximity of a filled medication bottle offered comfort. One person had medication containers in her car, coat pockets, and every room of her home. Other people shared similar experiences. "I do not ever want to be without my pills." "I consider myself like an addict, but not a bad kind of addict." "I'm very happy I've lived in a world that has dopamine. I cannot imagine not having dopamine."

It was considered supportive of self-adjusting medication practices when others did not recognize symptoms. This person described the feedback from friends:

All my friends ... look at me and say, "We don't know what the problem is. You're fine. You say you have this. You don't seem to have anything to us." That's because I respond so well to the medication.

The bonding relationship with L-dopa came in many forms. One person spent most of her time alone; her husband worked long hours and frequently was at home just to sleep. However, he was always with her on Saturday evenings and all of Sunday. Extra medication was routinely taken on Saturday evenings. She dressed-up and accompanied him to social events. The efforts provided meaning for her marriage.

Valuable commitments could be sustained by self-adjusting L-dopa. Participants relied on the fast-acting medication qualities, especially if they were going to be away from home. It was anxiety provoking (at the very least) to think of being stranded miles away and unable to move. One person drove over 100 miles round trip to maintain a volunteer position. He was fearful about tremors or freezing episodes occurring during the long commute, these symptoms always seemed to occur when least expected. He kept a bottle of L-dopa readily available on the front passenger seat or above the visor.

Medication controls symptoms and, generally, helped people feel better. Many attributed life-saving qualities to their medication, "I would never be able to do anything except lay in bed without the medication." Others described psychological preservation through L-dopa, "Some

people, I think, shrivel up and they say, "Somebody told me I had Parkinson's. That's not what I am anymore." While there were other people who expressed self-adjusted dopamine was done because, "it's what your brain wants; it's what your brain needs."

The body and understanding one's experiences became foreign and sometimes frightening when the medication wore off. One participant described noticing a change in his nighttime walking abilities. He tried to explain the feelings of being in a body that was not his own by using a metaphor of being a "zombie" due to stiffness, slowness, and rigidity. After gaining momentum, he demonstrated stomping as the means of propelling himself forward.

In the next section, I will develop *Medication as a Social Prosthesis* as a scientific concept, to develop its definition, attributes, and boundaries.

Part 2. The Concept of Medication as a Social Prosthesis

Medication as a Social Prosthesis is a scientific concept defining medication as being essential for a person to carryout necessary responsibilities while maintaining roles and relationships. A <u>prosthesis</u> is an artificial replacement for a missing body part, usually extending function or accommodating malformation. The design and construction are synthetic, contrasting with transplanted organs such as a heart or liver. In this case, dopamine replacement medication temporarily provides artificial enhancement of movement abilities and self-confidence. Thus, L-dopa is a <u>social prosthesis</u> as it enables social functioning of the person.

The conceptual attributes of *Medication as a Social Prosthesis* were developed from the analysis of qualitative data. Participant narratives and other case situations underwent a process of comparing and contrasting while defining characteristics were sought. These attributes must be unique; this does not mean the described behaviors are developed only by people with parkinsonian symptoms. Rather, it means that behavioral responses fitting this concept must have each of the following characteristics:

(1) The medication is essential for medical treatment. Dopamine replacement is the single most effective symptomatic treatment for Parkinson disease; although its benefits are short-term and does not alter the illness progression. Without dopamine replacement, people would initially become stiffer and slower with greater overall worsening.

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(2) The medication is essential for physical functioning. L-dopa was essential for regaining facial expression, walking, and (to some extent) controlling tremors. Physical functioning permitted social interaction, allowing participation in family conversations and the workplace. Improved functioning made daily life easier.

(3) The medication is essential for lay assessed symptoms. In the case of Parkinson disease, people had spent years living with a variety of vague, nondescript symptoms. After finding out the diagnosis, self-assessment skills refined while learning to read the body and taking action. People quickly understood the benefits of L-dopa.

(4) The medication is essential for daily life priorities. By self-adjusting L-dopa, people described feeling more assured of their identities and role capabilities. It allowed people to go to work, shop, complete household chores, and attend to their personal needs.

(5) The medication is essential for functioning as a person. Regaining a responsive facial expression ensured a level of closeness; movements became more controllable and permitted people to participate in work or social functions without eliciting embarrassing attention. This characteristic represents intra and interpersonal aspects of belonging and continuity.

(6) Embodiment of the medication container (device or object) is a fundamental attribute. L-dopa has a fast onset of action, but effects quickly wear off (two to three hours). A longer illness duration with increasing use of L-dopa brings unpredictable side effect timing. People devised innovative and personalized ways of carrying the medication to ensure immediate access, especially when away from home. Medication carrying devices were personalized, generally discreet, and contained sufficient quantities for at least one to two days.

Boundaries of Medication as a Social Prosthesis

The next step was to compare allied (i.e., similar) cases that shared one or more of the above attributes to illustrate what the concept is not. By delineating these boundaries, the concept domain becomes identified. I initially identified four allied cases for comparison with *Medication as a Social Prosthesis*: alcohol, recreational drug use, traditional prosthetic devices, and life sustaining prescriptions (such as digoxin or insulin). These cases were placed in the comparative situations column (see Table 5.1, p. 127) and studied to determine the presence or

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	Essential Characteristics					
Comparative Situations	(1) Medical treatment	(2) Physical functioning	(3) Lay- defined ª	(4) Daily priority	(5) Required to be human	(6) Embodied object
Alcohol	No	Possibly	Yes	No	No	No
Recreational drugs ^b	No	Possibly	Yes	No	No	No
Traditional prosthetic device °	Yes	Yes	Yes	No	Yes	Yes
Classified as routine medication ^d	Possibly	Possibly	Possibly	No	No	No
Life-sustaining medication ^e	Yes	Yes	Possibly	Yes	Yes	Yes
Medication as a social prosthesis	Yes	Yes	Yes	Yes	Yes	Yes

Table 5.1. Comparing situations with Medication as a Social Prosthesis (lay perspective).

^a Prescribed, but not necessarily used as prescribed

^b Examples: cocaine, heroin, oxycodone

^cExamples: artificial limb, heart valves, eyeglasses

^d Examples: vitamins, supplements, ear drops

^e Examples: insulin, epinephrine, digoxin

absence of each essential characteristic. The items in the comparative situations column were

then compared as being present or absent in each of the characteristics.

Some of the comparisons were not definitive. Alcohol or recreational drugs might be considered as essential for physical functioning related to possibilities of withdrawal (row 1, column 2), but this characteristic is not consistently present. Routine medications may possibly

be viewed by a layperson as necessary with the dosages adjusted up or down according to their

perceptions of physical responses.

The extent of social prosthetic use is dependent on aspects of a person's life needing supplanting. Sometimes fundamental needs (food or basic self-care) emerge, taking precedence. It is a requirement to function as a human being; however, the person defines that wholeness.

Discussion

Each participant experienced challenges needing constant reinterpretation of the self. They were required to make decisions about treatment options within the context of constantly changing symptoms and an unknown future. Feeling alone, worried about abandonment, and with little information, these were difficult decisions to make. For the majority of participants, dopamine replacement medication became an essential strategy for preserving familiar roles, relationships, and identities. People accepted the possibility of disabling medication side effects (which would compound any illness difficulties) and learned to self-adjust L-dopa for purposes of sustaining continuity and normalcy of themselves. This theory of *Medication as a Social Prosthesis* describes how people with Parkinson disease discovered the benefits of L-dopa, reconnected with familiar selves, and reformulated (Mayan, Morse, & Eldershaw, 2006) a new identity through dopamine replacement therapy. The benefit derived from supplemental L-dopa was enormous. The medication became embodied into the parkinsonian self.

Processes Surrounding Medication as a Social Prosthesis

The goal of antiparkinson medication is to reduce symptom burden and improve function (Miyasaki, Martin, Suchowersky, Weiner, & Lang, 2002). These goals are achieved immediately with L-dopa and, just as quickly, the benefit wears off within several hours. Yet, these medications are prescribed on a fixed and routine administration schedule. With advancing illness, the need for the dopamine replacement medication increases. Additionally, with increasing use, people need more frequent and greater doses to gain benefit. The participants of this study understood and accepted the possibility of dyskinesias as an adverse response to increasing their own L-dopa. Priorities were to maintain relationships and roles; it was essential to function and feel normal.

People with Parkinson disease understand and use their medications differently than healthcare providers. The following discussion highlights several differences in views of medication use. First, I will consider the concepts of adherence, concordance, and patientcentered care. A central theme when discussing topics of adherence, compliance, and concordance is whether a patient follows instructions given by a health provider for the professionally derived plan of care. Although a patient-centered approach evolved in response to consumer demands for greater involvement, patient-centered care frequently is simply a renaming of techniques for motivating people to comply.

Medication guidelines are not rules or legally binding requirements. They are suggestions based on best practice clinical evidence. Each prescriber has responsibilities for recommending prescriptions and teaching usage (Getchius et al., 2010), but cannot enforce or regulate how people take their medication at home. However, issues of power continue to permeate prescribing practices of healthcare providers (Upshur, 2002). By assuming an authoritative stance, long-standing views of body and mind separation are supported. These views influence the way treatments are offered, accepted, and used. While the provider has control over the prescribing, the actual use of the medication (frequency and dose) is under the control of the person and not the prescriber. As people with the illness learn to predict the medication effects and best timing to improve movement disabilities, speak more clearly, and think more logically; they become reliant on the medication to function socially.

Second, it is important to distinguish what the concept of *Medication as a Social Prosthesis* is not. It is reliance on medication for physical, social, and psychological functioning. It is not addiction; this is a critical dependency involving compulsive use overriding everyday responsibilities, isolation from typical pursuits, and physical withdrawal,

Medication as a Social Prosthesis is not a lifestyle enhancing technique, such as amphetamine use for enhancing school or work performance. Rather it is a concept describing the maintenance of essential daily functions and interactions.

Strengths and Limitations

Strengths. A variety data collection methods were used which built engagement and commitment with people. Home observations provided glimpses into previously private worlds and instances of intimacy. Knowing participants took time but opened up windows of opportunity for depths of perspective. Additionally, the unique variety of people during different stages of the illness progression contributed to understanding the experiential processes of parkinsonism.

Limitations. Recruitment strategies of group presentations, distribution of flyers, and a website posting were simple, yet effective. A very large number of potential participants could not be consented due to the intensive nature of the study design and time constraints. This limitation points to how little attention has been given to psychosocial issues.

Future Fesearch

The concept of *Medication as a Social Prosthesis* has broad implications for all instances of medication use including forms of drug availabilities (over-the-counter products, prescriptions, or illicit use), disease states (palliative conditions, chronic illness, or substance dependence), and age groups (parents, children, or older adults). Research is urgently needed to understand how the meaning of medication translates into daily use. The concept of bridging would benefit from further development. It may be particularly helpful for teaching safe administration of home medications.

Implications

The theory of *Medication as a Social Prosthesis* offers an innovative view of the ways people with Parkinson disease use their prescribed L-dopa medication, in order to maintain their daily lives. Data in this study brings to the fore variations between prescriber practices and user viewpoints. Optimal dosage of medications was determined in a process of trial and error, learning about the effects without adequate drug knowledge for self-administration. Further, prescribing norms were frequently discussed between peers at support groups or dance classes. These are the concerns about provider prescribing practices and the safety knowledge of people who self-adjust their medication. Satisfying lifestyles with decreased symptom burden is a goal for people with Parkinson disease. The disparity of prescriber and parkinsonian views may likely be resolved through the adoption new prescribing styles with a palliative care approach. This will necessitate listening to narratives (Dohan, Garrett, Rendle, Halley, & Abramson, 2016), understanding opposing views (Carman et al., 2016), and accepting ethical imperatives of engaging with individuals and their personal care goals (Solomon, Gusmano, & Maschke, 2016).

A program of care based on case management and relationship principles would necessitate the involvement of nursing and implementing a home visit component. A distinct advantage to this integrated form of care is the ability to evaluate and teach safe medication techniques in a naturalistic setting.

People K ith Parkinson Disease and Hheir Families

Organizing your medical information. Obtain a 3-ring binder and insert a tabbed divider for each month and a tab named medications. Within each monthly section, place a calendar and a large envelope. On the calendar, write your medical appointments and important information. The envelope is for receipts or notes. The medication tab has two parts. The first part contains your medications. Your daily schedule of your medications should include the drug name and time to be taken. Use this when you set up your medications. The second part of the medication tab should include drug information such as purpose, usual dosing, and side effects.

Using the healthcare system. For every medical appointment, bring your medical binder, medication containers, and questions. It is true, but often disappointing that doctors do not always have time, but having a close relationship with a provider can be helpful. Tell the doctor you would like to arrange routine meetings with the nurse practitioner to discuss problems that might arise during daily living.

Conclusion

The essential nature of medication for the everyday functioning for people with Parkinson disease demonstrated a reliant nature to the extent that medication and the self-managing procedures are embodied into the parkinsonian self. Thus revealing the concept and processes of *Medication as a Social Prosthesis*. This is an extremely useful concept for understanding the

relationship between people and medication giving a perspective that has not been previously identified. *Medication as a Social Prosthesis* is a strategy of *Preserving self* that is a beneficial, healthy, and therapeutic process.

References

Charmaz, K. (2014). Constructing grounded theory. Thousand Oaks, CA: Sage.

- Carman, K. L., Maurer, M., Mangrum, R., Yang, M., Ginsburg, M., Sofaer, S., . . . Siegel, J. (2016). Understanding an informed public's views on the role of evidence in making health care decisions. *Health Affairs*, *35*(4), 566-574. doi:10.1377/hlthaff.2015.1112
- Dohan, D., Garrett, S. B., Rendle, K. A., Halley, M., & Abramson, C. (2016). The importance of integrating narrative into health care decision making. *Health Affairs*, 35(4), 720-725. doi:10.1377/hlthaff.2015.1373
- Fox Foundation. (2012). The Fox Trial Finder. Retrieved from https://foxtrialfinder.michaeljfox.org/about-fox-trial-finder/
- Getchius, T. S. D., Moses, L. K., French, J., Gronseth, G. S., England, J. D., & Miyasaki, J. (2010). AAN guidelines: A benefit to the neurologist. *Neurology*, 75, 11216-11127. doi:10.1212/WNL.0b013e3181f4d883
- Hoehn, M. & Yahr, M. D. (1967). Parkinsonism: Onset, progression, and mortality. *Neurology, 17*(5), 427-442. doi:10.1212/wnl.17.5.427
- Joutsa, J., Gardberg, M., Röyttä, M., & Kaasinen, V. (2014). Diagnostic accuracy of parkinsonism syndromes by general neurologists. *Parkinsonism & Related Disorders*, 20(8), 840-844. doi: 10.1016/j.parkreldis.2014.04.019
- Mayan, M. J., Morse, J. M., & Eldershaw, L. P. (2006). Developing the concept of selfreformulation. *International Journal of Qualitative Studies on Health and Well-being*, 1(1), 20-26. doi:10.1080/17452620500534587
- Morse, J.M. (In process). Concepts in context (Chapter 7). In Analyzing and conceptualizing the theoretical basis of nursing. NY: Springer.
- Morse, J. M., Mitcham, C., Hupcey, J. E., & Cerdas Tason, M. (1996). Criteria for concept evaluation. *Journal of Advanced Nursing*, *24*(2), 385-390.
- Morse, J. M., & Mitcham, C. (1998). The experience of agonizing pain and signals of disembodiment. *Journal of Psychosomatic Research*, *44*(6), 667-680.
- Miyasaki, J. M., Martin, W., Suchowersky, O., Weiner, W. J., & Lang, A. E. (2002). Practice parameter: Initiation of treatment for Parkinson's disease: An evidence-based review: Report of the Quality Standards Subcommittee of the American Academy of Neurology. *Neurology*, *58*(1), 11-17. doi:10.1212/wnl.58.1.11
- Perlmutter, J.S. (2009). Assessment of Parkinson disease manifestations. *Current Protocols in Neuroscience, Chapter 10*, (11). doi: 10.1002/0471142301.ns1001s49
- Solomon, M. Z., Gusmano, M. K., & Maschke, K. J. (2016). The ethical imperative and moral challenges of engaging patients and the public with evidence. *Health Affairs*, 35(4), 583-589. doi:10.1377/hlthaff.2015.1392
- Upshur, R. E. G. (2002). If not evidence, then what? Or does medicine really need a base? Journal of Evaluation in Clinical Practice, 8(2), 113-119. doi:10.1046/j.1365-2753.2002.00356.x
CHAPTER 6

DISCUSSION

The findings of this study generated a substantive theory, *Preserving Self*, which provides insight into the challenging and strategic process of maintaining identity for people with Parkinson disease. In-depth interviews were initially conducted in the home environment with follow-up phone interviews. Data also included photos, videos, and participant drawings. Constructivist grounded theory was the methodological approach. Analytical procedures of coding and constant comparison were used. The theory consists of five interdependent stages: (1) *Making sense of symptoms*, (2) *Turning points*, (3) *Dilemmas of identity*, (4) *Reconnecting the self*, and (5) *Envisioning a future*.

In this final chapter, I discuss the significance of the findings and conclusions. Potential limitations are considered and described. Recommendations and implications for future research are suggested.

Significance of Findings

People with Parkinson disease face numerous identity threats. Lingering traumatic effects from hearing the diagnosis diminish capabilities for *Preserving self. Unsettling reminders* of life before the illness slowly dissipate, frequently taking years. Pressures of routine life become crises, contributing to and affecting episodes of overwhelming depression and paralyzing anxiety. Daily crises are experienced through freezing of gait episodes, medication side effects, or increasing physical losses. People living alone experienced a higher level of crises for a longer duration than people who had close relationships at home.

Feeling emotionally connected reduced the intensity of *Unsettling reminders* and daily crises. Relationships were a vital link for people to feel normal. But to be recognized as a normal adult means being in control of one's body and fully participating in relationships. Medication

functioned as a social prosthesis, so to speak, in maintaining and protecting valuable relationships and vital roles. The prosthetic effect was achieved through control of symptoms. Most people self-adjusted and took extra L-dopa when they needed to control physical symptoms for functioning at higher levels. Supplementing L-dopa dosage was effective for a short time; fears of emotional dependency or visible signs of illness were temporarily relieved. However, this solution brought additional problems, such as side effects (increasing involuntary movements) or unanticipated wearing-off while in public.

For people who had extensive functional disabilities (advancing illness), the social prosthetic benefit of medication was less effective. Fears of abandonment with resurging unsettling reminders induced depressive passivity regarding themselves and their situations. Acquiescing to unrealistic demands of family members or friends was a means of trying to maintain these needed relationships. For example, becoming the primary care provider for teenagers during later illness stages met spousal demands of the nonworking parent. Unfortunately, this brought emotional stress for everyone and increasing symptoms for the ill person.

For people with Parkinson disease, coming to terms with the illness is a complex psychological, social, and physical process (Pinder, 1990). Shattered beliefs of a fair and just world with visible signs of a stigmatized illness, influenced how people understood their lot in life (Lerner, 1980). This way of living contributed to understandings of the illness and medications used. The meaning of time changed, subsequently planning for a future was difficult. The future was today; as one participant stated, "When you have Parkinson's, today is the best you'll ever be..."

Health care professionals and lay people think about illnesses differently. How participants named and framed (Brown, 1995) their experience of Parkinson disease and their medication was a personal experience. People learned and developed understandings from multiple resources, forming personal definitions that seemed better fitting of their own symptoms or circumstance. Processes for *grasping the situation* and *coming to terms* played major roles in shaping each person's knowledge, beliefs, and actions. Consequently, anxiety, depression, or freezing of gait had multiple lay definitions. All seemed in contrast with medical descriptions.

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These personal definitions contributed to the shaping of strategies for *Preserving self*. People were creative in their use of strategies for Preserving self. Often, the implications of their actions were not considered. Compensatory behaviors of participants, such as driving with medications on the car seat, were a safety concern not shared by the participant.

Oscillating between stable emotions with normal movements or labile feelings and freezing episodes can be described as transitions between being normal or chronically ill. These transitional states enable a person with parkinsonism to access normal activities. However, this access was temporarily lost with each freezing episode, panic-filled hour, or periods of self-hatred. The transitions to a normal state gave family members and close friends glimpses of the capable person they had always known. Returning to the disabled self was frustrating for everyone and brought emotional pain and physical fatigue for the person with Parkinson disease. The varying phases of life and illness are uniquely experienced realities for each person.

Constructivist grounded theory is a method that enhances a researchers ability to understand the realities through those who live the experience (Charmaz, 2014). By applying this approach, a beginning foundation for establishing successful participant relationships was established. A major contribution of this study is the access to multiple forms of data as people lived through desperate challenging times. Other researchers have not had the prerogative of studying *Preserving Self*, in such a dynamic situation. Home visits provided a contextual awareness of the individual's self (Schatzman & Strauss, 1973). Participants viewed home visits as a demonstration of respect for their complex situations. Cherished possessions and memorabilia of life's achievements or regrets were shared; demonstrating how each person viewed themselves with a sense of continuity (Andersen, Raffin-Bouchal, & Marcy-Edwards, 2008; Butler, 1974). Participants seemed eager to share private stories about suffering, desperation, and risk-taking. Many times, the participants had never spoken about these matters before. Participants extended invitations to attend support group meetings, a dance class, educational opportunities, and offered to distribute recruitment flyers.

One finding of significance was the use of medication as a social prosthesis (Article 2). In order to feel normal and function normally, people learned through practical experience how to

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gauge when to take supplemental L-dopa. This extra dosing was beneficial in controlling symptoms and being normal with the people that were needed.

Placing Hhis Study in Context

There must be a loss or a potential loss for processes of *Preserving self* to begin. Prior research on *Preserving self* has described processes involving strategies that the person tries to get through a problematic situation or loss with a goal of maintaining their past identity. Each one of the following studies dealt with situations involving a variety of losses: people experiencing life threatening trauma (Morse & O'Brien, 1995), men with a chronic illness (Charmaz, 1994), women facing decisions about genetic testing (Howard, Balneaves, Bottorff, & Rodney, 2011), and women post cardiac surgery (Johnson, 1991).

The goal for each of the prior research participants was to retain or regain the self from before the problem or loss occurred. This was also the goal for people with Parkinson disease. Every person relied on others at various points during the process. Relationships became essential for participants to connect with and to maintain a sense of being normal.

Cognitive processes were also involved. Recognizing and defining the situation changed how people's identities were revealed to themselves. For the women making decisions about genetic breast cancer testing, decisions were made by considering the meaning of test results, paying attention to their emotions, and engaging with others. For people with Parkinson disease, learning practical means for handling the symptoms was a focused cognitive activity. Just as with the chronically ill men who paid attention to their appearance in order to give an impression that they were healthier than they were. In this way, they were preserving the public image to protect their position.

Reading the body is also a shared concept among studies of *Preserving self*. The chronically ill men paid attention to their body positions if in a wheelchair, while the women who were deciding about genetic testing used a decision style "if-then" and contemplated their actions and the future depending on test results. People constantly read their bodies and learned how to manage the changes through activities, diet, and medication. The findings of this study are confirmed with prior research surround *Preserving self*.

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Recommendations

All of the participants lived in their own communities for most of their lives. Where we live and work has profound impacts on our health and well-being. It is difficult to maintain these connections with an illness such as Parkinson disease. It is even harder to organize one's healthcare and stay within the community.

Healthcare rationing has been a controversial subject for many years; it remains an ethical concern every time service and care decisions are made. Decisions have to be made about prioritizing care when resources are limited. Obviously, there are moral reasons why services are not denied to people with parkinsonism or older adults. However, the implicit methods of healthcare rationing remain. It is a deterrent when access to treatment is limited by distance, without availability of public transportation (Kernick, 2002).

The cost of medications is prohibitive. At this time, a major drugstore does not offer \$4 prescriptions of dopamine replacement drugs. Few Medicare part D beneficiaries use the \$4 prescription service, this may change as an increased number of medications become available (Zhang, Gellad, Zhou, Lin, & Lave, 2012). Without insurance, the monthly cost would be several hundred dollars. People with Parkinson disease have to make choices for continuing employment to maintain health insurance, physical therapy options (when needed), and even whether to remain at home.

What are the healthcare resources for people with Parkinson disease within their own communities? There are not many options. It is frequently difficult for people travel distances to obtain healthcare. Some communities have visiting nurse programs. Nurses would make home visits to the sick and elderly. Insurance was not an issue as the programs were funded by each community. Due to budgeting issues, most health departments have reduced or removed these services. The home visit budgets are given to the maternal-newborn home visit program.

Being part of a community means belonging to a group of people who share similar goals, have common interests, and hold right and privileges (Anderson & McFarlane, 2012). One recommendation is a nursing center for older adults and people with chronic illness. An ideal setting for this center would be a local nursing home, or assisted living home, or even a community center. The placement of a nursing center for older adults within the community would permit easier access services by older adults and their families. By placing this center within a nursing or assisted living home would provide opportunities for people within the community to develop positive perspectives on alternate living arrangements for older adults. The services offered at this center would include individual or group education and primary care services. The center, after established, would extend its services to include home visits. A nursing center would benefit older adults, the community at large, and provide a clinical teaching site.

Implications for Future Research

In this dissertation, I presented the theory of *Preserving self*. Five stages abstractly described how people with Parkinson disease responded to challenges that threatened their emotions, relationships, and actions that represented their normal self. Several safety concerns were noted by the researcher as people described or demonstrated their strategies for *Preserving self*. Examples of safety concerns include: (1) driving with tremors or a potential for a freezing episode, (2) a chair-ridden person arising at night and ambulating alone to use the bathroom, (3) self-responsibility for medication administration without a check and balance system, and (4) medication setups were disorganized and inconsistently used.

Future research is warranted in applying this theory for intervention development. Questions for investigation include identifying actions that are protective of identities and subsequently influence the actions of individuals. Since drawings are so frequently used with other chronic illness, it should be pointed out that this drawing activity has not been done previously with people with Parkinson disease. This would be an area to consider for future research. Safety concerns are paramount. The findings of this study indicate strategies of *Preserving self* are often motivated by desperation to be normal.

Limitations

Several potential limitations were identified which might have potentially influenced the quality of the study findings or the ability to answer the research questions.

Participant Recruitment

Approximately 50% of the participants were recruited through the Fox Trial Finder (Michael J. Fox Foundation, 2013). Over 300 people expressed interest in this study through the trail finder. One reason to account for the high level of interest might possibly be several features of this study. *Preserving self* was one of the first qualitative studies posted at the website, did not have exclusion criteria regarding medication use, and offered opportunities to speak about personal experiences. Initially, this was considered a successful recruitment technique.

The referral network was analyzed prior to the study midpoint. At that time, more than half the participants were self-referred from the trial finder website. The potential impact on quality and the ability to answer the research questions was realized. Involving the trial finder website as the sole recruitment tool may have limited possibilities of maximum variation. Additionally, theoretical sampling may have been affected if the participants were highly similar. A decision was made to actively recruitment of people who were not involved with the website. Earlier participants, who were either self-or colleague-referred, were contacted and asked to share study information with people they knew.

Observational Data

A large amount of observational data was collected. This required a large amount of time to organize, sort, and code. The introduction of videos midway during the study meant learning how to use video editing software to remove identifying features and presentation formatting. Photos and participant drawings also required editing and added to the accumulation of visual data. The significance of the visual data contribution may be small in comparison to the amount of data collected. Instead, it may have detracted from answering the research question by changing the focus of analysis.

The visual data provided new and interesting insights into the challenges and strategies for people with parkinsonism. The opportunity to draw was well received by the participants, but since it was introduced midway through the study, not everyone was able to make a drawing. The participants may have been interested in the drawings due to issues with verbal communication disabilities.

Theoretical Contributions

Preserving self uniquely contributes an alternate basis for working with people that have a chronic illness. People have a fundamental need to belong; relationships sustain and maintain our self-images. It became critical for participants disease to maintain relationships while regaining as much normalcy as possible. At the same time, self-responsibility was accepted for the care of their illness. *Preserving self* provides a realistic glimpse into the why and how people with Parkinson disease maintain self-identity. This contribution of infrequently obtained naturalistic perspectives for neurological disorders provides a basis for reevaluating care practices.

References

- Anderson, E. T., & McFarlane, J. (2011). Community as partner: Theory and practice in nursing. (6th ed.). NY: Lippincott Williams & Wilkins.
- Andersen, E., Raffin-Bouchal, S., & Marcy-Edwards, D. (2008). Reasons to accumulate excess: Older adults who hoard possessions. *Home Health Care Services Quarterly, 27*(3), 187-216. doi:10.1080/01621420802319993
- Brown, P. (1995). Naming and framing: The social construction of diagnosis and illness. *Journal* of Health and Social Behavior, 35, 34-52. doi:10.2307/2626956
- Butler, R. N. (1974). Successful aging and the role of the life review. *Journal of the American Geriatrics Society*, 22(12), 529-535. doi:10.1111/j.1532-5415.1974.tb04823.x
- Charmaz, K. (1994). Identity dilemmas of chronically ill men. Sociological Quarterly, 35(2), 269-288. doi:10.1111/j.1533-8525.1994.tb00410.x
- Charmaz, K. (2014). Constructing grounded theory (2nd ed.). Thousand Oaks, CA: Sage.
- Howard, A. F., Balneaves, L. G., Bottorff, J. L., & Rodney, P. (2011). Preserving the self: The process of decision making about hereditary breast cancer and ovarian cancer risk reduction. *Qualitative Health Research, 21*(4), 502-519. doi:10.1177/1049732310387798
- Kernick, D. (Ed.) (2002). Getting health economics into practice. Oxford: Radcliffe Medical Press.
- Lerner, M. J. (1980). The belief in a just world. *The belief in a just world: A fundamental delusion* (pp. 9-30). Boston, MA: Springer
- Michael J. Fox Foundation. (2013). The Fox Trial Finder. Retrieved from <u>https://foxtrialfinder.michaeljfox.org/about-fox-trial-finder/</u>
- Johnson, J. L. (1991). Learning to live again: The process of adjustment following a heart attack. In J. M. Morse & J. L. Johnson (Eds.), *The illness experience: Dimensions of suffering* (pp. 13-88). Newbury Park, CA: Sage.
- Morse, J. M., & O'Brien, B. (1995). Preserving self: From victim, to patient, to disabled person. Journal of Advanced Nursing, 21(5), 886-896. doi:10.1046/j.1365-2648.1995.21050886.x
- Pinder, R. (1990). What to expect: Information and the management of uncertainty in Parkinson's disease. *Disability, Handicap & Society, 5*(1), 77-92. doi:10.1080/02674649066780061
- Schatzman, L., & Strauss, A. (1973). *Field research: Strategies for a natural sociology*. Englewood Cliffs, NJ: Prentice-Hall.
- Zhang, Y., Baik, S. H., Zhou, L., Reynolds, C. F., & Lave, J. R. (2012). Effects of Medicare part D coverage gap on medication and medical treatment among elderly beneficiaries with depression. *Archives of General Psychiatry*, 69(7), 672-679. doi:10.1001/archgenpsychiatry.2011.1402

APPENDIX A

RECRUITMENT FLYER

	An Ir	vitation to Partic	cipate in Parking	son's Research			
		RESEARCH	PARTICIPANTS NEED	ED			
	PURPOSE:	We would like to gain an have to face in everyday	understanding of the cha life. We would like to lea	allenges people with Parkinson's rn of the day-to-day strategies.			
		What How did you	obstacles have you had and your family solve th	to face? ese concerns?			
	We are interested in talking with you about your experiences. This is a conversational research project. The interview will take about (2						
	ELIGIBILITY	People who have Parkins	sonism and a friend or fa	mily member			
	CONTACT:	Terrie Vann Ward APN University of Utah, Colle	847-267-0979 ge of Nursing	Parkinson's Nursing Research			
NHCGNE				UNIVERSITY OF UTAH			

.....APPENDIX B

.....RECRUITMENT POSTING ON FOX TRIAL FINDER WEBSITE

FOX	TRIAL F	INDER			SHARE: SHARE: SHARE: English V TERRIE'S DA SHBOARD (log out
ABOUT FOX TRIAL FINDER	UNDERSTAND	ING CLINICAL TRIALS	BROWSE TRIALS	i.	FOR RESEARCHERS
EXPLORING THE	CHALLENGES	AND STRATEGI	ES OF		Interested in this Trial?
PARKINSONISM					Save as a Favorite
Exploring the Challenges an	d Strategies for People	with Parkinsonism			Contact Trial Team
					Share This Trial
The purpose of this res	earch is to understand	the challenges of ever	wday life for neonle with		
these concerns would praintain their fa	ammes. What are the s se we do not know wha provide information for	trategies you use in fac at people consider help visiting nurses to supp	cing these concerns? We a ful OR not helpful. Knowing ort people with Parkinson's		
RECRUITMENT INFOR	RMATION:				
Accepts Control Volunteers:	No	Study Type:	Observational		
Eligible Ages:	18 - 100	Status:	Recruiting		
Time Since Diagnosis:	Less than 60 years	Study Focus:			
More Details				•	
More Inclusion & Exc	lusion Criteria				
CONTACT A TRIA	L TEAM				
f you are interested in learni coordinator via email or pho	ing more about this trial, ne.	find the trial site nearest	to your location and contact	the site	
United States					
+ Chicago, Illinois		Status: Recruitin	9		
Chicago Chicago, Chicago, Illinois, U	nited States	Terrie Vann-Ward terrie vann-ward 847-267-0979	d @utah.edu		
• Madison, Wisconsin		Status: Recruitin	g		
Madison Madison, Madison, Wisconsi	in, United States	Terrie Vann-Ward terrie vann-ward 847-267-0979	d ©utah.edu		

APPENDIX C

DEMOGRAPHIC DATA

Demograph	iics
Exploring challenges and Strategies in PS/PD	ASSIGN Participant ID:
PARTICIPANT NAME	AGE:
ADDRESS:	PHONE NUMBER:
1. DURATION OF PS/PD	
2. GENDER: Female Mal	e
3. LIVING ARRANGEMENTS:	
4. FAMILY OR SUPPORTS: What	is their relationship with PS/PD person?
5. OCCUPATION:	
6. ETHNICITY:	
Hispanic or Latino Un	known
Not Hispanic or Latino	
7. RACE:	
American Indian or Alaska Native	White
Native Hawaiian or Pacific Islander	Asian
African-American	Unknown

APPENDIX D

MEDICATION DATA LOG

Medication Log	
Study Name: The Challenges & Strategies of PS / Ps	Date:
Participant ID:	Duration of PS/PD :

Record all medications the participant is *currently taking* as reported or identified from the drug containers. These can include prescription medications, over the counter drugs, vitamins, supplements, minerals, complementary/alternative medications, etc. Record self-reported recent and historical medication use.

Medication Name	Daily Dose	Start Date	End Date	Ongoing use?	PRN Med?	Average Freq. of PRN	Indication
				Yes	Yes		
				No	No		
				UnKn	UnKn		
				Yes	Yes		
				No	No		
				UnKn	UnKn		
				Yes	Yes		
				No	No		
				UnKn	UnKn		
				Yes	Yes		
				No	No		
				UnKn	UnKn		
				Yes	Yes		
				No	No		
				UnKn	UnKn		
				Yes	Yes		
				No	No		
				UnKn	UnKn		

Adapted from: (Grinnon et al., 2012)

APPENDIX E

THE HOEHN & YAHR PARKINSONISM STAGING SCALE

Indicate the best de	escription of the individual's present stage of observable disability
Stage 0	No signs of disease
Stage 1	Unilateral involvement only, usually with minimal or no functional disability Bilateral or midline involvement without impairment of balance
Stage 2	
Stage 3	Bilateral disease: mild to moderate disability with impaired postural reflexes; physically independent
Stage 4	Severely disabling disease; still able to walk or stand unassisted Stage
Stage 5	Confinement to bed or wheelchair unless aided

APPENDIX F

THE SCHWAB AND ENGLAND ACTIVITIES OF DAILY LIVING SCALE

The Schwab & England Activities of Daily Living Scale estimates the abilities of the person with Pd relative to complete independence. This scale is completed through observation. completely independent person = 100% complete lack of vegetative functioning = 0%

- **100%** Completely independent. Able to do all chores without slowness, difficulty, or impairment.
- **90%** Completely independent. Able to do all chores with some slowness, difficulty, or impairment. May take twice as long.
- 80% Independent in most chores. Takes twice as long. Conscious of difficulty and slowing
- 70% Not completely independent. More difficulty with chores. May take 3 to 4 times longer on chores for some. May take large part of day for chores.
- 60% Some dependency. Can do most chores, but very slowly, with much effort, errors, & some impossible
- 50% More dependent. Help with at least 1/2 of chores. Difficulty with everything
- **40%** Very dependent. Can assist with all chores but few alone.
- **30%** With much effort & needing much help, intermittently able to do a few chores alone or able to begin the task.
- **20%** Nothing completed alone. Severe invalid; able to do some minimal help with some smaller chores
- 10% Totally dependent, helpless
- 0% Bedridden. Minimal or lack of vegetative functioning (i.e., swallowing, bladder, & bowel) Adapted from: (Schwab & England, 1969)

APPENDIX G

CONSENT COVER LETTER

Terrie Vann-Ward APN, FNP-BC, GNP-BC Exploring the Challenges and Strategies of Parkinsonism Page 1 of 2

CONSENT COVER LETTER

The purpose of this research is to understand the challenges of everyday life for people with Parkinson's and their families. What are the strategies you use in facing these concerns? We are doing this study because we do not know what people consider helpful OR not helpful. Knowing these concerns would provide information for visiting nurses to support people maintain their goals.

- There are no medical treatments or procedures involved in this study. The study does not involve contact with
 your healthcare provider or medical records.
- An interview. This study will occur in a private setting, such as your home. For the people with Parkinsonism, information will be asked about your medications. It should take (1) to (2) hours for the interview. The interviews will be audio-recorded and transcribed. The recordings and transcriptions will be used for study analysis.
- Optional activities. There are several optional activities involved with this study:
 - 1. Photographs of places, activities, or things
 - 2. Photographs of you, and/or
 - 3. Videotaping of you.

You may chose none, one, or all of these optional study activities.

Photographs may help us understand the strategies you have used while facing the challenges of daily life with Parkinsonism. We may ask to photograph places, activities, or things in your home. You might have suggestions for helpful photos which represent your personal challenge or strategy. Videotaping may help us to understand how people with a movement disorder accomplish usual routines such as cooking or other daily life duties. These photographs and videotapes may be identifiable, which means they will show your face and people looking at them will be able to see who you are.

Participating in this study is as risky as a daily conversation. You might feel uncomfortable being photographed or videotaped. There may be no direct benefit to you from being in this study, but what we learn may help other people in the future. Every effort will be taken to protect your privacy and confidentiality, but cannot be guaranteed 100%.

- Audio Tapes of Interviews: Names and identifying information will not be used in the audio-tape transcriptions. The tapes and transcripts will be kept in a secured office. Access to the audio-taped interview is limited to the research team. The tapes will not be used for classroom teaching or public presentations. We may use portions of the transcripts publicly, but you will not be identified by name. The audio-recordings, and any photos or videotapes will be kept indefinitely by the research team for future study.
- Optional Photographs or Videotapes: Your name and identifying information will likely be on the video
 recordings or photos. The videos and photos will be stored securely and may be used for classroom teaching or
 public presentations. Photographs of places, activities, or things will be changed to shield your identity. In some
 cases, photographs and /or videotapes of you will have your facial image blurred to protect your privacy.

If you have any questions, complaints, or concerns, or if you feel you have been harmed by this research, please contact Terrie Vann-Ward, University of Utah College of Nursing (PHONE: 847-267-0979). If we have concerns about your safety, we will speak with you. If there are issues of abuse or neglect, the University of Utah requires authorities to be notified.

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University of Utah Institutional Review Board Approved 4/11/2014 Expires 9/11/2015 IRB 00066002 Terrie Vann-Ward APN, FNP-BC, GNP-BC Exploring the Challenges and Strategies of Parkinsonism Page 2 of 2

Contact the Institutional Review Board (IRB) if you have questions regarding your rights as a research participant. Also, contact the IRB if you have questions, complaints or concerns which you do not feel you can discuss with the investigator. The University of Utah IRB may be reached by phone at (801) 581-3655 or by e-mail at <u>irb@hsc.utah.edu</u>.

Your participation in this study is voluntary. You can decide to not start the study or you can change your mind after agreeing to be in the study. There is no penalty or loss of benefits if you decide to stop. By acknowledging and participating in conversation with the researcher, you are giving your consent for the interview and audiotaping of the interview. If you would like to participate in the optional portions of the study, we will ask you to initial next to the options you choose and sign the document at the bottom. Thank you for your interest and participation.

If you would like to participate in any of the optional portions of the study, please indicate below:

Initial	Option					
	1) I would like to be interviewed without any photos or videotaping. De-identified transcripts of the interview may be used for public presentations or in scientific publications.					
	2) I would like to be interviewed and have photos of places and things taken where my identity is kept private. De-identified photos and recordings may be used for public presentations or in scientific publications.					
	3) I would like to be interviewed, have photos of places, things, and myself taken where my identity is kept private. De-identified photos and recordings may be used for public presentations or in scientific publications.					
	4) I would like to be interviewed, have photos of places, things, and myself taken, and I agree to participate in photos and videotaping of myself demonstrating an activity where my identity is kept private. De-identified photos and recordings may be used for public presentations or in scientific publications.					
	5) I would like to be interviewed, have photos of places, things, and myself taken, and I agree to participate in photos and videotaping of myself demonstrating an activity where I can be identified. Identifiable photos and recordings may be used for public presentations or in scientific publications.					

[Signature only required if option 2-5 is selected]

By signing this consent form, I confirm I have read the information in this consent form and have had the opportunity to ask questions. I will be given a signed copy of this consent form. I voluntarily agree to take part in this study.

Printed Name of Participant

Signature of Participant

Date

Printed Name of Person Obtaining Consent

Signature of Person Obtaining Consent

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