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Preserving Self: Theorizing the Social and Psychological Processes of Living With Parkinson Disease

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Abstract

The purpose of this constructivist grounded theory article is to identify, explore, and theorize the social and psychological processes used by people with Parkinson disease. Analytic procedures generated the five-stage theory of *Preserving self* of people with Parkinson disease: (a) *making sense of symptoms*, (b) *defining turning points*, (c) *experiencing identity dilemmas*, (d) *reconnecting the self*, and (e) *envisioning a future*. Reminders of former selves and capabilities were painful; participants desperately sought normalcy. Participants developed creative methods for maintaining independence but frequently overestimated their abilities and took risks. Participants were 15 men and 10 women (ages 40–95), most of whom lived with their families. Disease status was ascertained through medication logs and two scales: Hoehn and Yahr staging and Activities of Daily Living. Data included 62 in-depth interviews, nonparticipant observation, and participant photos, videos, and related documents. Recommendations were derived from the theory to support processes of *Preserving Self* as interventions designed to reduce the loss of self and to enhance *Preserving self*. These recommendations included developing relationships, teaching expected and unexpected feelings and behaviors, and involvement with sensory integrating activities.

Keywords

Preserving self; constructivist grounded theory; Parkinson disease; illness experience; chronic illness; qualitative; midwestern United States

Introduction

Parkinson disease[1] research has primarily focused on drugs, genomics, or procedures (Li, Ho, & Li, 2008). Although the cause(s) remain speculative, much is known about the pathophysiology (Wichmann, DeLong, Guridi, & Obeso, 2011). In addition, various disciplines have examined the psychosocial experience of people with Parkinson disease using self-report or standardized measures (Abudi, Bar-Tal, Ziv, & Fish, 1997; Schrag, 2006). In comparison, little is known about how people face challenges in living with this progressive degenerative disease (but see Nijhof, 1995; Pinder, 1988).

People with Parkinson disease experience a wide range of troubling changes involving neurological, cognitive, and psychiatric difficulties. The disease is strongly associated with three major public health problems: falls, depression, and dementia. The disease subtly and deceptively changes how people function, interact, and subsequently view themselves. Yet they actively strive to maintain established roles and identity. The public and health care providers' limited knowledge of Parkinson disease and often stigmatizing attitudes (Pan, Stutzbach, Reichwein, Lee, & Dahodwala, 2014; Pescocolido & Martin, 2015; Tickle-Degnen & Doyle Lyons, 2004) influences both affected individuals' daily lives and professional treatment perspectives.

Health professionals know little about how day-to-day management of Parkinson disease occurs, how people handle the devastating changes, and how it affects the self-concept. The experience of living with Parkinson disease cannot be understood without adequate knowledge. Appreciating how people face life challenges provides favorable situations for health care providers to learn, offer guidance, and increase their effectiveness in working with them.

Thus, this article focuses on profound changes that occur over time and, despite these changes, how people with Parkinson disease retain their identity. The research

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provided detailed insight into their life experiences as parkinsonism progressed. Therefore, we aim to identify, examine, explore, and theorize challenging situations and processes people with Parkinson disease experience as they endeavor to preserve their prediagnostic selves. We address these questions: What challenges do people with Parkinson disease face in daily life? How do they maintain self-identity? The knowledge generated from these questions enabled us to develop a substantive theory, *Preserving self for people with Parkinson disease.*

Preserving self is an emerging concept, at a descriptive level of development (Charmaz, 1994; Doka, 1996; Howard, Balneaves, Bottorff, & Rodney, 2011; Irurita & Williams, 2001; Johnson, 1991; King & Jensen, 1994; Logan & Jenny, 1997; Morse, 1997, 2012, p. 127; Morse & O'Brien, 1995; Ryvicker, 2009). In this article, we treat *Preserving self* theoretically because it is a way of being that sustains self-identity through everyday activities, attitudes, and interactions. *Preserving self* represents the struggles, transitions, and strategies of people who feel they are losing the normalcy of familiar roles and interpersonal relationships. It is a social process involving making new meanings (in this case, for people with Parkinson disease) and taking action based on these meanings to maintain the former self. Common attributes of this concept are striving, asserting, protecting, and engaging. Failing to *Preserve self* may lead to diminishing roles, relationships, self-worth, and ultimately, the loss of one's prior self.

Strategies to preserve self may be identified through examining people's behaviors and emotions during trying times, such as managing chronic illness. Here, the concept of *Preserving self* served as an inductive frame for building interpretive understanding of actions and attitudes reflecting the process of maintaining self-identity by people with Parkinson disease. *Preserving self* consists of the following five stages that we discuss below: (a) *making sense of symptoms*, (b) *defining turning points*, (c) *experiencing identity dilemmas*, (d) *reconnecting the self*, and (e) *envisioning a future.*

Literature Review

Description of Parkinson Disease

Idiopathic Parkinson disease (without known cause) is the most common form of neurodegenerative parkinsonism,[2] consisting of approximately 80% of all cases (Dickson, 2012), yet, it remains less understood than other chronic conditions. It affects all body systems, although each person uniquely experiences symptoms, severity, and pacing of the disease. A "mask-like" face and voice softening diminish expressiveness. Swallowing difficulties lead to weight loss, malnutrition, and increased choking. Slowness and stiffness of movement begin as minor problems, but gradually reduced muscular function leads to balance impairment, gait disturbances, and subsequent falls. Increasing involuntary resting tremors disrupt deliberate movement, sleep patterns, and elicit strong emotions (Chaudhuri, Odin, Antonini, & Martinez-Martin, 2011).

Establishing a diagnosis is frequently difficult: People commonly attribute symptoms to aging, subsequently delaying health care for several years until symptoms can no longer be controlled or concealed. Treatments provide limited symptom alleviation and do not slow disease progression. Dopamine-replacement medications (e.g., levodopa/carbidopa) improve mobility and functioning only for a short time. Disabling side effects appear, and medications eventually become ineffective (Olanow, Stern, & Sethi, 2009). Furthermore, no confirmatory laboratory tests or procedures exist (Joutsa, Gardberg, Röyttä, & Kaasinen, 2014). Autopsy remains the definitive diagnostic standard (Hughes, Daniel, Kilford, & Lees, 1992).

Parkinson disease affects one of 250 people older than age 40, one of 100 people older than age 65, and one of 10 people older than age 80 (Eidelberg & Pourfar, 2007). Survival time after diagnosis has been estimated at 8 to 10 years (Elbaz et al., 2003). Regardless of the life span reports, remaining life is spent in varied and increasing stages of disability.

The Contributions of Quantitative Research

Diagnosis depends largely on quantitative scales for comparing, generalizing, and (subsequently) identifying the nature of the parkinsonism. Two widely adopted 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 (ADL) Scale (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.

These scales can assess stages of disability but offer limited insight, for example, on depression. Overwhelming sadness, despair, and tremendous loss contribute to personal suffering but are not measureable on such ranking scales. Even with the availability of multiple depression scales, more than 40% of people with Parkinson disease have undetected symptoms of depression (Shulman, Taback, Rabinstein, & Weiner, 2002). The depth of human feelings cannot be measured by numbers. Ranking personal situations and emotions does not measure a person's depth of feelings or offer a glimpse into their understanding of the experience (Galasiński, 2008).

The Contributions of Qualitative Research

We built on Charmaz's (1983, 1990, 1991) analyses 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 loss of self occurs on a continuum with varying levels of vulnerability, sensitivity, and diminished function. It is demonstrated through passivity, lowered self-worth, and social withdrawal. Although Charmaz's model of chronicity may be applied to Parkinson disease, from a pragmatic clinical perspective, we need to delve further into day-to-day experiences.

The 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 (Bramley & Eatough, 2005; Roger & Medved, 2010; Soundy, Stubbs, & Roskell, 2014). In addition, a few autobiographies offer a glimpse of living with the losses of Parkinson disease (Ali & Ali, 2004; Ronstadt, 2013). While qualitative research has begun describing the parkinsonian lifestyle, further questions and deeper concerns arise.

Theoretical Concerns: The Concept of Self

We begin with a working definition of the *self*, derived from symbolic interactionism (Blumer, 1969; Mead, 1934). Thus, we assume people actively construct their own worldviews as they interact with others. Through these interactions, individuals' experience, sustain, alter, and may transform their sense of self. Forming a self involves a sense of continuity across time that involves intertwining of the past and an orientation toward a possible future (Giddens, 1991). The self is a template of action (Blumer, 1969; Charmaz, 1983, 1990; Mead, 1934; Schwalbe, 1983). People use their self-concept notions as a frame of reference for making decisions and guiding subsequent behaviors.

Method

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 individuals' subjective experience (Charmaz, 1990, 2014). Subsequently, this interactive method adopts a problem-solving approach. By focusing "on process, patterns, and meaning" of experiences within contexts of daily lives, roles, and relationships (Tweed & Charmaz, 2012, p. 134), researchers can view problems from participants' perspective.

The Setting

This community-based study spanned three Midwestern states. The region contains a diverse mix of cultural, racial, and socioeconomic groups ranging from the wealthiest in the United States to the poorest. Environmental hazards resulted from epic winter snow and cold (Erbentraut, 2014) and spring floods (Rathbun & Gottfried, 2014). Usual distances and access to food, medication, and health care posed even greater concern for people during these taxing times.

Recruitment Strategies

Recruitment goals focused on involving people over age 40 with self-reported Parkinson disease, who might typically be hard to find because of age, mobility problems, or social isolation. Study flyers were distributed to support groups, libraries, grocery stores, and professional colleagues. Recruitment information was posted on the Fox Foundation's (2013) Trial Finder website, and presentations were conducted at two support groups. Most participants were identified through snowball and theoretical sampling.

Data Collection

Data collection took place from September 2013 through December 2014. Multiple sources of data included interviews, observations, documents, photographs, and videos. These data opened opportunities for engagement and understanding the meaning of the participant's world (Blaikie, 2000). Interpretive sufficiency signaled the completion of data collection.

Demographic and Descriptive Data

Demographic data included age, race, marital status, educational level, living arrangements, and occupation for each participant. Medications, disease staging, and ADL capabilities were the descriptive data.

A list of all current medications was obtained by examining original containers, whenever possible. Participants more commonly described how and when medication was actually used. A medication data tool was adapted from The National Institute of Neurological Disorders and Stroke Common Data Elements for notating information (Grinnon et al., 2012).

The Hoehn and Yahr (1967) parkinsonian staging criteria (Goetz et al., 2004) is a 5-point categorical scale describing the clinical presence of motor disability; it does not measure function. Higher numbers indicate greater degrees of impairment. Lay organizations, providers, and people with Parkinson disease commonly designate the terms early, middle, or late to represent disability stages (National Parkinson Foundation, 2017). T.V.-W. completed the HY while taking into account other conditions influencing motor function and followed the scale instructions to "rate what you see" (Goetz et al., 2004).

The Schwab and England Activities of Daily Living Scale is a descriptive 10-item scale ranking 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 0% score indicates a vegetative state (Perlmutter, 2009). The ADL scale was completed through observation and participant self-report.

Qualitative Data

The first author, T.V.-W., conducted 62 in-depth interviews; all interviews ranged in length from 1 to more than 4 hours and consisted of 25 initial face-to-face and 34 follow-up interviews (including one dyadic and 22 phone interviews, as well as 12 home visits).

Interview pacing followed leads given in each participant's verbal and nonverbal responses (Charmaz, 2014, 2015). Several guided questions encouraged reflection and spontaneous sharing. When people talked about what they had been through, strong emotions were revealed. Most people cried, some softly, others sobbed wrenchingly. Being attentive meant acknowledging feelings. It also meant pausing the conversation, giving people space to regain composure (Corbin & Morse, 2003).

Observations

Conducting in-home interviews allowed seeing how participants moved about, completed ADLs, and interacted with family members. T.V.-W. also attended two support groups and a dance class. Participants' shared personal photos during the interviews. Other visual data included personal memorabilia, self-portraits, researcher photographs and videos of participants and their environments. Documents included participant emails, notes, celebrity autobiographies, and popular movies. These data provided essential understanding about living with Parkinson disease and the course of illness over time (Dahlke, Hall, & Phinney, 2015).

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 male and 10 female) volunteers with self-reported Parkinson disease. Their ages ranged from 40 to 95 years with most people (19) being in their 60s and 70s. A variety of backgrounds, occupations, and economic situations was represented. 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 the consent form. The disease duration ranged from 3 months to more than 30 years. Disease staging 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. Participants in Stage III completed ADLs 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 of the 25 participants.

Analysis

Audiotapes were transcribed verbatim. Transcripts were read with reference to corresponding pictures and videos. During the first phase of analysis, the researcher sorted data into broad categories and then explored them by comparing incidents-to-incidents. The second phase of analytic abstraction consisted of focused coding (Charmaz, 2014) with the groups of initial codes compared, refined, and synthesized with increasingly abstract labels.

The technique of constant comparison informed the entire analysis by expanding possibilities for seeing the similarities and differences between various data. Theoretical questions arose that suggested missing data needed for building concepts. Thus, theoretical sampling directed reexamining data from a new perspective or finding additional participants for understanding and refining the emerging concepts (Charmaz, 2014). Theoretical sampling also guided ongoing data collection to represent maximal variety of experiences, including negative cases (Charmaz, 2014; Morse & Richards, 2002). The ability to see participants' challenges and strategies gained conceptual clarity through theoretical sampling.

Developing the Theory of Preserving Self

Decontextualizing narratives and grouping segments into broader categories (reflecting experiential phenomena) provided an analytical means of organizing and explaining the relationships between major concepts. This approach provides a framework for observing, understanding, and making clinical predictions (Charmaz, 1990). It enabled *Preserving self* to be adopted as a clinically derived substantive theory, developed abstractly from the experiential processes of people with Parkinson disease. This theory may be applied to other disabling conditions.

Results

Preserving Self: *An Overview of the Theory*

Preserving self represents the hurdles people encountered and the various means used to counteract experiential intensity and its impact while trying to remain their pre-illness self. The actions and emotional states of the people with Parkinson disease can be "seen" through the theory logic, which explicates intensely personal experiences.

The theory of *Preserving self* is comprised of five interdependent stages: (a) *making sense of symptoms*, (b) *defining turning points*, (c) *experiencing identity dilemmas*, (d) *reconnecting the self, and (e) 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 1 illustrates the stages and transitions; the following paragraphs descriptively explain *Preserving self.*

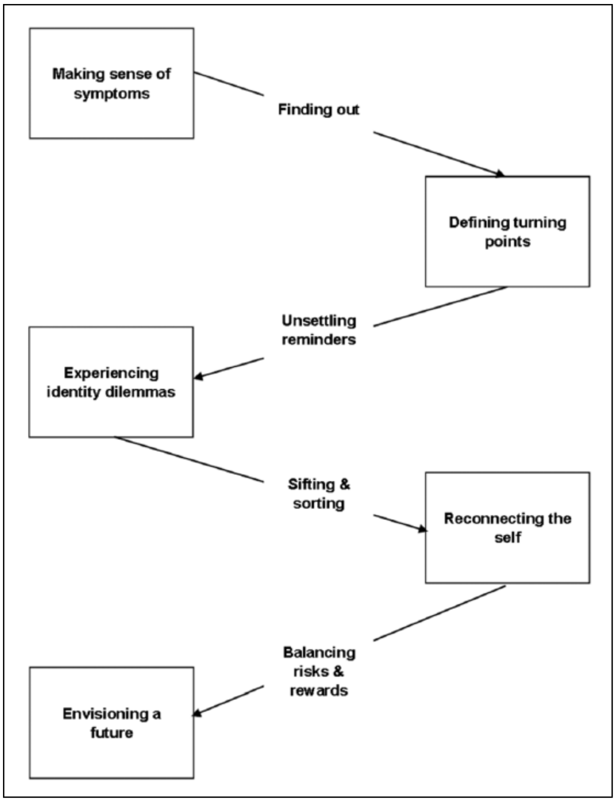

Figure 1. *Preserving self* for people with Parkinson disease.

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. Other conditions often complicated these difficulties and confounded the person's ability 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.

Confirming that something is different. Participants increasingly questioned and monitored symptoms as they became more serious. A jolting awareness was described when one or more symptoms signaled a "wake-up call" indicating a startling confirmation of something being very different. One man had been feeling increasingly fatigued for "a time" but paid little attention to the symptoms. He correlated the intrusive fatigue to aging and a cross-country driving trip. 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, went to his internist promptly, who scheduled an urgent neurology appointment.

Interpreting the symptoms. Participants studied the symptomatic nuances and recognized developing patterns. Their concerns persisted, frequently for several years, before they considered their situations serious and needing closer attention. These patterns, however, were typically viewed as normal responses to aging or increasing computer use. Retrospectively, participants recognized symptoms they believed were probably pre-Parkinson changes. One such symptom was scrawled handwriting, which was sufficiently concerning for one man 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. Participants wondered what caused these physical and emotional symptoms. Tremors and muscular stiffness were blamed on specific activities such as excessive exertion or carrying heavy items. They 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. Those who worked blamed a "bad situation" and felt exasperated while trying to sort through emotional changes and physical discomforts.

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

Sudden acute changes were easily recognized as more serious. Participants described traumatic injuries (especially old injuries to the head) as having lingering effects throughout their lives and 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 thought a home accident (involving a television falling on his head) caused his right leg tremors. As he had emergency treatment at the time, he believed that he should "learn to adjust."

Of the 25 participants, 10 (40%) had emergency room visits. Experiencing a health crisis was alarming. A sudden onset of tremors or chest tightness brought concerns about the possibility of seizures or a heart attack. Several participants wondered if they "would make it" through. One older man (late stage) 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 felt 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 exasperated and were described as stalling or even avoiding conversations about a definitive diagnosis. Doctors were recalled 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. Hearing the diagnosis of Parkinson disease, however, was unexpected. *Finding out* brought a range of emotions: relief, numbness, or shock. Several participants felt relief and thankful the diagnosis was not something "more serious." They considered various forms of cancer, multiple sclerosis, and Huntington's disease 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, participants asked questions of God and of themselves. 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?" Her loud sobbing interrupted her speaking as she talked about finding out and the intensity of daily reliving.

Several participants did not know what to think. Some recalled driving around aimlessly, while others remained sitting in their car, finally realizing it was time to go home. The unexpectedness of the diagnosis cast shadows on the future. Participants 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. Participants older than age 60 usually worried about ways to keep working while retirees looked at continuing an active lifestyle. 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: Defining 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 participants knew themselves. They encountered demanding tasks that taxed their 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 man 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 participants 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, the most worrisome fear. 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 participants looked for research articles about dementia, but had difficulty understanding the scientific language, and subsequently became more anxious. When browsing the Internet and reading dementia "horror stories," participants feared for their own futures: "The scariest thing is that dementia." One recently diagnosed man 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.

"Just in case" strategies were intentionally developed for remembering aspects of themselves and significant relationships. Family photographs lined the walls. Pocket-sized albums were 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 individually unique. 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 participants mentioned the difficulties of raising teenagers, complicated unimaginably by a soft, nonprojecting voice.

Spouses were most affected by their partner's 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 (midstage) 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 reluctantly considered it.[3]

Seeking knowledge of a new circumstance. Most participants lacked information about the disease course or impending challenges. Important activities entailed learning about the disease, 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 cognitive and emotional strengths to grapple with issues involving chronic illness living. Most participants were passively compliant, taking prescribed medications and recommended therapies. They were not yet ready to consider themselves as permanently parkinsonian.

Generally, participants received information when they were diagnosed; however, it was usually "hard to understand." One recently diagnosed man described the information received from his doctor, "He said he would start me on this patch. But, he gave no insight. I had no idea whatsoever as to what to expect." Participants 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 chose not to discuss relationships, lifestyle problems, or work-related disabilities with the doctor. Instead, they turned to the Internet for answers, which became their primary information source.

Everyone knew about the presence of support groups from brochures or the Internet. Participants 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 woman 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. Participants who began taking L-dopa expressed amazement at how much better they felt.

Participants did not always fill recommended medication prescriptions. Some people postponed using medication; several hoped to participate in clinical trials requiring de novo status. Other participants expressed reluctance 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 middle-aged woman (midstage) waited years before considering L-dopa, even with her inability to rise from a chair.

Disclosing. Participants quickly realized the limited knowledge of other people regarding Parkinson disease. Sharing personal information with work colleagues posed difficulties, 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 limit staring colleagues and reduce intrusive questions.

Occasionally participants received little support after telling their families. Some family members avoided hearing about the illness or the person's experience. Family responses were described: "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." Worries over family reactions prompted many people not to speak about their situation. One woman (midstage) 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

Participants tried to do for themselves, but sometimes, old familiar ways no longer worked. For example, a person's mouth could not easily form words or tremors meant holding a martini with two hands. Knowing that other people saw these changes was embarrassing (Nijhof, 1995). Feelings of interpersonal inadequacy and increasingly obvious physical limitations jolted awareness that life had changed. Self-defining characteristics were no longer clear. Participants had perpetual reminders that they were no longer the same.

Communicating the meaning of unsettling reminders was difficult. Most participants, 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: Experiencing Identity Dilemmas

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

Desperately holding onto former selves. Participants were fiercely determined to be themselves as before. Behaviors continued, without recognizing or taking illness changes into account. Sensations of numbness, emotional disconnectedness, and reliving of diagnostic events frequently occurred. 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. Taking risks was a gray area of personal negotiation in which participants took risks that lay between former and new attributes of self. They took compromising chances as they fiercely tried to determine their self-boundaries by retaining old familiar ways. Participants 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 getting to work, purchasing household necessities, and obtaining medical care. Most participants tried to drive less during heavy traffic or winter weather; however, they did not consider driving with tremors or possibilities of freezing episodes as risk-taking. One man 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 was boosted by having containers of L-dopa medication within reach on the passenger seat. For each person, choosing risky situations supported some aspect of former identities, but also pointed to *overwhelming* new limitations. People tried avoiding risks, but because circumstances had changed, determining what defined a risk was difficult.

The vulnerable self. Emotional pain and continuing physical changes gave concerning reason that future circumstances might worsen, thereby perpetuating a sense of helplessness. Participants tried but sometimes the "best strategy" contributes to difficulties. 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. Participants described feeling disconnected from their lives. Facing confrontation with changing circumstances was delayed by increasing activity involvement. They tried, but failed to maintain their former busy activities: babysitting grandchildren, traveling, community activism, cultural events, movies, and exercise. Feelings like "the same old self" were reported after successfully completing even one familiar routine.

Eroding self-worth. Outlooks on life were described 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 unknown impending dooms were common. Anxiety becomes paralyzing when it dominates feelings, thoughts, and actions. For some participants, incapacitating worries developed when former skills were challenged or decisions were required. Instances of anxiety producing decisions include morning clothes selection, dinner meal planning, or driving alone through snow for necessities.

Suddenly being unable to move (freezing of gait) caused enormous anxiety. During one of the first author's home visits, a woman stood up to obtain something. She could not turn after rising, her face becoming a sheet of fear. Swaying from side to side did not help; her lower body just would not move. When T.V.-W. extended her arm, the woman held onto it with both hands and was able to walk into the next room. They talked about what happened to cause the movement inability:

> 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 complicating the integration of a past and present self, leaving a person without well-rehearsed defense strategies. Enormous energy and effort were required to remain self-reliant, yet, dependencies occurred with frightening frequency.

Physical dependencies. Parkinson disease gradually diminishes ADL capabilities. Personal hygiene, feeding oneself, or remaining diaper-free were important; however, how participants treated these concerns changed with increasing disability and altered personal views. This middle-aged man (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 disease stage, every participant worked diligently at doing all they could, risking discomfort or injury. Even when they could no longer feed themselves or walk, participants struggled to continue caring for themselves. One man (Stage V), while relying on daily nursing care, described his determined attempt to independently shower.

> 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.

The fears and realities of physical dependence compounded with conflicting images of past and present identities brought strong emotional responses. This man (midstage) 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 concerned participants, before they routinely occurred. 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." They made promises to themselves and family members to stand up 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–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.

This man made self-determined independence 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.

Relationship dependencies. Participants expressed worries of being abandoned by spouses or children when the disease diminished mental and physical abilities. Some people felt marrying a dating partner would ensure permanency. It was relieving that at least the doctor knew about their 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.

Embarrassing, humiliating, or demoralizing situations occurred routinely. 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 well-intentioned family members used hurtful words or actions. For example, one end-of-life bedridden woman's voice filled with great sadness when she spoke 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) disease symptoms could be overcome and frequently 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.* They became attentive to subtle nuances of expression, sidelong glances, and even well meaning efforts of friends. Participants developed personal phrasing codebooks to use when facial muscles stiffened, speech became garbled, or with an especially soft voice. For example, "I've had a cold" or "It's loud in here" helped discretely explain innocent symptoms.

Finding direction. Participants developed new understandings of Parkinson disease by paying attention to symptoms and evaluating their responses to situations, activities, and medications. One man 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 daily routine. Dietary intake was monitored to avoid interference with medication absorption. Some participants hired a food delivery service to avoid driving due to unpredictable muscle freezing episodes.

Learning practicalities. Participants realized the importance of people in their lives and the value of trying to maintain prior relationship approaches. This usually involved degrees of silent compliance to achieve personal goals. Household chores were taken over 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 closer to their only child and soon after became full-time babysitters for their 2-year-old grandchild. A cherished experience became difficult. 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." Participants gained firsthand practical knowledge of how to use the L-dopa by "experimenting" with self-adjusted doses to improve functioning before activities or interactions. Dosing information 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 unable 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. Embarrassment and humiliation were common. Participants addressed such 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. One middle-aged woman (late stage) 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 midstage older adult, "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. 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 participants expressed animosity for their lot in life. Statements of anger were directed toward neurological research, doctors, employers, and family members. Exasperation was described with brain research efforts that still had not identified a cause or cure. Doctors were blamed for medication side effects. Family members were resented for not providing desired levels of attentiveness, while the capabilities of friends and colleagues were coveted. "Without Parkinson's, I would still be young. It's very discouraging." Participants expressed stigmatizing statements at themselves and others, "I'm such a clod," or "That person looks too good to have Parkinson's."

Resolute. Participants 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 a.m. to care for his wife and complete daily tasks before 8:00 a.m. 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 in this study.

Reformulated. Participants redefined themselves as accommodating the parkinsonian symptoms.[4] Acknowledging losses of past identities was a means of coming to terms with their circumstances. Living with Parkinson disease became a reality. Participants gained increasing self-tolerance by recognizing differences between the disease and themselves. This man (midstage) 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 effects 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. One older woman (advanced stages) developed a ritual of taking lettuce leaves with medication to aid in preventing vision loss. This man 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.” They examined and adjusted former interests while developing new interests. 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 late stage woman, with hand contractures, devoted time daily for exercising her index fingers to ensure capabilities for sending emails to distant family members. One woman acknowledged the diminished dexterity of her hands and put away a lifelong hobby of crocheting without remorse. She 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 man (late stage) 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. One 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 disease or 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, a sense of continuity became disrupted; participants could not see themselves as 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

The difficulties of envisioning a future were described by a midstage man: “With Parkinson’s, today is the best day you will ever be. Today is tomorrow.” Diminishing movement abilities causes people to become firmly anchored to the moment (literally and metaphorically), subsequently changing sensations of continuity; the past was compressed, the present became expanded, and the future was shortened. Becoming a connected self and having a place in the world relies on experiencing time as a continuous flow. Recognizing the inevitable and moving forward were difficult.

Recognizing the inevitable. Initially, participants did not realize the major impact Parkinson disease would have in their lives. This man was diagnosed 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 of their disease stage or severity. Most had heard of the HY from the Internet. Driving difficulties, memory changes, labile moods, and increasing movement problems were not discussed with families or physicians. Parkinson disease was recognized as having early, middle, and late stages, but participants did not know what this meant. For instance, a man (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 older man (late stage) 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 firsthand knowledge of the unique debilitating decline occurring with Parkinson disease; it became easier for participants 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, participants felt a duty for monitoring their health, evaluating changes, and becoming treatment proactive due to beliefs 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 disease. 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. As medication taking is a private event (unmonitored), it must be acknowledged that most serious problems were not reported to providers.

Common sense and feedback from family members aided participants as they strived to make daily life simpler. Several people moved within the year before the diagnosis. Other participants moved within 3 to 5 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 guide moving 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. Participants 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. One man (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 participants reported having space in their homes for a nursing aide, “if it should come to that.” One middle-aged woman (late midstage) lived alone in her “dream home,” but realized she was essentially living in the basement because stair climbing was difficult. She hadn’t thought about future possibilities of home services, but has considered a rental arrangement. Other participants made decisions to move into nursing homes if assistance was required, such as urinary incontinence. 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 resources is not easily accessible.

Advanced directives were completed by fewer than four participants. Explanations were given, “I still have time” or “I thought that was just for heart attacks or comas.” One woman (midstage) considered asking her neurologist to serve as her power of attorney over health care, knowing the doctor would make wise decisions. The woman had limited alternatives; family members were a great distance and she felt unsure of other relationships. However, she was worried that her request would be denied. Participants, generally, did not know or have information about advanced planning. The people who had this information, felt they needed to self-advocate for ensuring their advanced directive goals.

Moving forward. Every participant knew that Parkinson disease was permanent, had no cure, and disabilities would increase. It was difficult for them to imagine what this might mean. Some people felt overwhelmed by the larger than life qualities of the disease. One middle-aged woman (midstage) described her world:

> 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).

Participants described needing to change their views of the illness before being able to think of a future. "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; 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, occasions arose 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 participant 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)."

Participants strove to be engaged in daily life. Most people became involved with volunteer activities; they wanted to "give back" to the Parkinson community. They started support groups, actively sought to participate in research, and offered guiding friendship to recently diagnosed individuals. 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's treatment or research. Physically assisted by two nursing aides, using a walker, then being placed onto a bench, he continued his longtime 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 pointed out as relationships were vital. One man (late stage) 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 (the 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 participants responded to daily life challenges was clear; routines and evolving strategies functioned to preserve favored pre-diagnosis identities, roles, and relationships. People faced their challenges based on past roles and identities while functioning based in the present moment. This stance 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 continuity and normalcy. 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. The data highlighted two *Preserving self*-strategies for maintaining self-identity: (a) interacting and (b) 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 participant'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. His wife, adult children, and his employer all reinforced his self-view. Neither of these individuals wanted to get hurt, but past self-images warranted their actions. They set aside their present disabilities (bracketed) as though not applicable to themselves. Roger and Medved (2010) described how the need for normalcy extended to family members for people with Parkinson disease.

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 health care that provide the meaningful basis for how people feel, think, and act. Maintaining and developing relevant social identities was identified as a key to well-being for people with Parkinson disease (Soundy et al., 2014).

Participants were determined to retain their former self. However, by continually facing *identity dilemmas* (Stage III), 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. Wide-ranging difficulties have also been described by other studies (Bramley & Eatough, 2005; Roger & Medved, 2010; Soundy et al., 2014). Subsequently, taking risks became a method of trying to reestablish former identities.

Taking risks. It became evident that participants 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 connect their actions with risk-taking. Their self-perceptions remained as before the illness and thus affected their decisions and actions. Driving with the possibility of a freezing episode brings a potential for hazardous situations. Self-adjusting L-dopa without knowing side effects or consequences poses potential risk. In both of these examples, participants 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. Participants who could reconnect and reformulate themselves demonstrated using strategies involving bodily movement, cognition, and emotions. Engagement with important relationships provided respected and ongoing feedback. Involvement in activities such as bicycling, music, or playing with children required planning, coordination, and activated feelings.

Generalizability

This research was conducted with a unique participant sample, their illness experiences, with contrasting and often hazardous settings, required diverse researcher skills. Nevertheless, the theory is generalizable to those with Parkinson disease, and may be generalizable to those who have a variety of chronic conditions, and who have memory changes or depression, or live in the community with mobility problems.

Strengths and Limitations

Strengths. A variety of 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. In addition, the unique variety of people during different stages of the disease progression contributed to understanding the experiential processes of this unique chronic illness.

Grounded theory provided a means to capture the instability of Parkinson disease and the chronic deteriorating nature of the condition. The inclusion of varied observational data added invaluable richness which contributed to the clinical utility of the *Preserving self* theory.

Limitations. Recruitment strategies of group presentations, distribution of flyers, and a website posting were simple, yet effective methods of locating participants. Yet, more than 100 potential participants could not give consent 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

Learning the diagnosis was shocking but was time-limited and surpassed by conflicting images of past and former selves. Every participant experienced great difficulty reconciling unsettling reminders of former selves preceding *identity dilemmas*. People reexperienced these dilemmas (of varying duration and intensity) throughout the illness. However, people who had strong relationships and became involved with specific activities demonstrated forms of reconnecting and reformulating. This point does not mean that people accepted the illness; instead, they accommodated illness in their lives.

Interventions designed for reducing the impact of unsettling reminders and *identity dilemmas* would enhance *Preserving self* and potentially reduce the loss of self. These recommendations are for health care 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 became 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 et al., 2011; Lewis, Annett, Davenport, Hall, & Lovatt, 2016; Snijders, Toni, Ružička, & Bloem, 2011). Even though people in the later stages participated in dance, this may not always be practical. Integrating activities in the course of daily activities include preparing vegetables for dinner, folding clothes, humming, or singing.

Conclusion

The lives of people with Parkinson disease portray their desire to assume responsibilities, satisfy obligations, and share fulfilling relationships as they had done in the past. Meaningful explanations of their situations were sought, relying on family, friends, and health care providers, as they struggled through day-to-day living. Substantiating these statements is this fact: more than 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. The clinically derived theory of *Preserving self* fills this gap in the literature and clinical practice for supporting and encouraging processes of preserving self.

Experiencing Parkinson disease changes how people experience the past, present, in future and how they view themselves within these time frames. The past provides taken-for-granted markers and measures of the person's present actions. These serve to preserve the familiar self, as known in this past. Thus, those with advanced disease devote concerted efforts to activities and practices used in the past that they believe will maximize their health and minimize disabilities. When this strategy fails, people then realize that they are no longer the self they were in the past. Discontinuities between past and present self lead to reevaluating daily activities and focusing on what they considered "most essential." Yet, they based their imagined selves for the future on the present self, and subsequently underestimated the effects of progressive impairment.

Last, through analyzing the processes constituting preserving self, we theorize a descriptive construct and thus show how it offers abstract understandings of experiencing Parkinson disease. These understandings can enable health professionals to assess their patients' situations, make predictions, and refine treatment plans. In this way, constructivist grounded theory analyses make valuable contributions to clinical practice.

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Notes

1. *Parkinson's disease* is an eponymic term. These terms have served as a reward for an individual's contribution regarding a condition (Fargen & Hoh, 2014). Style guidelines, such as those from the Council of Science Editors (2014a, 2014b, 2014c) or the American Medical Association (Glass, 2007), recommend eliminating the use of possessive eponymous. Parkinson disease is the correct form. Even with these guidelines, practices are inconsistent. Parkinson's is often used alone, usually when a plural or possessive form grammatically fits a sentence.
2. 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).
3. 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).
4. Mayan, Morse, and 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.

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