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The Experience of Parkinson's Disease in Middle Life:

An Interpretive Account

by

Barbara Habermann-Little

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

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The Experience of Parkinson's Disease in Middle Life:
An Interpretive Account

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Barbara Habermann-Little

Dedicated to my children,

Gregory and Erin Little

Acknowledgements

First, sincere thanks must go to the participants who opened their lives to me. They welcomed me into their homes and lives and shared their stories. Even with emotional and difficult questions, they never pulled back. They were committed to having their stories told in hopes that it would help others understand. I am deeply grateful for what they taught me.

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The Experience of Parkinson's Disease in Middle Life: An Interpretive Account

Barbara Habermann-Little

Research involving people with Parkinson's disease has focused on factors related to depression and psychological adjustment to the disease. Primarily this research has been done with elderly populations and has largely ignored the perspective of the person with the illness. The purpose of this work is to explore the experience of the person with Parkinson's in middle life. It aims to explicate the participant's understanding of the illness, the day-to-day demands they face and the coping patterns utilized in living with this illness.

An interpretive approach, specifically a clinical ethnography, was utilized. Sixteen middle-aged individuals participated in three interviews during a three month period. Participants were asked about their understandings of the illness, stressful situations, day to day demands, practical knowledge gained and their ways of coping with the demands and challenges.

Day-to-day demands directly attributable to the illness were considerable. Demands most commonly discussed were: acknowledging symptoms and seeking help, balancing emotional responses, dealing with a changing body/self, gaining formal and practical knowledge, and dealing with unpredictability and ambiguity. Demands existed related to work and family roles, relationships and identity.

Participants demonstrated both commonalities and differences in coping that were shaped by the nature of the disease, the bodily experiences associated with symptoms and medications, personal and cultural meanings of the illness and self and professional care practices. Participants maintained an intact self in the context of many changes. They experienced a range of possibilities within the framework of the disease trajectory. Interventions by professionals which recognize the meaning of the illness for the person, the specific day to day demands and the coping strategies they utilize, will be more effective in meeting the needs of these persons and lead to more compassionate and caring practices.

Patricia Benner

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CHAPTER 1

Introduction

> "They say you don't die with Parkinson's. Parkinson's isn't that serious and I think that's wrong. It may not be life-threatening but it is certainly life-changing in a magnitude that is extreme. I may be alive but I'm not moving. I'm sitting on the couch frozen stiff in a sense. So I suppose this is living."

This is a story of sixteen middle aged people who have Parkinson's disease. It is a story of people's changed lives, of their experiences, their feelings, their suffering and losses, their humanness and their ways of living meaningful lives.

It is _their_ stories I wish to tell. I come to this research from a clinical background with people with this disease but this is an outsider's view. A view of someone looking in; what I attempt to provide in this work is an interpretation of the world of the person with this illness. Though not truly an insiders account for that can only be given by one who has experienced the illness, I am challenged to tell their stories as best and as fully as I can. In doing so I hope to provide professionals who work with people with Parkinson's, a different understanding of their worlds, a perspective which provides access to their changing worlds and what matters to them. My goal is to move from explaining the disease to understanding the meanings of the illness and the daily self-care and coping required by it. As a nurse, I ultimately hope this will lead to a fuller understanding that will shape practices of compassion and care.

Before I begin to present their stories, some background information, literature and views need mentioning. First I review how Parkinson's disease has been discussed in both professional and lay literature. The current state of research relative to this disease will be described. Both of these discussions set up the distance and contrast between the formal explanations and the lived experience.

Misconceptualization as a Disease of the Aging

> "A degenerative disease of later life characterized by rhythmic tremor and muscular rigidity, caused by degeneration in the basal ganglia of the brain."
> (Websters Dictionary, 2nd Edition, 1978)

> "A relatively common chronic malady of the central nervous system that produces such striking symptoms that almost any observant person could recognize it at a glance. The stooped posture, the slowness of movement, the carriage of the arms in front of the body, the quick short-stepped gait (as if to keep from falling), fixity of facial expression and the tremor of the hands are the characteristic signs. The onset of the disease usually occurs in late adult life."
> (Encyclopedia Britannica, 15th Edition, 1988)

These two definitions are provided as examples of how Parkinson's disease is presented in the most readily accessible sources to the lay or public. While factually true (i.e., most people experience some of the symptoms listed), one can imagine a person newly diagnosed experiencing a rather emotional response when reading these descriptions.

Parkinson's disease is labeled as a "disease of later life" in both lay and professional literature. While one can not argue with the statistical fact that the peak onset is after age 50, the characterization of the disease as one of "later life" creates problems. As we are an aging society with the fastest growing population being the oldest old (85 and over), to call age 50 later life is grossly inaccurate (United States Administration on Aging, 1991). Descriptions of this nature leave an image and imprint on the public and on professionals who may not routinely meet people with Parkinson's. For the person in a post-retirement phase of their life, being labeled as in "later life" may not be an issue. But for people who are younger (as are the participants in this research), the prevalent discussion of the disease as one of the aged is very problematic. The description does not "fit". It can lead to one feeling more isolated and perhaps even stigmatized. Not only does one have to deal with the reality of having this chronic disease which changes one's being in many ways, but also the reality of not fitting the mold of the person who typically has the disease.

Equally misleading as the label of "disease of later life" is the discussion of prognosis found in both lay and professional literature. Often immediately following the notion of Parkinson's being relatively common in the elderly is a discussion of people living with the disease for 10-20 years due to its slow progressive course. While people who are diagnosed in their later years may only live an additional decade or two, for the person who is younger they will more than likely live with this disease for a much longer span of time.

Statistics of prevalence of people diagnosed with Parkinson's before the age of 50 range approximately 2-10% (Teravainen, Forgach, Hietanen, Schulzer, Schoenberg & Calne, 1986). While certainly not the majority in numbers, they are virtually an ignored group. Patient education materials, support groups, professional publications and research endeavors have primarily focused on the older person with Parkinson's.

These were some of the reasons I choose to study participants in middle life. Previously, as a clinical practitioner I felt ill-prepared to care for these individuals. As a clinician I could only see suffering and loss when I worked with younger clients. These participant's stories have enabled me to better understand the suffering and loss and have expanded my understanding of the possibilities experienced by younger persons with Parkinson's.

Literature Review

Basic Sciences: An Historical Overview

The majority of bio-medical literature related to Parkinson's disease is in basic science research. While it has long been established that there is a loss of dopamine containing neurons in the substantia nigra of the brain (Carlsson, 1959), the reason for this loss remains unknown. The discovery of the underlying neurochemical imbalance ultimately led to the introduction of levodopa (and later

Sinemet, a levodopa compound) as a therapeutic intervention. Over twenty years later, it is still the most widely used pharmacological agent. However within a few years of its introduction, the limitation of this therapy became apparent. Perhaps most interestingly described by Sacks (1983) was the gradual diminution of the effects of levodopa. During the 1970's and early 1980's, the research primarily focused on development of additional drug therapies.

With the discovery in the early 1980's of an environmental protoxin (1-methyl-4-phenyl-1,2,5,6-tetrahydropyridine, i.e., MPTP) which resulted in a Parkinsonian syndrome, basic science research refocused on the possibility of discovering the etiology of the dopamine deficiency (Langston, Ballard, Tetrud & Irwin, 1983; Ballard, Tetrud & Langston, 1985). For the last decade research has continued in this vein along with efforts to either stimulate growth of new dopamine producing cells or stimulate the remaining brain cells to produce dopamine by laboratory (e.g., growth factors) and experimental procedures (e.g., intravenous levodopa infusions, adrenal and fetal cell transplants in humans) (Goetz, Stebbins, Klawins, Koller, Grossman, Bakay, & Penn, 1991; Pezolli, Zecchinelli, Ricciardi, Burke, Fahn, Scarlato, & Carenzi, 1991; Cadet, Zhu, & Angulo, 1991; Sage & Mark, 1992).

Ultimately research in the basic sciences may lead to a clearer understanding of the etiology of the dopamine deficiency and ways to prevent loss of dopamine containing neurons. This certainly has ramifications for those at risk for developing Parkinson's disease. However, what the ramifications will be for persons who already have lost a significant portion of these neurons and the resultant, accompanying loss of motor function, is unclear. It does not seem likely, within the immediate future, despite current basic research efforts that those who have lost significant motor functioning will recover from that loss. Thus, while the efforts in the basic sciences are noteworthy, the implications of their work for people living with the disease are unclear.

Depression and Parkinson's Disease

The second major area of study in the bio-medical literature focuses on depression and Parkinson's disease. Literature reviewed over the last two and a half decades (1967-1993) addressed the following questions related to depression: (1) What is the incidence of depression in Parkinson's patients versus other chronically ill people and/or those non-chronically ill (Warbuton, 1967; Marsh & Markham, 1973; Horn, 1974; Robins, 1976; Morham, Brown & Marsden, 1986; Kostic, Djuric, Covickovic-Sternic, Bumbasirevic, Nikolic, & Mrsulja, 1987)?; (2) Is depression a reaction to the disability (Celesia & Wanamaker, 1972; Horn, 1974; Hoehn, Crowley & Rutledge, 1976; Lesser, Fahn, Snider, Cote, Isgreen & Barrett, 1979; Todes & Lees, 1985)?; and (3) Is depression biochemical in nature (Mayeux, Stern, Cote &

Williams, 1984; Santamaria, Tolusa & Valles, 1985; Santamaria, Tolusa, Valles, Bayes, Blesa & Masana, 1987)? While the answers to these questions remain controversial, it is generally accepted that depression is a common problem associated with Parkinson's disease although the etiology remains unclear.

Primarily this literature has attempted to pin-point a single explanation for the occurrence of depression in some people with Parkinson's disease. Variables such as disease severity, disease duration, age of onset and gender have been exhaustively studied but have failed to be consistently linked to depression. Lacking in this research has been an exploration of the illness from the perspective of the person. For example, researchers have measured disease severity by using established Parkinson's scales. While on a scale the disease may be rated as mild, this may not be the lived reality. The person may no longer be able to do their job or manage their career as they once did even though by a scale measure their disease is mild. Thus, Parkinson's disease in the depression literature has been studied as a disease from the practitioner's perspective and not from that of the person. Kleinman (1988) made a very clear distinction. Disease is the problem from the practitioner's viewpoint (an outsider), it is the alteration in structure or functioning. Whereas illness is how the person lives with and responds to symptoms and disability. The depression in Parkinson's literature gives a disease perspective but fails to examine the illness or the person's perspective on the illness.

Psychological Adjustment Literature

Review of this literature revealed a handful of studies which examined responses to and adjustment to Parkinson's disease. Although no study specifically examined middle aged people, these studies will be summarized as they may illuminate some of the issues in living with Parkinson's.

With the introduction of levodopa therapy in 1970, Singer (1973, 1974a, 1974b, 1976) undertook a 9-month longitudinal study of 149 patients to evaluate the "social and economic consequences" of this new drug. Singer found people with this disease: often felt embarrassed, bored and lonely; were socially isolated; had given up many social roles and were less likely to be working or participating in household management. In addition, younger patients (55-64 years) felt more stigmatized and distressed than older (> 65 years) Parkinson patients.

Pinder (1988) studied the daily contingencies and demands of living with Parkinson's for 10 subjects, aged 54-75 years. She found a central demand was "balancing". This included balancing the side effects of drug therapy against control of disease symptoms. Another major aspect was balancing the drug regimen around the activities of daily living.

Dakof and Mendelsohn (1989) studied 44 individuals with Parkinson's and their spouses. They found all persons were bothered by how their illness affected their daily activities including work, leisure and social activities. Individuals were clustered according to similarities in their adjustment. They were categorized and labeled as follows: (1) sanguine and optimistic (N=16), (2) depressed and worried (N=11), (3) depressed and misunderstood (N=6), and (4) passive and resigned (N=7). Patients who made up for the four clusters were similar to each other with respect to education, income, gender, disease duration and existence of other chronic illnesses. Patients in Cluster 3 were younger (cluster 3 mean age 60.5 as compared to mean age of 65.25 of all participants) and overall more objectively impaired than patients in all other clusters. Dakof and Mendelsohn (1989) concluded more seriously impaired patients responses seemed to be directly related to their physical condition. Whereas the more mildly impaired patients responses were related more to their beliefs and resources. Thus, the context of the disease may be a crucial factor in the meaning, appraisal and psychological consequences of this chronic illness.

These studies have demonstrated what some of the issues in living with Parkinson's might be. Both Dakof and Mendelsohn (1989) and Singer's research (1973, 1974a, 1974b, 1976) suggest the younger person may experience more problems with feelings of stigma, being misunderstood, and being socially isolated. It is alarming there are so few studies in this area. Our understanding of what it is like to live with this chronic illness is very rudimentary. There is a greater need for further study particularly with middle aged people with Parkinson's.

A Phenomenologic View of the Person

The scientific literature reviewed deals with explaining the disease. These scientific studies view the person as a disengaged subject. The goal of this research is understanding, and the view of the person is that of an engaged participant. This research is grounded in a phenomenologic view of the person (Heidegger, 1962; Taylor, 1985; Taylor, 1989; Leonard, 1989; Benner & Wrubel, 1989; & Dreyfus, 1990). In this view the person is a self-interpreting being. People encounter situations and grasp situations based on meaning. A person has an understanding of the self because they live in a meaningful context and encounter the world in an engaged, involved manner.

Persons live through background meaning; it is how we understand the world although these meanings can never be made completely explicit. Background meaning is provided by our culture, family and our language. These meanings determine what shows up, what matters to us versus what is covered over. Background meanings are not private or idiosyncratic but rather are shared, public meanings.

What is crucial about persons is that things do matter,and that perceptions and appraisals are guided by meanings and personal concerns. It is through particular concerns and actions that the person becomes involved with the world. Even in infancy, persons both shape and are shaped by their human world. In studying the meanings and lived experience of persons with Parkinson's disease, I have sought to understand their world, and the ways their world has both shaped the illness experience and been shaped by it.

In this view the body as well as the mind are knowers. Our body first encounters and negotiates the world in a non-reflective manner. We grasp the world with a culturally skilled habitual body. In Parkinson's disease, the body no longer is experienced in a non-reflective, taken for granted manner. The body and what the body cannot do becomes very visible. Participants often spoke of telling their body or a part of their body (such as their arm or leg) what to do. The body was experienced as unwilling or uncooperative.

Summary

In this chapter I have attempted to lay the foundations and framework for this project. The scarcity of research related to the experience of Parkinson's, particularly in middle-aged persons along with how the illness has been conceptualized in literature has been discussed. This work broadens the discourse on what it is to have a chronic, degenerative, progressive illness. It changes the dialogue from one of predictive variables related to outcome to a dialogue of understandings, demands and how people cope with the realities they face. In the next chapter I will describe the interpretive methods utilized in this research.

CHAPTER 2

The Research Approach

This chapter begins with a discussion of the research approach including philosophical assumptions which underlie the method. This is followed by a description of the participants and the data collection procedures utilized. Data analysis and issues related to evaluating an interpretive account will be addressed.

Hermeneutics

The research approach utilized in this study is hermeneutical or an interpretive approach. Hermeneutics is an ancient discipline, originally developed as a tool of biblical exegesis. Hermeneutics, as discussed in this chapter, derives heavily from Heidegger (1962, 1982). Through his writings and others the relevance of hermeneutics to the human sciences has been made explicit (Benner, 1985a; Benner & Wrubel, 1989; Leonard, 1989; Packer, 1985; Packer & Addison, 1989; Van Manen, 1990, Dreyfus, 1990).

Hermeneutics aims at understanding everyday skills, and practices and finding commonalities in meanings (Leonard, 1989). The goal of this approach is to illuminate and explicate the everyday experience and practices of the person under study. The challenge with this method is to uncover the meanings and concerns in such a way that they are not decontextualized. It was the method chosen because it provides the ability to understand the world and experiences of the person with Parkinson's disease. This study was concerned with studying the illness experience within the context of the disease process. Clinical ethnography, as a form of interpretive phenomenology, was utilized to gain in-depth, "thick", rich descriptions from participants (Benner, 1985a; Doolittle, 1990). Clinical ethnography supports studying the relationship between the bio-medical disease process and the personal illness experience.

Several assumptions, derived from a Heideggerian philosophical stance, underlie the research approach. First, the researcher has a preliminary understanding of the human phenomena being studied (Leonard, 1989; Packer, 1985; Packer & Addison, 1989). Because the researcher shares with the informants a common culture and language, she approaches the phenomena or action being studied with some understanding. However the hermeneutic method aims at progressive uncovering and explication of this understanding. By "pushing" this understanding through attending to what is pervasive, similar, problematic, contradictory or incoherent, the understanding will be richer and more comprehensive. There is no terminal point to this understanding. There are always possibilities for change or transformation in understanding. Resolving contradictions, confusion and attending to what may previously have been screened out, offers possibilities for enriching our understanding (Taylor, 1989). The interpretive process does not come to a final resting place. Because it works off the common, taken for granted background meanings, habits and practices, these background meanings can never be spelled out completely. The background is always making aspects of the clearing or foreground visible.

Second, there is no one outside detached viewpoint from which we gather and interpret data (Taylor, 1987; Rabinow, 1987). A privileged position which is atemporal, ahistorical or acontextual is impossible. The researcher is involved and constituted by a world as is the participant. For Heidegger (1962), Taylor (1987) and Packer and Addison (1989), this means as soon as we begin an inquiry we are caught in the "hermeneutical circle". The only way out of the circle would be to find "brute", simple, eternal data which could be agreed upon by all (Taylor, 1985). But this could not happen because we can never stand outside of the human situation. Rather we live in a world of meaning and significance that constitutes us and what we are able to see. Also this world is capable of change even as a result of research.

Finally, the aim of this approach is to explicate context and world as opposed to uncovering universal laws or extracting theoretical terms or concepts to a higher level of abstraction (Benner, 1985b; Rabinow & Sullivan, 1987). The goal is not the development of formal, testable theories. But rather to discover meaning and to achieve understanding as a form of explanation appropriate to self-interpreting agents (Taylor, 1985).

Interpretive inquiry must not be misunderstood as "just an effort to describe, or even just understand human phenomena" (Packer & Addison, 1989, p.229). Interpretation always arises from being engaged in a world of meaning and significance. To do hermeneutical research is to question the way we experience the world, to explore aspects of the nature of being, and to ask meaning questions (Van Manen, 1990).

Research Aims

In this study I was primarily interested in how the person with Parkinson's disease understands their illness and how this understanding shapes personal meanings and coping patterns. Specifically, the research aims were: (a) to examine and describe the individual's practical understanding of Parkinson's disease and self-described relationship to the illness, (b) to explicate the discontinuities and losses experienced as their disease progresses, (c) to examine coping strategies utilized, and (d) to explicate the practical knowledge gained experientially as a result of living with the illness. The goal of the study was to explicate the *experiences and realities* of having this chronic, progressive illness in middle life.

Sample Description

Sixteen individuals participated in this study. Of the sixteen, eight had a partner or spouse who participated. The partner data will not be presented in the dissertation but will be dealt with in later writings. Occasionally the partner's narrative may be referenced if it adds a richer understanding to a particular concern raised by the individual.

The participants were recruited from neurology practices and Parkinson support groups throughout the Bay Area. All participants met the following criteria: (a) 40-60 years of age, (b) had been diagnosed for at least one year, (c) on anti-parkinsonian medication and (d) had no other neurologic disease. Table I summarizes demographic information about the participants.

Participants ranged from ages 42 to 59 with a mean age of 48. Nine of the participants were married, although one of which was recently separated from her spouse.

There was a significant range in the number of years since diagnosis. Almost two-thirds had been diagnosed less than five years (11/16), nearly the remainder being diagnosed less than ten years (15/16). There was one participant who had been diagnosed sixteen years. These numbers document length of time since diagnosis. Many participants spoke of having symptoms for 2 to 3 years prior to diagnosis. Only 6 participants were working outside of the home (3 men, 3 women). Nine participants by their explanations had stopped working because of their disease.

Participants were recruited from two neurology practices and several Parkinson's support groups. From the neurology practices, individuals were identified by office staff who met the criteria for age, length of diagnosis, medication requirements and geographic location within the Bay Area.

Additionally, since one of the physicians was multi-lingual, the practice included patients who were not fluent in English. This information was available in files and these individuals were screened out due to the investigator's language limitations. A letter was mailed by the staff to nine individuals explaining the study and requesting the stamped postcard be returned to the investigator if interested in being contacted. Three letters were returned as undeliverable with no forwarding address. Of the six potential responses, five returned their postcards. One gentleman on screening was not included as it was unclear if his disease was idiopathic Parkinson's or a drug-induced Parkinsonian syndrome. Another potential participant declined as she anticipated moving out of the area within a month or two. Thus three individuals were recruited from the practices, with the remainder of the participants (13) being recruited from one of three Bay Area support groups. Nine of the thirteen attended support groups but an additional four responded to announcements placed in support group newsletters. These four individuals had never attended a support group but did receive mailings.

It is difficult to estimate a response rate from the support groups as one can not determine the actual number of people who would meet the study criteria in each group. Each of the support groups was visited once where the investigator made a brief announcement about the study. People either returned the postcard by mail or provided a phone number for contact while at the meeting. The greatest number (6) were recruited from a group aimed at "Young Parkinsonian's". It was the investigator's sense (as accurately as one can estimate age visually) that the majority of people in attendance who met the age criteria volunteered to be in the study.

All potential participants were screened via telephone for the study criteria. The Mini-Mental Status Questionnaire (MSQ) was administered to screen for dementia (Kahn, Goldfarb, Pollack, & Peck, 1960) (Appendix A). This tool did not result in any potential participants being excluded as they all scored at an acceptable level (either 9 or 10). After phone screening an initial appointment was set at which time any further questions were answered and written consent was obtained.

Data Collection

Participants were interviewed on 3 occasions during a three month period. Interviews on the average lasted one hour to 1 1/2 hours. The investigator believed it was essential to have multiple interviews in order to assure that themes were reoccurring and to provide sufficient data for patterns to emerge in individual cases. The investigator was sensitive to the issue that some of the questions might be emotional and difficult for the participants. A significant part of the first interview was spent getting to know the person by asking about their background, childhood years and family life. It was hoped this would be a comfortable starting place for participants. It provided an opportunity for the investigator and the participant to establish a rapport in a non-threatening manner. Not fully anticipated prior to data collection was how helpful this data would be in explicating different coping patterns.

The majority of the interviews took place in the participant's homes. Interviews were tape recorded and transcribed verbatim. In almost all cases the transcription was completed prior to the next interview. This allowed clarification of earlier interview material at the second and third interview.

Field notes were also kept by the investigator relative to the setting of the interviews and other information such as observed interactions with spouses or family members. The investigator also kept a diary related to her interviewing skills and her emotional response to the participants and the study as it progressed. Many of the interviews required driving for about an hour. Frequently after the interview, the investigator would dictate her field notes while traveling thus capturing thoughts and reflections while the interview was fresh.

Interviews

At the time of the first interview, demographic data were collected (Appendix B). In addition, the Modified Hoehn & Yahr (Hoehn & Yahr, 1967) and the Schwab & England Activities of Daily Living Scales (Schwab & England, 1969) were administered (Appendix C & D). Table 2 summarizes the participant's scores on these scales.

The first interview focused on life history, illness understanding and paradigmatic coping episodes since being diagnosed. (see interview guide, Appendix E). The first interview tended to be semi-structured initially when discussing background and life history. As the interview began to focus on getting diagnosed and their understanding of the illness, the interview became less structured. Participants needed less probing. They told their stories with minimal direction. The interview guide was utilized to ensure that all areas were discussed. Different aspects of the guide was influenced and adapted from the works of Kleinman, Eisenberg & Good (1978), Benner (1984b), and Chesla (1988).

The second interview focused on the lived experience, coping episodes and social support (Appendix F). Typically this interview was 4-6 weeks after the first meeting but it varied depending on the participant's schedule and needs. Often when participant's were asked to describe an event or situation that went well and one that was difficult since we last had spoken, they provided more than one example of different coping situations. It was not uncommon by the second interview for participants "to have thought of some thing" that they wished to discuss. Thus time was always provided to discuss any concerns that did not get prompted by the interview guide. The interview guide was influenced by

Benner (1984b) and early pilot work with this population by the investigator.

The third interview focused again on recent coping episodes along with issues related to the future (Appendix G). For many participants, this interview was emotionally difficult as it addressed concerns about an uncertain future. As an investigator this interview was essential as it often was pivotal to uncovering meanings and concerns.

Data Analysis

Initial analysis began with data collection. As individual interviews were completed, transcripts were read and re-read for commonalities. Major interpretive work began after a significant number of participants had been interviewed. This process continued through the remainder of data collection and the writing process itself.

Three interpretative strategies: thematic analysis, exemplars and paradigm cases, provided strategies for recognizing meanings and patterns in the text (Benner, 1985b). It must be emphasized this is not a linear process but rather circular in nature (Packer & Addison, 1989).

In thematic analysis, each case was read through several times to gain a global, preliminary understanding. Attention was paid to understanding the person's context and situation. After reading several cases in this manner, initial themes were formed. These preliminary and rudimentary themes (ex: future hopes and fears) resulted from the initial research questions and common issues which emerged from the data. The remainder of cases were then read with these preliminary themes as a framework. However, the investigator was cognizant to remain open to the data and focus on text that was incoherent or contradictory. Other themes emerged as new cases were read and earlier cases re-read. A computer program, MARTIN, was utilized to facilitate storage and retrieval of the data by identified themes (Diekelmann, Lam & Schuster, 1991).

Exemplars are stories or vignettes that are a strong example of a meaningful situation or transaction. Many exemplars existed in the data, an example involved being diagnosed. These sections of the data were read in their entirety. Whereas the events surrounding the diagnosis varied greatly, common meanings emerged by carefully reading these vignettes. Listening to the participants including what they thought was going on, how they felt, what they did, what they were most concerned about and how their responses changed with time explicated the meaning of being diagnosed.

A paradigm case is a strong instance of particular patterns of meaning (Benner, 1985b). Paradigm cases were pivotal for this investigator to understand the experiences from the participant's viewpoint. While thematic analysis uncovered preliminary common themes, it was through the paradigm cases that the investigator recognized ways of being with an illness and ways of coping. The paradigm cases provided the access to an insider's account rather than an outsider's. Thus, four paradigm cases will be presented in the chapters immediately following.

Evaluating Interpretive Work

The issue of evaluating qualitative research has been the discussion focus in recent nursing literature (examples Beck, 1993; Kahn, 1993). Kahn (1993) points out there are currently two discourses about validity in qualitative nursing literature. One involves using language analogous to that used in quantitative research (Beck, 1993; Sandelowoski, 1986). Another approach is to discuss a metaphor, the use of self as a research tool (Lipson, 1989). Kahn (1993) proposes an alternative way of discussing validity. He suggests the investigator needs to discuss three key relationships: the relationship of investigator with informants, the data and the reader. It is likely the discourse on how to evaluate qualitative work will continue for awhile, much as the relevance of qualitative research for nursing science continues to be discussed. I have chosen for this chapter to narrow the discussion to how one can evaluate an interpretive study and specifically what I did as an investigator to attempt to ensure credibility.

One can not discuss evaluating an interpretive account without being mindful of the aims of this type of investigation. How one evaluates or judges an interpretive account must be appropriate for the methodology. Interpretive methods aim at uncovering or "letting-something-be-seen"

(Heidegger, 1962, p.56). Inquiry arises from a concern, a question or problem which then directs our research.

There is no way to "validate" an interpretive account as validation assumes there is "a way things really are" (Packer & Addison, 1989; Madison, 1988). Rather than validating Packer & Addison (1989) suggest ways of considering whether what has been "uncovered" answers the concern or question which motivated the inquiry. A good interpretation answers the concern, the problem or the breakdown in understanding which directed the research. The account offered should be plausible, fit with other available material, be convincing and have the power to change practice.

Several strategies were utilized as part of this research to ensure the credibility of the work. First, the study was designed with multiple interviews of each participant. This helped prevent the researcher from focusing on nonrecurring themes.

Multiple stages of interpretation occurred. Hirsh (1967) has stipulated the "fundamental difficulty" with interpretive work is that the perspective the investigator brings to the inquiry shapes the reading of the text. He claimed researchers find evidence which supports their perspective and ignore evidence which questions the perspective. There is no doubt as an investigator with a clinical background with this population I entered the inquiry with a pre-understanding. But by revisiting text over and over, reading from different perspectives, checking for cases that didn't fit and looking and dwelling with text which didn't make sense, one is forced to challenge initial understandings. Another related strategy I used involved the paradigm case of Mr. Suyigami (Chapter 4). His case was a sharp contrast to the other cases in many ways. I recontacted him by phone to ask more clarifying questions which ultimately helped me gain a different access to his interviews.

Early interpretations were presented to two different Parkinson support groups. Non-verbal (such as nodding during the presentations) comments, questions and other verbal feedback indicate the interpretations could be identified with and rang true to them.

Ultimately an interpretive report should elucidate the lived experience of the participants (Sandelowski, 1986; Van Manen, 1990). Readers must be able to evaluate it for consistency with their own experiences, it should resonate with a sense of life. Van Manen (1990) has described a good phenomenological description as something we can recognize as an experience we have had or could have had. A good interpretation is capable of being extended. The interpretation raises questions that can stimulate further research and interpretation (Gadamer, 1976).

Interpretation is more than procedural techniques in the sense one can not become a good interpreter simply by mastering certain steps. This does not imply that it can not be a rigorous approach. The goal is not to arrive at definitive explanations that stop the conversation. As Taylor

(1987) cautions the ideal of a science of verification belongs to the natural sciences, not the human sciences. "There is no verification procedure that we can fall back on. We can only continue to offer interpretations; we are in an interpretive circle" (Taylor, 1987, p.75). Although Taylor (1989) cautions there is no one absolute interpretation, one interpretation can be superior to another. If one can show an interpretation has gone through a transition and in doing so has resolved a contradiction, this constitutes a gain epistemically. Also if the account provides a richer, more comprehensive explanation, then it can be judged or evaluated as superior (Taylor, 1989).

Van Manen (1990) has described hermeneutics as attempting to accomplish the impossible. The aim is to construct a full interpretive description of the lived experience but yet to remain aware the lived experience is always more complex than any uncovering of meaning can reveal.

As a researcher I have attempted to have my understandings and perspectives, challenged and questioned. The account which follows attempts to answer the practical concerns and questions which motivated this research.

Summary

This chapter discussed the interpretive approach and presented the specifics of the study. Chapters 3 through 6 present four paradigm cases. These are followed by a discussion of the demands experienced by the participants relative to their illness and it's impact on roles, relationships and identity. Chapter 8 describes different ways of coping and how this is influenced by the participant's understanding and self-experienced relationship to the illness. Finally I conclude with the implications of this work for clinical practice.

TABLE 1

Demographic Information

Participant *	Age	Age at Diagnosis	Duration of Illness	Primary Support
1. Mr. Suyigami	59	51	8	none
2. Mrs. Hampton	46	30	16	husband
3. Mr. Timmons	59	55	4	wife
4. Mrs. Egan	57	53	4	husband
5. Mr. Nickel	57	49	8	wife
6. Miss Ryan	57	53	4	roommate
7. Mr. Smith	42	36	6	girlfriend
8. Miss Laird	54	53	1	roommate
9. Mr. Brown	50	43	7	wife
10. Mrs. Dunn	50	49	1	husband
11. Mr. Howard	55	51	4	none
12. Mrs. Carroll	50	46	4	daughters
13. Mr. Miller	44	42	2	wife
14. Mr. Shimer	49	47	2	friends
15. Mr. Francis	49	47	2	wife
16. Miss Carson	44	41	3	friends

*Pseudonyms have been utilized

TABLE 2

DISEASE SEVERITY INFORMATION

Participant	Hoehn & Yahr (Appendix C)	Schwab & England (Appendix D)	# of ** medications
1. Mr. Suyigami	2.5	90-80	2
2. Mrs. Hampton	3	90-30	3
3. Mr. Timmons	2.5	90	2
4. Mrs. Egan	1	90-80	2
5. Mr. Nickel	3	90-80	3
6. Miss Ryan	2.5	80	3
7. Mr. Smith	2	90-50	3
8. Miss Laird	2.5	90-80	2
9. Mr. Brown	2.5	90-50	4
10. Mrs. Dunn	1.5	100	2
11. Mr. Howard	2	90-80	2
12. Mrs. Carroll	3	60	2
13. Mr. Miller	1	100	2
14. Mr. Shimer	2.5	60	2
15. Mr. Francis	2.5	80	2
16. Miss Carson	1	90-80	3

* Two numbers indicate ranges or fluctuations in activities of daily living. The higher number indicates when the person is functioning at their best, the lower number indicating when they are functioning at their worst level.

** Refers to number of anti-Parkinsonians medication they take.

CHAPTER 3

Paradigm Case: Staying Alive and Living Life to the Fullest

Mary Hampton was 46 years-old. Of the participants in the study, she had Parkinson's disease the longest (16 years) and had been diagnosed at the earliest age. These unique factors were not what made her so memorable though. Mary's physical symptoms fluctuated dramatically. From minute-to-minute, hour-to-hour, day-to-day; she vacillated from being unable to move to not being able to stop her movements. As a clinician of many years I have never witnessed such astonishing swings back and forth in symptoms and functioning level. Driving up to her home for the interviews, I wondered if she would be in her words "on", "dead in the water", or "too much". One morning she unlocked her front door before my arrival because she began to "experience resistance" and knew she would not be able to get out of the chair when I arrived. I found her sitting at the kitchen table very stiff, motionless, and with little expression ("dead in the water"). About 20 minutes later, she was in motion ("too much"). Standing while speaking her body was in constant motion rocking back and forth, her arms and legs flailing uncontrollably. This lasted for an exhausting 1/2 hour although Mary said the periods could last for an hour or two several times a day. The constant motion was followed by a period where she was able to move without much extraneous or involuntary movement ("on"). By the end of the interview, approximately 1 1/2 hours later, she was again "dead in the water" with her voice barely audible. This is how Mary fluctuated daily.

Mary was memorable for her personal strength. She was engaged fully and enjoying her life. Despite the radical changes which had occurred as a result of the Parkinson's and were continuing to occur in her functioning and abilities, Mary was satisfied with her life and found it meaningful. To understand the experience of Parkinson's for Mary, entails knowing what matters to her and what is salient for her. I therefore will begin to introduce Mary's story by describing her family background and her life prior to Parkinson's.

Background

Mary grew up in a close knit family, the eldest child of a Methodist minister later turned professor of theologic seminary, and his wife. Her sibling was a deaf brother, 16 months younger. She described their relationship:

> "And we grew up best buddies. For a long time I was the only one that could understand him...I just intuitively (knew) what he wanted. And I interpreted what he wanted."

Her mother was also very involved with ministry. She, along with her husband, wrote Sunday school materials for deaf children. The influence of her deaf brother and her parents involvement in deaf education was evident in Mary's initial career training. After college she obtained a masters in education of the deaf. She taught in this field for two years.

Mary met her husband of greater than 20 years, Steve, during college. They both attended a small religious-affiliated college in the midwest with an extensive service orientation. They married after college, relocated to the East for graduate school for each of them. After Mary graduated, she taught briefly:

> "I taught the year after that and I was pregnant with my first kid who was born 2 weeks after school got out. And so I quit for a year and a half or so and got a call in the middle of the year to help. "One of our teachers is pregnant and her doctor won't let her work, continue working, can you fill in?" So I filled in the rest of that year. And then we moved out here. And I had not a particularly good experience teaching. I did not enjoy being a first time teacher and when I filled in I substituted, I was doing it at a whole new level, so I was not continuing what I'd done the first time. So I experienced two first years of being a new teacher and then I just didn't want to do that again. So I basically lost contact with the field.

Influences from Mary's upbringing and young adult years are evident in her present day life. Mary was raised in a family where children were valued and the family centered around children. Her experiences with her parents and the way she was raised resulted in a strong commitment to family and parenting. This was a shared value for her and Steve.

> "The most important functioning we have as adults is being parents, good parents. And so he appreciates parenting, and all the energy and the time...He is very family oriented."

The importance of their children in her life is evident throughout Mary's narrative. Her children, though college-age now and no longer living with them, remain very central to who Mary is. During our last interview Mary expressed how excited she was both children were going to be home for the summer. Mary has also continued to have a close relationship with her parents who were now retired and living in the Midwest, Mary and Steve try to visit once a year. They made one of these trips during the study and had an enjoyable time. Mary has remained especially close to her mother in recent years. Approximately six years after Mary was diagnosed, her mother was diagnosed with Parkinson's. After returning from visiting, Mary compared how the Parkinson's affects her versus her mother, identifying different indicators of progression.

> "She has a lot more balance problems than I do. Again, I think she--I would have said until this last visit that she had progressed quite a bit further than I did. But on the other hand, she doesn't seem to have the real dead periods that I do. When we're doing dishes, if she's not functioning, she's slow. I am not there. I am just not moving. So this was something new that I had caught up in a different way".

Mary was raised in a people and service oriented family. Her father's chosen career, her mother's involvement in deaf education and ministry are examples. This orientation was reinforced during her college years. The college she attended encouraged involvement in education and service and her graduating class had the highest percentage of volunteers to foreign service of any college in the country. A valuing of "giving something" and a strong people orientation was evident in Mary's narrative. She spoke with great pride of her daughter, who was attending the same college, recently returning from 5 months of volunteer foreign service.

When her family relocated to California, Mary had anticipated being an active faculty wife at the institution where Steve taught. Her mother had held such a role in the seminary, and at both the college and graduate school she attended, the faculty wives were involved in student activities. Thus when Steve began his position, Mary looked forward to university functions, student picnics, faculty gatherings and social events being an integral part of her life. She explained this did not exist at the institution though.

> "There was no community and that's what I had anticipated, was the community, and it didn't exist. So that sent me looking for other things. In part I found it with nursery school. I developed some real good friends there. And in part it left me hanging. So that's when--It left me open to doing other things."

In addition to her nursery school involvement, she became reinvolved with the League of Women Voters, a group she had been active with while living in the East. Her previous experience with this group had been that they could effect change on a community and societal level. Thus she was married with two young children, involved in voluntary organizations when Parkinson's entered into her life.

Getting Diagnosed: "What is it? What is it?"

Mary turned 30 the month before being diagnosed. She began experiencing stiffness of her right index finger and thumb which she attributed to "stress from being on the board" (nursery school) and thought it would resolve after her term was completed. She had mentioned it to her internist during a routine visit but he did not think it was significant. Over the next several months she noticed her handwriting seemed slower especially when writing checks. On a visit to her parent's home she noted that her runs on the piano were slightly slower. Then she noticed particular movements were not automatic.

> "I would put my hand up to wave goodbye and I 'd put it up and it wouldn't wave. And that was a peculiar feeling. I could lift it and it wouldn't automatic--And I'd think wave. Oh, yeah. I had to consciously do it. Scrambling eggs--for some reason, "How do you do this?" and then I could think it through and do it."

She found herself consciously thinking how to do things in order to make them happen. Her taken for granted pre-reflective movement was not available to her. At this time she returned to her internist who referred her to a neurologist that gave her the diagnosis. She described it this way.

> "He said, "You have a neurological condition that will probably deteriorate over time. There are medications available." And so I kept thinking the minute he said "You've got a problem" in a sense, "What is it? What is it?" so I wasn't listening to his patter. I wanted a name put on it. I wanted a label. And so finally he said it's Parkinson's disease. And I knew (as I say), the most I knew about it was little old men who shake. And I guess my immediate response to him was "Can I drive my car home?""

The neurologist suggested she begin drug therapy and return in three months. Mary refused, she was overwhelmed having no true idea of what Parkinson's was.

> "The only thing I remember is sitting there hearing him talking, thinking what is it? What is it? What is it? If he had said it was Parkinson's from the

> beginning I might have gotten, I would have known and then I could have listened to him. There were all sorts of words going past me. That I didn't begin to hear. I didn't hear at all."

She shared the diagnosis with her husband who also knew very little about the disease. They contacted relatives who were in health care whose initial responses were "You can't" because they associated Parkinson's with older people. Mary, accompanied by Steve, obtained a second opinion a few weeks later. In the interim, they had begun reading on various neurologic conditions and had decided Parkinson's was one of the better options. As she said:

> "I hope it's Parkinson's. I mean it could be worse than that. It could be a brain tumor."

When questioned about Parkinson's being a better option, she explained:

> "This was like a 3 week period, 3 or 4 weeks as I remember, before we could actually get into him. And so by this time, Steve had done a lot of reading and came home and explained what they knew at that time, in 1975, Sinemet had just come out. So they were that far into knowing what was going on."

It was reassuring to Mary that the underlying physiologic problem was known. She contrasted this to the lack of knowledge related to multiple sclerosis (MS), a disease a good friend of hers had. She had solicited from her friend the symptoms she was experiencing when she was diagnosed.

> "Her symptoms were an inability to step where she was anticipating. This was one of the first things she experienced. And so I knew I could step where I wanted to and so when he had me walk across the room, I was thinking I don't have MS. I'm not going to have MS cause look I can walk right. Not realizing at that time that my right arm was

> absolutely rigid and non-swinging. I had not been aware at this point that this was a symptom. But I was just holding it, cradling it, typical Parkinsonian. So I demonstrated for him very vividly."

The diagnosis was confirmed at the second consultation.

The next several months for Mary were times of many emotions and mixed feelings. She embarked upon reading everything she could find about Parkinson's disease.

> "I wanted anything I could get my hands on because I didn't want anybody knowing something about Parkinson's that I didn't know. I wanted it out in the open in terms of my understanding of what was going on."

This "I want to know" was supported by her husband. Steve read the professional literature.

> "He came home, I remember, drawing axons, neural axons, and explaining chemical transmitters to me and I can still see his little drawings. So I found I had a tutor at home...He came home and he said, if you have to have a disease, you've got a real interesting one. Well, I mean that was his response. Boy, have you got something interesting. Wow. And because he responded that way, was so much better than Oh, my God."

His response balanced some of the fears and concerns she was developing as she read lay literature from the various parkinson organizations.

> "And I can remember in some of the literature, in fact, all the literature that I was given by the doctor that came from all the various organizations was now that you are on new medications and are unfreezing for the first time, it was addressing people that had Parkinson's for twenty years without medication and were now being put on Sinemet and were regaining. Well, here I was chasing nursery schoolers around, doing all these things and this had no reality and relationship to me whatsoever. And I can remember laughing with my mom over the phone, I wish it'd say you don't have to clean your oven. You know. They say take it

> easy but they don't say don't clean your oven or don't chase your five year-old down the hall."

She recalled being deeply concerned about how she would function physically with her children and what impact it would have on her relationship with her husband. His initial response and his continued responses of focusing on the positive made her fears subside or as she stated "I wasn't having my nightmares come true".

The week she was diagnosed Mary decided to go to law school.

> "I simply said "If I've got this problem, I don't know how long it's going to be a problem. I've always wanted to go to law school. Let's start exploring the possibilities." So I did. And then I entered law school the next Fall."

In addition to having always wanted to attend law school, her involvement in the League of Woman Voters had influenced her decision to apply. In addition, a close woman friend of hers was applying to law school. Several months prior to being diagnosed she had investigated review courses for the LSAT. Getting the diagnosis and not knowing what the future held served as a catalyst for applying. Steve's encouragement to "do it" along with her friend applying provided legitimacy and direction. Mary recalled concerns about the future when she made the decision to apply to law school, although she admitted she did not have the "full picture" about Parkinson's and it's trajectory.

> "I don't remember any more at what point I got the full picture. I don't think it really happened until I began seeing what this looked like. And one of the first times, they had a symposium put on

> by a Parkinson foundation. Let's see, we're into 75ish. It may have been in '75 or '76. And that's the first time I had ever seen a really affected Parkinsonian who couldn't walk."

That coupled with meeting an elderly woman from her church who visited Mary regularly for awhile helped provide the "full picture".

> "And she would explain her symptoms and there I was chasing nursery schoolers around and going to law school and writing motions and it was kind of unrelated to what was happening in her life because she was getting very stiff and a lot of advanced stages of Parkinson's."

Mary identified a problem for the younger onset person. Most of the people with this disease are older and therefore many of the resources available (such as symposiums, reading materials) are geared towards that age group. Her concerns and her life were very different than that of the 60 year-old woman who visited.

In the first several months after being diagnosed, she explained there was a constant awareness of the Parkinson's.

> "Something had defined me in a new way and it took me. I just remember being aware that I have Parkinson's. And just sometimes it would be a refrain. It wouldn't be a matter of dealing with the world. I won't respond differently but just I've got Parkinson's. I've got Parkinson's. I just remember being aware, that I could not forget. It was a matter of trying to forget it at times and not being able to."

Mary continued with all her regular activities and relationships although they were tempered by repetitive thoughts about her diagnosis. She remembered a specific turning point to this continual consciousness and a sense of the burden lifting several months after the diagnosis.

> "I was sitting studying for the LSAT and all of a sudden it occurred to me that "Hey, this is going to be okay." And it just--It's kind of like a burden lifting. And I had been under a shadow as I felt looking back on it. I don't think I had been depressed in terms of functioning or affecting my relationships with anyone else but I just suddenly felt better."

In retrospect Mary realized she had been overwhelmed by the diagnosis and its potential impact on her family's life. She spent the first several months reassuring herself everything would be alright, she was no different than before except now she knew what she had, and that Parkinson's was better than many other neurologic conditions she could have. The moment she described was a turning point. Having Parkinson's no longer dominated her thoughts. She knew everything would be alright no matter what happened. This moment represented a moving into a new way of being with her illness. Her understanding changed from burden and impossibility to one of situated possibilities.

Mary's retrospective account does not include a "why me" aspect.

> "I have talked with other people, young Parkinsonians, and they're angry. And I don't honestly ever remember feeling anger. I remember being afraid and ignorant, this feeling of tell me cause I want to know. And this sense of depression I realized after the fact that hey, this is going to be okay."

While it is possible many years later her recollection of anger has faded, more likely anger is not a feeling that she sanctions in relation to being ill. Possibly having faced her brother's disability confronted her with the possibility of illness without blame. She recalled her feelings of fear and ignorance vividly. She also recalled feeling an initial false sense of control.

> "I went through well, I know my fate. I'm going to have Parkinson's. Then I had to go through the realization I could also get cancer, have a heart attack, you know, do all these other things, and this was kind of a mind game that I have playing with myself. Sort of like the future is now mine to control because I know what I've got. And then I realized it ain't that way."

Because of her family and strong support from her husband, Mary was able to move from a position of burden to one of possibilities. Her family pulled her in to seeing possibilities within her situation. She was able to remain engaged in her life despite the changes and losses she experienced. She came to see Parkinson's as the particular challenge within the context of her concerns, meanings and goals.

> "I would have to relate to people whether I had Parkinson's or not, I would of had to raise kids whether I had Parkinson's or not. If I hadn't dealt with Parkinson's, I might have dealt with cancer, heart disease or kids getting into trouble or not getting into trouble. It's been the particular challenge at this particular time, that I've dealt with."

Mary went to law school part-time for four years. These were busy, hectic years.

> M: "When I started law school I really couldn't write well. So what I did is I taped all my lectures and then I'd come home and I could still type, and I would transcribe everything."
>
> I: "That's very time consuming."
>
> M: "Oh, it was very time consuming. It doubled the amount of time for each class. But it was the only

> way I could feel I could do it adequately. And that's what I did. That was my job. I would--I was going to night school so I would study all day and the kids would come home around 2:30 or sometime, and they would be here. And I got really good. I studied in the bedroom and I got really good hearing when it got too quiet. And I was home and they always had a mom at home, which I was comfortable with. And then Steve and I would literally play touch tag as he would come in and take over. I would have supper ready for him and the kids...I always felt comfortable because the kids were covered. That was important to me and so I managed that".

Mary chose to do part-time evening law school because of the children. She admitted going to school put a strain on her marriage.

> "Because he was bending over backwards so much to be nice and good and giving up his time that I had a feeling he needed to express himself. There were times when I needed him to say, let me do something. Or if I would say, oh, you're not going to leave me with the kids right now? To say, yes I am. I need some time too."

She credited they're surviving these years to a mutual commitment to their children and his wanting her to accomplish law school.

Starting Sinemet: A turning point

For the first four years, Mary took only Symmetral (a dopaminergic drug) for her Parkinson's. This was a common way to initiate drug therapy in the late 1970's. Gradually her neurologist increased her dosage until she was at the maximum therapeutic dose. He then wanted her to begin Sinemet therapy.

> M: "No. No way. I don't want the big guns. I want to hold off as long on that as I can."

I: "Because?"

M: "Well for fear that it would wear off and I was only in my early 30's. And so I put it off but obviously needed something. I was no longer basically writing...I graduated in the summer or the Spring of 1980. Shortly after that I began going downhill and it became clear I needed something more but I still didn't want to be put on the Sinemet. And so during the period I was waiting for the bar results to come in, which came out in December, that Fall I was really having trouble and I can remember sitting on the couch--And thinking "Oh, I want to do this and then I would try to stand up--The mind was going like crazy and had all these plans, and then to begin moving the muscles to execute them was unreal."

How difficult functioning had become was evident when Mary spoke about taking the bar the first time. She had set up provisions to type her exam because she could not write.

> "I had been very careful to make sure I had permission to type and then I find out there's this section which wouldn't count against you, they said, but if you did well it would count for you. Well, I get in there and I find out over the lunch period that we aren't going to be able to type. So I spent the entire lunch period trying to get in touch with the bar examiners and being shuffled from one end of Berkeley to San Francisco all on the phone trying to find out what was going on. And finally the woman said tough. Well, this really upset me. And although I can't blame it for not passing the bar, it certainly didn't help my frame of mind because I was so upset that they pulled this...So I took it under protest and I simply wrote on my paper, and it took me 15 minutes, "I can't write, I protest."

Her voice was quite emotional when she told me this story. She did not begin Sinemet at this point despite her physician's strong recommendation. She tried a muscle relaxant as a last resort to help with the stiffness. She said "it put me absolutely to sleep" but did not help the physical symptoms. She described herself as becoming virtually chair bound. On Saturdays, she watched Steve organize the children to do household chores. As she watched the kids fold the laundry she felt tremendous guilt mixed with relief however things were getting done. It was then looking at her family, she accepted it was time to start Sinemet therapy. Her response to Sinemet took about 6 weeks. She described a vivid response, even remembering the exact date many years later.

> "And so I was taking it, I think it was the end of November. Nothing happened and nothing happened. And then I began the bar review course to retake the bar in January. And I remember sitting in class January 14th...and all of a sudden I felt as--It was kind of like a flow of heat go through my arm. And I could write for the first time...And it was so sudden. I came roaring home. And I said, "I can write! I can write!"

Mary successfully passed the bar the second time and practiced family law for the next four years.

Downhill Trajectory

> "The big change came when I had to stop working. And this was a combination of leaving my practice because Steve went on sabbatical to Washington D.C., and we all went along. And then having the neurologist there say he didn't like to see me in motion at the time. He didn't like what he was seeing. He cut me back (medication) and the result was my on/off periods were much more. I was off a lot more than I had been...My off periods were so unpredictable. It became pretty clear that I wasn't going to be able to function well enough to continue with the law practice."

For Mary giving up law practice was the initial and most crucial change in her life as a result of the Parkinson's.

> "It was kind of a blow to my ego not to--It's a very heavy thing to be able to say to somebody, I'm

> an attorney. It's a power trip, to be perfectly honest. And so that in a sense is gone, although still I was an attorney sounds nice. On the other hand, I was never much of an attorney. I didn't have that long of a time in practice. My war stories are very few in terms of what the average attorney can say. I'm not real fond of the law--the people in the law field. It's such a litigious, it's such a competitive profession. There is so much stress...To be the final head honcho where all the decisions rest on you is very intimidating to me. And if I make a mistake, then it's all over. But if I can work under somebody and say hey, how do I go about writing this motion or is this what you had in mind? I enjoy that, and enjoyed working...And yeah, I have missed. And, for instance, I got itchy last night--I was one of the League of Women Voters observers to the City Council. And there was an attorney up there giving an opinion...I can taste it. I can say he's arguing well. And I get itchy to get in there. So, yeah, there's some of me that really wishes I could get back in there."

Mary considered all options including practicing part-time or working out of her home but decided these were not truly options.

> "...Because I'm too unpredictable and when deadlines come due I don't want to put somebody's life in jeopardy..."

The potential risk of this happening because of her inability to function was too great.

Mary had begun to experience the limitations of drug therapy compounded by disease progression. End-of-dose phenomenon, dyskinesia and on-off phenomenon are widely recognized limitations and complications of Sinemet therapy. These terms are discussed in the literature in nearly every article about Parkinson's and in any material produced by the various Parkinson's groups. Clinicians and persons with Parkinson's talk about on periods, off periods and dyskinesia.

In the medical world, on is equivalent to good mobility, whereas off is sudden inability to move. Dyskinesias are abnormal involuntary movements. These definitions are the outsider's account. These accounts provide little understanding of what is it like to experience these phenomenon. Mary having struggled with these marked fluctuations in functioning provided the following account.

Some of the words were changed to reflect the experience. On remained on but off became "dead in the water" and dyskinesia was "too much".

> "And then I go into what I call dead in the water. I just, I stop functioning. It's as if I'm built of lead, I can't move, to make a decision is really difficult. So often I will read and I'm to the point where even holding a newspaper is too much..."

"Dead in the water" is more than the inability to move but rather the inability to function and to think. When Mary is "dead in the water" she can't cut her meat, get her food on a fork, hold a newspaper, get off the toilet or do anything which requires much movement. As a clinician and an observer I had always thought of off (or "dead in the water") as difficulty in mobility because of stiffness and slowness. Mary illustrated "difficulty" was a gross understatement. She described what clinicians term stiffness as "experiencing resistance".

> "It feels like when you are walking in water and you try to run it's harder and the more you try to run, you know like in a swimming pool the harder it gets."

She explicated that being "dead in the water" is not purely a physical experience but involves mental processing. She provided an account from earlier that day.

> "I had wanted to analyze this report where I really am sitting down working with it--somehow I didn't feel as though I could bring that much analysis to it. I didn't have the sharp edges there."

Being "dead in the water" is part of Mary's day, everyday. Though not a new experience for her and now occurring more frequently throughout the day, it has not gotten easier to deal with. Describing the hardest thing about her days:

> M: "Not being able to function in the morning. I still, despite all the time, and this kind of permanent fixture in my day, have that dead period. You know, you want to function in the morning. Mornings tend to be the most productive part of people's day, and I'm not doing that. It's easiest when nobody's here because I don't feel guilty. What is really hard is like on Saturdays, is having everybody doing Saturday chores and I'm dead in the water. That kind of thing."
>
> I: "And how do you deal with it?"
>
> M: "Grit my teeth and bear it. I mean, there isn't much else to do".

Here Mary revealed the lack of control she has on her functioning level. She knows she can not prevent these dead periods. All of the fine tuning of her medications, planning of her days around medications can not prevent these dead periods.

Just as she can not control dead periods nor can she prevent "too much".

> "So often I tend to go from boom to bust. I'm either dead or I'm too much and so it's very frustrating."

Mary prefers to be "too much" than "dead in the water".

> "I want to function. And so if I were given the choice of the two, I'll always take the thrashing. The thrashing is more embarrassing because it's more visible. But I can function, I can think".

When "dead in the water" Mary can not maintain being engaged in her world. Functioning means being "emotionally alive", engaged in her life and maintaining her sense of self in her world. With "too much" she can do this though not easily at times. While "too much" opens up possibilities, it is not without negative effects. She described the physical effects:

> "Because I'm in motion, it's part of the whole turn on system. And so one of my real problems, particularly the past 2 or 3 years, is keeping weight on. And I'm constantly hungry. And so I'm hungry and I'm hot."
>
> "When I'm in motion I'm kicking the table, I'm spilling things, I threw my fork one day and I'm not physically comfortable...What happened when I was at my worst I was thrashing so badly it was uncomfortable to do anything except be on the floor or on a bed thrashing. And this was just devastating. This was very uncomfortable. And I felt like a drug victim having convulsions...It really scared me and it was very uncomfortable."

The psychological effects:

> "With my thrashing I became much less comfortable leading groups and putting on programs. So I'd say in the last year and a half to 2 years it's gotten to the point where being in front of people has made me uncomfortable...The things I worry about most are getting up in front of a group of people and freezing or else thrashing."

During each interview, Mary had periods of "too much". While not to the extreme she described above of lying on a bed thrashing, watching her was difficult. Her discomfort and pain were obvious, she was physically struggling. She was not in control of her body. Her arms, legs and trunk were flailing in all directions. Merely watching her was exhausting. She got very diaphoretic and would take off her sweater. I then understood why the temperature in her home which often left me shivering was not cold for her. The amount of energy expended by this constant, frantic motion was phenomenal. Equally amazing as the obvious physical discomfort Mary experienced was her ability to continue a conversation while in motion. She never seemed embarrassed to be thrashing in my presence. She continued to talk, her thoughts flowing, providing rich narrative despite her bodily discomfort. I began to understand how "too much" opened up possibilities which didn't exist with "dead in the water". Mary demonstrated remaining engaged is what matters.

Mary had come to accept she can not prevent these marked fluctuations, they are what she must live with. She provided an expert account of what it feels like and what she does during these periods. When "dead in the water" :

> M: "I'm cooking supper and I feel my medication wear off, which it does, boom, it does very suddenly. I'm not given a lot of lead time. Then I'm very stiff and I have a hard time moving my arms, my legs. I tend to feel very weak. If I need to function, and I want to stir something, I want to wipe dishes, then if I can march or if I can sway from side to side, for some reason that tends to start me up again, or else keep me going if I'm stopping. If I jump--sometimes running in place, I can--for instance, if I have trouble at night undressing because I'm so slow, if I run in place I can unbutton a blouse".
>
> I: "As you're running in place".
>
> M: "As I'm running in place. Where if I stop, I can't".

I: "How did you figure this out?"

M: "...It just feels as though it's sometimes that's what I should do. We were walking just one night, oh, a couple of months ago, and I froze up. My medication dropped in the middle of the walk and I thought," oh, how am I going to get home?" And so I had this urge to run and I found out I could run where I couldn't walk, and so we jogged home. And it was great. I just use the term priming the pump--just something about that gets it going. It's really strange."

I: "And you described it as an urge. A sense you should do this".

M: "A sense that I can and should do this. Because I'm feeling, I'm feeling so much resistance than somehow if I can throw myself over the cliff in a sense, it'll loosen up."

The notion of running in place so you can unbutton a blouse is not something a person without Parkinson's disease would ever think of doing. But by doing this she was able to overcome the resistance she was experiencing. In contrast to situations where she described having to consciously think and instruct herself (recall quote related to waving and scrambling eggs), this was different. Here there was not a conscious deliberation on how to unbutton a blouse or how to pick up one's feet to run. She described a bodily urge or solicitation. When thrashing:

> "When my medication is really turned on, I feel my leg kick, and I feel kind of a squirming sensation. It's a combination of tensing and releasing in a sense...And it's one of those things where I'm more comfortable standing and rocking as you have seen."

She described it as feeling right to stand. Her body does not want to sit but stand and be rhythmic. Again, her body solicited her.

Mary's accounts of "dead in the water" and "too much" demonstrated the transition she had made. In the early years she consciously reflected on how to do things which previously had been automatic and pre-reflective. Along with this was an instructing of her body on how to do it. Thus she was experiencing an alienated body. In contrast now Mary was solicited by her body. There was no conscious reflection and deliberation on how to get her body moving or stop moving but the body knew what to do. To run when she can't walk, to jump in place so as to unbutton, to march or sway to be able to cook. Her body was a skilled, knowing Parkinsonian body.

Finding Substitute Activities

The chief challenge Parkinson's disease caused Mary was finding "substitute activities that have been satisfying and fulfilling without being busy work". When Mary gave up her law practice, she became reinvolved with the League of Women Voters, becoming the Unit Chair for the area. Also at this time she joined a parkinson's support group. She described her getting involved with the support group.

> "It was also something to do. It was not that I needed it. It was I can give something. I can get in there and do something. So I joined this organization and I saw a lot of things I wanted to change about it, and so I became active. And here I am now, basically." (currently is President of the group)

These activities were by no means time fillers for her. Participation in these voluntary organizations provided Mary stimulation, connection, a sense of doing something meaningful and giving something and kept her as "emotionally alive".

Mary "takes on" activities and challenges herself to do them well.

> "I have to do things. The idea of sitting at home like a toad stool just freaks me out...Whatever I do I'm constantly challenging myself to do it better, to do it more thoroughly. This kind of thing."

Many examples existed in her narrative of "taking on" activities. She began law school shortly after being diagnosed and successfully completed it even though she had to tape all lectures and then type all her notes. She practiced as an attorney until her functioning level became unpredictable. She held the position of Unit Chair for the League for four years until she was uncomfortable being in front of the group. She remained in the group but in other capacities. As Mary put it, being a "toad stool" is not an option for her.

> M: "I could withdraw and I don't want to do that. But it's tempting at times."
>
> I: "Because it would be easier at times?"
>
> M: "Oh, yeah. Well, it wouldn't be though."
>
> I: "Not for you."
>
> M: "No. It would be and it wouldn't be."

Withdrawing might spare her the fear and frustration she has experienced but it is not something she could do because she wants to stay "emotionally alive".

Mary has approached her life and continued to do so in a confident manner. She has experienced many physical limitations in activities but she continued to do whatever meaningful, satisfying activities she could. This did not happen without some fear and frustration.

> M: "And this is one of the greatest problems that I'm dealing with now is in a sense what do I expose myself to? And how well can I function at a given time?...And so it's new for me to be afraid. I won't be afraid of doing it. I'll be afraid of my ability to do it. In other words, to get up in front of a group like president of the organization and open a meeting--It's not that I'm afraid of. It's will I function while I'm doing that?"
>
> I: "So it is very related to what is going to be your level of functioning because of Parkinson's?"
>
> M: "Absolutely. Absolutely...My frustration level is I can do it, but this is stopping me. It's not the doing that I'm having trouble with. It's the ability to do it."

Mary always believed she was a competent person and therefore approached situations with confidence. She remained confident of her abilities and skills. But Parkinson's disease has caused her to be unsure of her physical capacities and functioning level. Recently this had become a significant issue. Her fluctuating symptoms had gotten to be more unpredictable. She had experienced several incidents where in front of a group she was either "dead in the water" or "too much". This was both frustrating and embarrassing to her. The frustration resulted from knowing she was a competent, able person and could do the activity without any difficulty if not for her disease. She described the embarrassment this way.

> "It's more fear than guilt and what I'm afraid of

> is that I will be in front of a group and freeze...Fear of embarrassment that I'm not functioning...Other people aren't embarrassed but I'm embarrassed to either slow it down or to be in that position".

The exception was when she wore her "Parkinson's" label.

> M: "And if I wear a "Parkinson" label then I can function, then I don't mind being in public as much."
>
> I: "Like with the support group?"
>
> M: "Right. Right. Or I was able to get up with fear and trembling in front of the city council, asking them to make April 13th, give us a proclamation that April 13th was Parkinson's Disease Awareness Day. And that was scary but I made myself do it and they had me be the spokesperson for putting on the public service announcement. And that just scared the heck out of me. But I figured, what can I do? I can fail. Big deal. But I didn't. So I just keep pushing myself."

She coped with her frustrations, fear of not functioning and potential embarrassment several ways. First, she had pulled out of some activities which had become too difficult such as being up in front of the league. However although she pulled out of a specific role she did not withdraw. Instead of being Unit Chair which entailed leading meetings, she became the League's representative to the City Council. This entailed attending the council meetings as a member of the audience. This she was comfortable doing. If she was "too much" during a meeting, she moved to the back of the room and swayed. Second, she continued to take on activities where her fluctuating functioning level was not an embarrassment. Being president of the support group and experiencing wide fluctuations was not stressful for Mary. And lastly, she formed contingency plans. She asked and prepared other people to take over for her in case she was "dead in the water" and couldn't move. Thus she made accommodations for the disease when necessary but still continued to push herself.

Staying active and involved was a central theme of Mary's story. Her life was busy and her days were full. It was not uncommon during our interviews for her to receive a minimum of three calls related to her various volunteer activities. When asked what helps her deal with her Parkinson's, she explained:

> M: "The stimulation of all that I'm involved in. It's what keeps me going. I know I just can't imagine not going...I take on activities."
>
> I: "What is important to you?"
>
> M: "I suppose keeping--I want to say staying alive. Staying active, staying involved, being interesting, not fading away."

Her family was a major part of staying active and involved. Her children along with her son's girlfriend were coming home for most of the summer. Knowing this she had spent time reorganizing the house, painting and fixing up their old bedrooms. At the end of the summer, Steve and she were going to help move their son and his girlfriend to Arizona. Mary had planned and mapped out a camping trip for them after they got the children settled. She took on family activities much as she did her volunteer activities. Family has continued to be of great importance to Mary.

> "I have not felt that keeping a marriage going has been a problem, keeping children, keeping in touch with children, that's not been a problem."

As you remember this was one of her early concerns after being diagnosed. But it never became a reality. She attributed this to Steve.

> "He's so supportive. He's just--It's personality. It's his attitude that's what is important. I don't know why this hasn't shaken him. He says I'm normal, I'm just like I've always been...He's very accepting. He does not place demands on me. He never has. He is very calming in many ways. I guess it's just his ability to accept this without being traumatized by it...That's how I perceive him dealing with things. But I've heard him say I don't put any stress, strains on him. I don't put any demands on him. So that, he says, there isn't anything to live with...He seems to be able to separate the disease from me, which I think I have not become the disease. That's true of both of us."

Parkinson's disease is part of her life. But both Mary and Steve have fought to hold on to their pre-illness identity and sustain their relationship. She felt they avoided much of day-to-day stress and strain by being flexible.

> "And Steve's really great because he's very flexible and if supper comes at 7:00 or 7:30 then we eat at 7:30 or 8:00. I mean he snacks when he comes home and I just say to him I'm not functioning and so we will wait and I'll cook when I can. Or else he'll pitch in. It just depends. He'll either do that (pitch in) or won't care when it gets done...He's definitely not one of those husbands that comes home and walks in the door and picks up things as he goes through the house, which I've seen for instance, a brother-in-law of mine do. And Steve doesn't put those expectations on either of us. I mean, we live very comfortably."

What about the future?

> "I continue to experience new symptoms like freezing, which has come on in the past several months. I'm aware that I have not stopped progressing. But I don't hold any expectations now other than I look at new medications and I mean, I am still functioning in a very capable way in a lot of instances...So I don't know how much just doing things and keeping active is critical--I think

> there's a mental that's real important to the physical state and so by staying involved, staying active at whatever level with whatever activities is going to keep me from deteriorating."

The future for Mary is unknown. She acknowledged her disease has continued to progress because of her new symptoms. She looks to new medications with hope of slowing the progression. She does not try to anticipate how she will be in a few years or more. These efforts are useless to her because there is no way to know, it's too unpredictable. Rather she places hope in new drugs because she had a marked improvement when initiating Sinemet and more recently with Eldepryl. Even after being on medications for many years she has been surprised as to how beneficial they are for her. She told me a story of camping a year ago when she took extra medication and was able to hike for five miles keeping up with Steve the entire time, much to both of their surprises. Through these experiences there is hope for new therapies in the future.

She believed staying active may make a difference, and slow down the progression of the disease. She believed being active in conjunction with her younger age were to her benefit.

> "You know you look at all sorts of patients with, I guess it's partly being older, the older they get the more aging effects which I have to realize I'm going to be, a little freer just because I'm starting this a lot younger."

When asked if her progression has been relatively slow:

> "No, living with it. But when I realistically step back I think I'm a lot less badly off than a lot of

> people. And so because I'm living with it seems to me it's terrible. But when I put it in perspective, yes, I've been at it for 15, 16, 17 years.

Her fears of the future are related to the deterioration and it's impact on her husband and relationships with her family.

> "I suppose the final one is just incapacity. It's scary when I freeze up. I guess just dependency on him or other people. I don't want him to become burdened. I don't want him--I'm sure there will come a time where I won't be able to turn over in bed, for instance. And I hate to get to that point where he is sleepless. I have seen spouses who are just exhausted because they become the handmaiden of this patient and they never give themselves space and I want him to know that it would be okay to take space, to be other things than a caregiver. I think that's the--I'm afraid of all the physical limitations...One of my biggest fears is that I won't be in a position to help out my kids, like with babysitting."

Mary and Steve have discussed the future and her concerns for him.

> "I don't know whether he's heard that (taking space). We don't talk about it much but it's obvious, as we're doing financial planning, this is one of the things that we've been--the fact that there may be a time when certainly housekeeping will become a necessity. Who knows whether wheelchairs, mechanical devices, whatever help. I just don't know what the future is so in a sense you hate to plan everything for the future when you don't know it's going to pan out because you want to give yourself enough cushion. And so it's partly setting up finances with an eye to the future needs that we're dealing with."

The future remains an unknown. Mary has accepted it is not within her control, all of the planning in the world will not bring it under her control. The future cannot be grasped. She embraces the present focusing on her family and the meaningful activities she does. She offered this advice to fellow Parkinsonians:

> "...to keep active, to keep your mind busy, to accept challenges, to keep a supportive whatever community you function in...People are so important and how you relate to people is what counts. Yeah, I guess just live life to the fullest."

Mary was a paradigm case of living life to the fullest. She was a vivid example of living in the present and expanding it's possibilities.

CHAPTER 4

Paradigm Case: An Objective View, A Way of Seeking Control

> "I can look at myself and try to figure out what stage I am or why I'm, you know, suffering such a condition and there's no sentiment attached to it. I just look at myself as another patient".

Ed Suyigami was a single, retired Japanese-American who had been diagnosed with Parkinson's for 8 years. Born in the United States, his childhood had been disrupted by World War II. His family was placed in a prisoner camp with his father later being moved to a different camp in another state. After four years and the conclusion of the war, his family returned to Japan and was reunited there.

> "Because my father, he had come back to Japan because he had lived here for over 30 years and they threw him in camp and he says if your government can't trust you here after you live that many years in the United States, then you can't trust it, trust them. And he wanted to get back to Japan because, well, I guess he just didn't want to live here anymore".

He spent his adolescent years living in his father's ancestral home. He described how difficult life was in Japan post-war.

> "I lived in Japan for about 8 years. During all that time I think I was suffering from malnutrition to a certain extent. I think rice was still rationed, yeah, even at that time. Our staple food used to be either rice, wheat, corn, pumpkins, sweet potatoes. These were called the staple foods. They would try to give you rice as much as they can. They really didn't have enough. So, in place of rice you would get sweet potatoes and things like that. It was pretty rough for me the first few years because, well, I really didn't know I was sick because it's part of growing up and if it's something you're feeling every day, I guess you get the feeling it's kind of normal. At least, I did anyway. So in retrospect that I was probably suffering from malnutrition at that time. And I don't know. I think I was also psychologically

> depressed because I think I was thinking a lot, not a lot, but suicide and dying and all that. Probably, because I was afraid that malnutrition would lead to some kind of severe illness and I'll be gone. I don't think I really was enjoying life at that period because I couldn't see the future, so to speak. And it was so hard in the present."

Ed Suyigami returned to the United States (U.S.) after the death of his father in the early 1950's "because selective service was on my back". A U.S. citizen, he served two years in the Army. Meanwhile, his mother and siblings returned to the U.S. While in the Army he took correspondence courses to obtain his high school diploma. After getting out of the service, he was accepted into college initially studying pre-medicine but changing to a basic science major.

Identity: A Scientist and a Loner

Being a scientist is central to Ed's identity and his approach and understanding of Parkinson's disease. What he saw as treatment options and his coping strategies were guided by approaching his disease as a scientist.

He traced his early development as a scientist to a mentor he had while living in Japan.

> "I guess if I consider myself as a scientist I would have to give credit to Dr. M., my mentor, he's the archeologist I was talking to you about. And I think he had the greatest influence as far as the rational side of, the scientific side is concerned. I think I'm a scientist, if I am that, because he sort of influenced the most strongly as to what that means. You know, you just don't go around digging up old sites. First, you survey it, then you go in inch by inch, record what you find. I think that's called a scientific technique because you have a precise record of what you're doing and he kind of instilled in me this is how we

> should go about doing things. And so I guess that side of me, which considers me as a scientist, I'm heavily indebted to him."

As mentioned, he initially studied pre-medicine in college but then switched majors. He was concerned about his ability to get the high grades needed for medical school because of some remaining difficulties with the English language. Also he didn't feel medicine was a true science.

> "I've always thought that medical science isn't what it advertises to be. I mean, it's not a perfect science. I think it's more like art to a certain extent. And it's kind of strange that I wanted to be a doctor but I guess I had this strong curiosity of finding out whether medicine was really what it was cracked up to be."

Medicine not being "a perfect science" has continued to be a major issue for Ed especially in relation to his Parkinson's disease. In each interview he expressed frustration that neurologists weren't more "precise", or "objective" or "scientific" related to diagnosing, drug therapy or identifying the stage of disease.

Ed worked for over 20 years as a microbiologist. His work was central to his identity.

> "It was quite important I think because well in a sense I'm a workaholic. I'd rather be doing work than maybe playing around. It's not always like that but--I felt like I was fulfilling a mission so to speak."

For Ed work not only provided a structure to his life, but it supported both his identity as a scientist and his culturally bound need to be a productive member of society. He stopped working because of his disease.

> "My right hand would occasionally do a lot of

> things that it shouldn't do as I'm working on serums and things like that. So. I felt that I was becoming a danger to myself as well as to my colleagues."

Although retired, he continued to keep abreast of developments in the basic sciences by attending professional society meetings and reading from the many scientific journals he subscribed to.

Ed was single, never having married.

> "I never considered getting married and having a family as a happy thing. I always look at myself and just feel afraid of the whole thing...I've always had this problem with being responsible for somebody or someone. And maybe it's the same feeling which separates me more than I should be separated from the rest of my family. I can't communicate with them any more, on an intimate level..."

Being independent and not relying on anyone else had been an issue throughout his life. For example he worked such long hours while going to graduate school it obstructed his studies (he did not complete the program). Even though he had significant savings at that time, he worked full-time while going to school.

> "I had enough money stashed away but I felt I should hold that reserve because living by yourself, you know, I don't know what is going to happen."

Being self-reliant was not limited to financial matters. Ed lived his life in such a way that he did not solicit or receive help from anyone. This may have been related to his childhood events and his family being separated. He had much difficulty either identifying anyone he was close to or could call upon for assistance. His family, although living close by, were absent from his narrative. He did not see them on a regular basis nor perceive them as people he could call upon if help was needed. He mentioned a long term friend he went out to dinner with weekly. He described their relationship:

E: "I think he's a friend because we don't ever try to poke into each other's life."

I: "Okay. So there's some distance."

E: "Yeah".

He acknowledged he was comfortable with his friend even if he was not physically functioning well.

> "He doesn't question me too much about Parkinson's. He doesn't think about it, you know, we just talk about whatever we usually talk about."

Although they routinely saw each other, he did not speak of his friend as someone he could call upon for help. When he shared a specific situation of when he was ill and had much difficulty getting out of bed, I inquired had he considered calling anyone for help. He had not considered calling either his friend or any family member.

Besides this friend, his only other social contact was the Parkinson's support group he attended monthly. He described himself this way:

> "I'm not too sociable in a way. I'm kind of a loner I guess. I'm not sure whether people look at me as being a loner or not but I feel like I am because I don't socialize too much."

Occasionally he questioned whether he should socialize more but always concluded he enjoyed being by himself. He was comfortable with his identity as a loner though he realized as his disease progressed he would not have many supportive resources to call upon and would need to rely on professional resources for care.

Ed lived in a second floor apartment. He had moved to this apartment after retiring approximately four years ago. He explained:

> "I thought it would be easier to be with a group that's familiar with say Asians, Japanese-Americans, Koreans and so forth. And that's one reason I moved back to San Francisco because I felt the care is a little more advanced here."

Although he had lived in his apartment for four years, it was sparsely furnished and still contained boxes. The living room furniture consisted of a desk and chair, a small television, another chair and several bookshelves filled with scientific journals. The rest of the rather large room contained at least a dozen boxes which he explained were filled with more journals. The desk top was basically empty except for his medication bottles and his diaries where he recorded daily related to when he took his medications and his responses to the medications. Missing from this room were any personal touches such as pictures, wall hangings or mementos. The only traces to whose apartment it was were the scientific journals and the medication bottles.

I Knew I Had Parkinson's

> "...the typical symptoms of Parkinson's, when I first started L-dopa, taking Sinemet, they would disappear and to the point where I felt quite normal. And so that had to be the clincher, you know, psychologically, I was convinced from top to bottom, (you know) that I had Parkinson's at that point because L-dopa worked as it should."

Ed had begun experiencing symptoms such as tremor in his leg and dragging of his left foot. A diagnosis was not immediately made. In the interim, he read from professional texts about various neurologic conditions.

> "I was reading these texts on the brain and so forth and I would sort of match my symptoms against what they described."

He was convinced he had a neurologic problem but was unable to determine which one. He recalled reading about Parkinson's but did not make "the connection at that point". Upon getting the diagnosis he read in great depth about the disease.

> "Once the diagnosis was made that kind of helped me stabilize myself psychologically so to speak because I could read about the thing...And so the diagnosis was made (you know) there's something you can measure yourself against."

Reading raised questions and concerns about drug therapy.

> "...from the readings I knew that if I took too much of the L-dopa there could be severe side reactions. And I also knew over a period of time that the dosage would have to be increased because you're becoming more tolerant. And anyway, even after the diagnosis was made, I was worried about that particular point, where if you take too much L-dopa eventually it's not going to work for you and I wanted to hold off as long as I can from reaching that point."

These concerns raised by Ed were not unique. The issues of a tolerance or what happens when you really need the drug were discussed by seven of the sixteen participants. He took anticholinergic and dopaminergic drugs for 2 years before initiating Sinemet therapy because of these very concerns. Starting Sinemet was also a turning point for him as it was in other cases. The abatement of his symptoms in response to the medication was "the clincher", convincing him he truly had Parkinson's. He clearly distinguished between reading and intellectually knowing Sinemet should help versus experiencing Sinemet.

> "Although in my mind I knew that if I had Parkinson's, Sinemet would work because I had read about the thing. But you have to actually feel it to really get a psychological response...You read about it but when you really feel it that's something else again...I felt quite normal. Happiness because I was able to move the fingers freely and my legs won't drag anymore and generally feeling normal."

He spoke of feeling "normal" after one dose of Sinemet. He had a very similar experience when he started Eldepryl less than 1 year ago.

> E: "...but physically I felt that I was almost back to normal, 100%"
>
> I: "When you say normal do you mean--"
>
> E: "Before having Parkinson's. I could do anything I wanted to..."

His reference point was pre-Parkinson's disease. Throughout the years this remained his reference point. As time passed, he has experienced "on" phases and "off" phases. During "on" phases, he described feeling "quite normal" referencing his pre-Parkinson's physical sense.

Response to Sinemet and later to Eldepryl were examples of experiential learning. He had a theoretical understanding of how each of these drugs worked in the cells of the brain. But yet until he "felt" or experienced their beneficial effects he was not convinced. A similar experience occurred with hallucinations. He read about hallucinations as a side effect of drug therapy and had met people via a support group who had described their hallucinations. He remained skeptical until he saw squirrels in his bedroom during the night.

> "But I truly believe that you can hallucinate now. I've had that experience."

Having the experience was the convincing factor. This was true related to other aspects of his disease. He was extremely well versed on all treatment modalities and on complications. His physiologic explanations of how various drugs worked, how protein interfered with Sinemet absorption and how environmental toxins worked on a cellular level were often above my own level of understanding. But despite this in-depth physiologic and neurochemical understanding, how he came to believe a drug worked or a complication occurred was by the experience. As a scientist he awaited direct empirical evidence from his own experience. The experience backed by a scientific explanation were the essential ingredients to his understanding. The solid scientific explanation had to exist though. An example of this was when asked were there other options for treatment or therapeutic intervention other than medication.

> "Aside from medication I don't really think there's anything else because I think we're , as far as the research goes, I think we are at a stage where we're barely beginning to understand why, you know, the substantia nigra cells, die off. Or perhaps what metabolic pathway is being affected to cause the cells to die and so forth. Now, if they were to find out, if the researchers were to find out, the exact reason why dopamine is not being produced or why the substantia nigra cells are dying, then there might be some others...I think the researchers have to do a little bit more work,

> especially on the molecular stage or level. Because at this point we really don't know why the substantia nigra cells are dying in our brains."

Therefore for Ed interventions were limited to the current medications available. Unlike other participants, he did not discuss exercise, walking, or staying active as helpful interventions. Nor were the experimental surgical procedures options because the knowledge level for these procedures was inadequate from his reading of the current scientific literature.

Living with On and Off Periods

> "I would rather take this off period penalty because I would like to know when and how long the Sinemet is working. As long as I know it's working for me, then psychologically it's a plus for me."

Ed had "on" and "off" periods. On was the time he felt most "normal" and he correlated this with his Sinemet dosages.

> "And I can distinctly feel the on time, most of the time, at least for the first 1, 2, or 3 pills. The 4th pill maybe not."

When asked to describe what "feel the on time" meant he had difficulty, responding very slowly. (underlining added for emphasis)

E: "I feel normal."

I: "What does normal feel like. Try to tell me not in what you look like but what your body feels like?"

E: "To be normal means I can move around well and not <u>look abnormal</u>. I can do what I want to do. It's hard to say. Maybe I'm more relaxed when I'm on.

I: "Because?"

> E: "If I'm with somebody especially it's better because I'm not conscious of any tremor as I would be in the off stage with somebody. I think that's what it's like to be on for me."

Thus, "on" was not appearing abnormal and being able to move well without experiencing self-consciousness. He identified the "on" periods occur typically within one hour after taking his Sinemet. "Off" periods referred to Sinemet "wearing off" approximately 2 - 2 1/2 hours later. During our first interview he went into an "off" period and provided this description:

> E: "If you look at me real closely you'll notice that it's beginning to shake a little bit."
>
> I: "I noticed your right hand was shaking a little."
>
> E: "And then this--It's not a numbness, well I guess you could call it a numbness but it begins to feel that." (pointing with finger)
>
> I: "So sort of a numbness going up your fingers and palms and up your arm a little bit."
>
> E: "Yeah. Same thing on this side. And I call it stiffness. It's not a pain or ache or anything like that. It's just that I can't make the fine movements that I am able to make during the on phase."

When asked to contrast what it felt like to be "on" versus "off" in terms of bodily sensations, he answered:

> E: "Well, rigidity first. I notice the difference with the rigidity most clearly. When I'm off, when the medication is not working or running out or whatever you want to call it, I notice my fingers are kind of rigid, feels like they're fat. I have trouble doing things with my fingers. When I'm going into the on stage, the rigidity gradually goes away and I can move my fingers more normally. Also my posture tends to be better during the on stage and I feel better. During the off stage I am leaning over. Well it's obvious the vertical axis is improper. And when I'm going back into the on

> stage, I go back to the vertical reference. Let's see what else. The gait changes. During the off stage, the gait is more, the best way to describe it is taking shorter steps."
>
> I: "I could look at you and probably notice these shorter steps. Tell me how does your body feel taking these steps versus you're not taking shorter steps. You're aware that you're taking shorter steps?"
>
> E: "Well, I don't have a feeling of wanting to run as people do in the end stages of Parkinson's. In my case, I don't have that nor do I have to try to keep from falling. At least I'm not at that stage yet. When I get into the on stage, things get better."
>
> I: "What's the difference or how is it better?"
>
> E: "I'm taking bigger steps and my body is not stooped over . When I compare myself to the others in the support group bunch, I tend to look more normal then. It's probably because I'm one of the younger ones in the bunch. Gait, rigidity, posture, what else. I think that's it. That's what it is like for me to be on and off."

Missing from his account of "on" and "off" periods was a bodily experience or sensation language. He spoke mostly in terms of what was observable. Further probing did not provide a different account.

During "off" periods he explained many activities could not be done or were more difficult to do. Eating, taking a shower, driving, writing, turning over in bed, and walking were all impacted. This obviously had tremendous significance for day-to-day life and when he accomplished activities.

> "My day is usually a one event or two event day. Because I try to do everything during the on phase including meals and shower and whatever else."

Thus during a two hour window period that each dose of

Sinemet provided he attempted to accomplish everything needing to be done. He described the off period as the "penalty" he pays. He would rather experience an on-off cycle than have a steady level of functioning. Because having a steady level required more medication which had it's disadvantages.

> E: "I'm taking less than what Dr. M. recommended because I want a distinct off time so I can time the on time. That's what I've been doing for the last half a year or more."
>
> I: "And there's a benefit to you to do it that way as opposed to having a constant kind of on and maybe taking more medication?"
>
> E: "Yeah. I feel I'm not suffering as severely as I used to as far as side reactions go...It's sort of a twisting motion. And it would go on without my being conscious of it. And so I decided to experiment a bit."
>
> I: "Was that disturbing to you?"
>
> E: "Yeah, it was because I would be doing (it) even during the on phase."
>
> I: "So it was all the time?"
>
> E: "Yeah. Just about all the time...I felt--well, I shouldn't say clearheaded as opposed to not clearheaded, but it's very difficult to describe...I think I felt that my brain was waterlogged...And for me, taking less meant that during the on phase I would I guess much sharper if you want to call it that, although I will have the off phase. I would rather have it that way."

Ed choose to have an on-off cycle rather than an relatively even level of functioning because he felt mentally clearer and did not experience dyskinesias. Related to this was his fear of taking too much medication because he will build a "tolerance" to the Sinemet. But also key to his experimenting with medications was his desire to feel and appear "normal" at least for some periods of time. By having distinct on periods he carefully planned his days so everything happened during those times. This included social contacts, occasional family visits, appointments and any interfacing with other people. An example:

> "I went to see a dentist. There was no problem there. I timed it so that I didn't shake or get stiff when he worked on me. I left the dentist as soon as I got out because I wanted to be in the on phase, I wanted to be back here before I went into the off phase, and that worked pretty well."

During this incident he had planned to visit colleagues at his former employment after his dental appointment. Because of the timing, he decided not to for fear he would go into his off phase before he got home.

> E: "I hate to see myself shaking in front of every one. And most of my friends understand that but I'm still kind of reluctant to be in the off phase when I'm with them."
>
> I: "It's uncomfortable for you to be that way."
>
> E: "Yeah, uh huh. And it's stressful. I have to admit that because I do get kind of anxious. It makes it worse."

One of the central themes throughout his narrative was planning around these cycles. Common to all his examples of a situation which went well (a question that was asked in each interview) was when the planning worked and he accomplished what he had hoped to accomplish during the "on" phase. The content of the examples were different ranging from going to the store, eating in a restaurant or being a passenger on an airline but the concern remained planning to be in the on phase and appear "normal".

On most occasions his efforts were successful or in his words "I can generally fool most of the people around me". And indeed there were tremendous efforts to do that. When asked to describe a typical day, he guided me through a day where he would drive to the store. From his waking moment, the central concern was "*pinpointing*" his on periods. He awakened, took his medication, returned to bed and *waited* for the start of the on phase.

> "Because if I want to drive I have to know when I go into the on phase. And if I have to drive, I will not eat breakfast, or I will try to skip it, because sometimes, not always but sometimes, the breakfast that is, will shorten the on period."

He doesn't risk shortening the on period because he had to shower, get dressed and drive to the store within that window of time. After arriving at the store, he took his second dose of Sinemet without eating and *waited* for it's effects before shopping and then driving home. Thus he accomplished those activities during his second "on" phase. If unable to *pinpoint* the beginning of an on phase or if it does not occur, he does not go out that day. For example, he noted if he has eaten a protein rich dinner the night before he might not experience an "on" period with the first dose of Sinemet. This happened in relation to shopping whereas he postponed it for 2 days to be precisely sure he was functioning at his best and would appear "normal". He does not go out in the evenings because he can not rely upon having an "on" phase.

"I don't go out at night because I'm not sure how

> well I will function, or will I function. It's one of those things that I can't really tell what's going to happen after I eat dinner, you know. Sometimes the on phase never appears. It's just a gradual change for the better but I still shake and I'm still stiff."

Each day was structured around these cycles. The only activity he identified where he did not feel anxious being in the off phase was attending support group meetings because "half the people are caregivers and the other half are Parkinson's disease patients". To be seen shaking was very difficult for him.

> E: "I know that before, or shortly before, I retired that the other people were noticing the tremors, you know, the shaking and the way I was walking and so forth. So it's nothing new to them, but I always felt not ashamed but kind of inadequate. And I just didn't like to expose myself too much."
>
> I: "It's really hard for you to have your symptoms show around other people."
>
> E: "Yeah. I worry about it. I shouldn't but--Because they tell me not to worry about it cause we know what you have and we have some idea of how the disease progresses, so. And they're all professional scientists so to speak. So maybe I shouldn't worry too much but I still do."
>
> I: "Is this a cultural issue, is it a Japanese cultural issue not to show differences in physical aspects?
>
> E: "Could be. I'm not sure."

For Ed to be visibly shaking results in feelings of shame, inadequacy and failure. He had a strong moral code to appear "normal" and be in control of his body. This was consistent with his objective or scientific stance. Taylor (1989) discussing objectifying as a stance or way of being in the world, stressed the key to this stance is control. Ed was deeply rooted in his scientific mode of engagement and the sense of control it provided him. But when control failed, when he was seen shaking (i.e., not "normal"), he experienced shame and guilt.

These same feelings were evident when he stopped working. He expressed for at least the first year and a half he experienced guilt and shame over not working.

> "Well, you know there's a lot of cultural background that goes into this. In Japan they don't look at any person who doesn't work as being a useful member of society."

He stated the guilt disappeared with time but could not offer any explanation as to how this transition occurred. He no longer struggled with guilt related to not working because he accepted that work was no longer a possible. However, he continued to struggle with feelings of shame and inadequacy on a daily basis because he had a disease. Despite his extensive neurochemical knowledge, he viewed the disease as a deficiency or weakness.

> "Kind of surprised I caught it because I don't think I had any inkling there might be something wrong with my brain, you know, I don't think any of my relatives had any problem related to brain disease...No history of any mental conditions or disease."

Many times he referred to being healthy until he had Parkinson's.

> "I've never been in a hospital since 1953, since I moved back from Japan and I've been relatively healthy. In fact when I retired I had quite a bit of sick leave time. I think over 6 months."

Because of this, it was unexplainable to him he had a disease let alone one which involved the brain.

His feelings of shame underlaid why Ed did such detailed planning so he was only seen in the on stage. To be seen shaking or to "expose" himself carried much risk and vulnerability. Through careful planning and limited social contact, Ed was able to "fool most of the people" and potentially prevent his feelings of shame and inadequacy from being affirmed by society.

Tracking Progression, Constructing a Future

Monitoring new symptoms experienced, observing more advanced cases and staging the progression of his disease were all strategies utilized by Ed to comprehend what the future held. For him these strategies were a way of coping and trying to grasp the unknown.

Monitoring Symptoms

> "It's always progressed slowly. And since I've seen the doctor last time...I feel weaker now during the off phase. When I'm in the off phase I notice I don't have as much strength as I used to and then in bed, after the medication, or Sinemet, has worn off, I feel weaker. And I notice I have to struggle more to get out of bed or change position."

Monitoring subtle changes was an ongoing activity for Ed. He kept an extensive recording of when he took his medication and all responses or reactions experienced in his daily dairy. The detail in which he did this was amazing. Diaries are a common activity for many people with Parkinson's especially those who have on-off cycles. It was common among participants who kept a dairy to record information such as duration of their various cycles. But Ed's approach was much more detailed not only recording the duration of cycles but documenting every symptom (examples: leg beginning to shake, increased shaking, increased amplitude, gait changing) experienced during the off cycles often making entries as frequent as every 5- 10 minutes. His diary included what he ate, timing of meals to dosages and basically every activity he did.

> "Maybe it's not publishable data but at least, over a long span of time, it should be an accurate average...Before I see Dr. M. again next time I'm planning to graph it or make a table to show her what's happening."

He approached his diary as a science with the goal being an accurate, precise record. This was important so he could have an objective picture of what was happening and going to happen to him. He believed other people had a more accurate view of his disease and symptoms. Referring to former colleagues from work:

> "They can take a look at me and know what's happening to me I think better than I can you know because they're sort of looking at me objectively...If I notice it, they must notice it much more than I do because they're looking at me."

As a basic scientist, he values outside, objective observations more than his own experiential account. Keeping an accurate diary was one way of monitoring symptoms but also having "objective" data. He explained another strategy.

E: "I'm not emotional about the disease. And I think

> I'm more objective."
>
> I: "What does objective mean?"
>
> E: "I can look at myself and try to figure out what stage I am or why I'm, you know, suffering such a condition and there's no sentiment attached to it. I just look at myself as another patient. I mean I don't cry about it. I don't feel depressed."
>
> I: "Are you detached from it?"
>
> E: "Sort of yeah. If I had my way, I would cut my brain open or skull and take the brain out and open it up and put it under the microscope."

Ed strived to have a detached objective view as he believed others had of him. He was able to neutralize himself and view himself with no sense of emotion or loss. This detachment was congruent with his identification as a scientist. It was also a way of dealing with his frustration with medicine not being a science.

> "I think most neurologists are quite reluctant to tell you about how you are progressing--because I don't think they know themselves. It's something that the doctor watches and then based on what she knows about Parkinson's comes up with some probable type of thing where you really can't pin them down."

He strongly believed medicine needed to develop a way to provide "definite answers to how you're progressing".

> "I wish they had some way of keeping track of the progression of the disease. I wish they had some way of grading what stage you're at...In serology you're looking for the antibody level so to speak. And that will tell you what stage of disease you're at...I just wish there was a blood test that we could use to grade Parkinson's as well."

Since medicine could not provide the answers, he with the most accurate data available (his diary, and objective stance) attempted to monitor progression and grasp the future.

More Advanced Cases

E: "In order to figure out what's going to happen to you, later on, you have to look at somebody who's in the more advanced stage and try to figure out what part of the problem they're having as far as movement and so forth, are due to Parkinson's and possibly side reactions to some of the medication...I think it helps me understand the disease. Well, on a broad level."

I: "Do you think it helps you have the bigger picture?"

E: "Yeah. And it helps me understand what the medication's doing too because you sort of have to look at that angle too. And so I think I have a better overall understanding of what Parkinson's disease is than say those who are not trained as a scientist so to speak."

Assessing advanced cases with a scientific eye provided additional data in his attempt to grasp what the future held. Ed started attending a monthly support group after his retirement. He attributed his being able to take an objective view partially to this fact.

> "Because when you look at the other people who have Parkinson's you know, just like I do, in that group they consider me the youngest. And a couple of the patients have had Parkinson's for over 20 years and I can see some of the symptoms that the text describes in front of you and you have to figure out that eventually you might reach that stage too."

He was candid about support groups providing this opportunity though admitting he feels sorry for some of these people.

> "I like this idea about support groups. You know where--I mean, we shouldn't go to a support group meeting to self-diagnose. I say that but, you know, that's what I do."

<u>How long will I be independent?</u>

E: "What is the worst condition that a Parkinson's patient can suffer? Since I live alone I have to look at that realistically and, you know, I have to start figuring out what to do if I am going in that direction because I will definitely need nursing care and so forth. Financially I am pretty well off right now but once I get into that stage it's going to go pretty fast."

I: "When you say that stage what are you--"

E: "Ambulatory, is that the right word to use?"

I: "So you're talking about being ambulatory versus chair bound or something of that nature?"

E: "Yeah. I guess when I am in a wheelchair I am quite sure I'll need some assistance so I can't live alone so to speak. I'll probably have to move into a facility which will--I don't think I'll need 24 hour care, you know, during the initial stages but eventually I might reach that point. I don't know how long but sometime in the future. And the problem with thinking about this is that nobody's able to give you a time table as to when, you're going to reach that stage. And since nobody will tell me, I'm constantly trying to figure out exactly where I am and how far I can still go and still be independent. And see if I can gauge how fast I'm going toward the worst state or whatever you want to call it."

I: "Does it work? Can you do it?"

E: "I'm not very successful at it. I still haven't the slightest idea when I'm going to reach that stage. I wish there was some kind of reference that will tell you but there is none."

Ed central concern was how much longer he'd remain independent. All his efforts related to monitoring his symptoms, observing more advanced cases and staging his progression centered around determining when he could no longer care for himself. He was aware this would happen because of an experience he had several years ago. He described this as a paradigm case of a difficult situation since being diagnosed.

> "...I caught this cold I felt kind of nauseous and I thought I might throw up but I wanted to go to the bathroom just in case I did throw up, but I couldn't move. It was like I had glue all over me and I was stuck to the mattress. I just couldn't twist myself or anything. But I did find a way. I think I kind of inched my way to the edge of the bed and rolled out. And I tried to stand up. I was quite dizzy so I decided it might not be a good idea to stand up so I kind of crawled to bathroom. And I sat there for a while figuring I might throw up but I didn't. And I beginning at that point, I think it was about 2 or 3 o'clock in the morning, whether to call the doctor or an ambulance or something."

From this experience, he concluded:

> "It made me aware that I may reach a point where I won't be able to take care of myself".

After this experience, his neurologist increased the Sinemet dosage. Although a similar experience has never occurred, this situation convinced him there will be a time when he will no longer be capable of caring for himself.

Ed was very cognizant of the progression in his disease and the resultant impairment of physical movement. When he spoke of becoming chair bound, it was in a non-emotional way. The physical limitations were changes he had expected to experience and he anticipated further physical limitations in the future. His fears were not connected to becoming chair bound but rather to other changes.

> "How long am I going to be mentally competent? You know, when I get to a stage where I'll need a wheelchair will I be mentally competent? I think I will be but I'm not sure...I hope I don't reach a stage where I won't be able to write or read. Well, frankly I hope I'm dead before I reach that

> stage."

He spends a significant portion of each day reading. It is one of the few activities (other than watching TV) he can do without difficulty in the off phase. When asked if his mental capacities were changing, he replied:

> "No, at least I don't notice it in myself. Perhaps somebody looking at me might."

Again there is the notion others have a more accurate view.

Ed felt his efforts to "gauge" the disease progression were largely unsuccessful. Based on the current, limited treatment options available to him and the inability of medicine to provide definite answers, these efforts were his way of dealing with the unknown future as unsuccessful as they were.

Related to his future concerns, he had investigated care options available when he was no longer independent.

> E: "I don't know when I'll have to get into a wheelchair or something like that and that means I would have to ask for help from somebody. I knew about this outfit that takes care of senior citizens...And one of the social welfare people there has taken me to these various nursing homes in San Francisco, the expensive ones, the cheaper ones. They're usually run by Korean families or Filipino families, these homes that allow 5 people."
>
> I: "Like a board and care or a residential home?"
>
> E: "Residential home, yeah. But they won't take you if you need 24 hour care. For that type of thing you have to get into a convalescent hospital. I don't know when I'll be at that stage but I have to think about that too. So I think I've gone about it rationally."

Throughout the interviews when discussing the future, he remained very calm and non-emotional. Even when discussing being wheel chair bound or in a nursing home, his voice was composed, speaking in a very collected and untroubled manner. His approach to this topic was consistent with how he approached every other topic in the interviews, discussing as comprehensively and rationally as possible. Initially during the interviews I was quite surprised as to how calm, analytical and objective he could be related to his own future. But as I began to understand Ed, I realized a rational approach was deeply ingrained in his identity as a scientist, and expanded to his most general ways of being in the world.

His hopes for the future were centered on remaining independent.

> "I'm hoping that sometime in the near future--I don't expect a complete cure, you know, from Parkinson's but for instance this fetal cell transplant, I hope that works out well to the point where it might be one way of alleviating or stabilizing Parkinson's...something that will stabilize it at a certain level."

> "I think my condition will worsen and I hope the present medication will still be able to help me. I hope I don't reach a point where Sinemet won't work at all or, you know, the medication like Permax won't work either. Of course, if I'm at that stage I'm probably at a stage where I won't be able to move anyway. Well, anyway, 2 or 3 years, I hope I'm still able to live by myself so to speak, you know, be independent. Do a little-some things that I like to do."

These hopes were rooted in treatments; for a way to halt the progression or for current modalities to continue working. In the second quote the concern of what happens when the medications no longer work resurfaces. As noted earlier, this concern has been present since being diagnosed.

His hopes do not include a cure or return to previous levels of functioning. Rather his horizons have narrowed to a future in which he hopes to remain independent enough to do some of the basic things for himself. At least for a few more years, while he waits and hopes, for a treatment option to halt the progression.

CHAPTER 5

Paradigm Case: Hopelessness to Control, Creating a New Future

> "I've had problems with severe depression with the Parkinson's and where at the end of November I took a drug overdose and a suicide attempt and ended up, they took me to the emergency ward, ended up in intensive care, and on their psychiatric ward for about 11 days. And that's kind of--after that, after working through that I've kind of changed my outlook greatly about a lot of things. At that point I hadn't told my friends that I had Parkinson's disease...I wasn't paying very much attention to my Parkinson's. I was just trying to go on like it would--ignoring it or not giving it the attention that it deserved. That really is wrong."

Dave Smith was the youngest participant in the study, being 42 years-old. We met at a support group meeting, the first time he had ever attended such a group. He had Parkinson's for 6 years. Central to his story was his suicide attempt of the previous year. His story was one of helplessness and hopelessness turned to a narrative of control and positive thinking.

Background

Dave was a single man, who lived alone. He had been in a relationship over 7 years with his girlfriend, thus predating his diagnosis. When initially asked if I could approach her about participating in the study as a partner, he refused explaining "I have put her through too much". After our second interview, he indicated it would be alright to ask her and provided her work phone number. On an initial phone conversation she expressed interest in participating. When later contacted to set up an appointment she did not return my calls. I recontacted Dave after several attempts at reaching her, and he indicated they were no longer together. Throughout the interviews with Dave, he did not speak of any other close relationships either with friends or family. His family including his only sibling resided in the Midwest.

All the interviews occurred in his rented office space. He had worked as a mechanic. His work was the source of financial support for what he truly enjoyed.

> "My job generated money for my everyday upkeep but it also pays for what I really want to do which is make experimental films, what I have been doing the last 15 years. It's very expensive and all my money goes to that so the work kind of generated support for the film."

He stopped working as a mechanic approximately 2 years ago.

> "I didn't want to have to explain to all my clients what was happening medically with me so I was trying to hide the symptoms. And also the biggest part of it was problems with fine motor skills, that I just didn't, I started to not have the fine motor skills necessary to do the work...Your best tools are your hands as a mechanic."

Although he no longer worked as a mechanic and was limited in his film making because of financial constraints (his income was federal disability and social security), he maintained his office space.

> "It's a nice way to keep in contact with people. I wouldn't want to have to be at home alone. It'd be pretty awful...I'd kind of like to keep the office just to be able to work out of. It gives me discipline. I get up in the morning and come down here and I do certain things."

Our interviews took place during late spring/early summer. He was at a transitional point in terms of career, planning to enter graduate school. This point will be elaborated on later in the discussion.

Getting Diagnosed

> "It would be just slightly off but it was enough that I could notice that my foot wasn't landing in the right place every time. And also at the same time I started to have headaches in the front, right side, and so I put those two things together and I was afraid it was a brain tumor."

He sought medical care via a neighborhood clinic. He described it as an "indoctrination to poor medical care".

> "...I told him the symptoms and he examined me and he gave me two alternatives. He said, well you can take the Parkinson's medication and if it improves things then you'll know that's what it is, or you can go to see a neurologist and he can make a further diagnosis. But I thought initially that was a poor medical approach, because if it hadn't been Parkinson's disease--he was right. It was Parkinson's. But if it had been something more serious or more acute, not taking any other diagnostic action could have been very dangerous."

He opted to see a neurologist who recommended a diagnostic work-up which took approximately 1 year to complete due to CT scan failures, unavailability of MRI scans and several other delays. This lengthy process reinforced his frustration with the medical system.

> "And through that whole period the symptoms were getting worse and I was feeling worse. I had increased weakness especially in the left side and increased fatigue."

He felt, as did several other participants, Parkinson's was a better diagnostic option than some of the other possibilities.

> "I was familiar with the fact that there was medication treatment that was fairly effective for Parkinson's disease. I remember as a kid reading about when they introduced levodopa treatment for Parkinson's, so I wasn't panicked. The clinic

> doctor said that there was a possibility, the initial state, that it might be ALS, which that I was much more worried that it might turn out to be something like that so I wasn't particularly panicked when I discovered it was Parkinson's."

He began Sinemet therapy almost immediately.

> "At first I was on real minuscule dosages and they didn't have any effect. And then after awhile I changed from the clinic neurologist to a private neurologist and he started me on a pretty normal low dose of Sinemet. Then I noticed some definite improvement of symptoms of the Parkinson's...The Sinemet is a terrific medication. Because it isn't like being drugged or it isn't like these--it's like being, taking you back to normal."

Dave's story illustrated similarities and contrasts to the other paradigm cases presented. He did not experience an initial hesitancy in starting Sinemet therapy as discussed in Mary's and Ed's cases. Possibly because of his lengthy ordeal in getting diagnosed and experiencing worsening of his symptoms during this time frame, he began therapy immediately. However, he did express concerns related to Sinemet's decreasing effectiveness. When discussing a particular situation, I asked if he had considered taking an additional Sinemet as an option. He responded:

> "I try never to do that. Because Sinemet is my friend and I don't want to abuse it. It's the only thing that makes me feel really good. And I know if I start taking it more and more often it's going to be less and less effective, so I've always wanted to kind of stretch it out as long as I could."

Similar to Ed, Sinemet made him feel "normal".

> "The Sinemet, basically it's only effect is to kind of make you feel like you have got yourself back to normal."

The Lived Experience: Cyclical Nature

Whereas he experienced definite improvement with Sinemet therapy, his experience as time progressed included fluctuating patterns. He described the nature of the illness to be cyclical both on a daily and a three-four month cycle.

> "On an ongoing basis there's a double periodicity, a double, cyclical thing happening, that all day long with a fairly routine pattern of up and down with the medicine, but there's also a longer rate cycle of the illness where it might be better at times and worse at times. And that might cycle over a 3 to 4 month period, where it's up and then it slows down and stuff. And that, the big cycle kind of each time gets a little bit worse and when it's done, and each time it doesn't get as good when it comes back up. It kind of cycles the further involvement of the illness, the degeneration is kind of smeared by that, how that big cycle is going. So that's how I gauge I am doing at any one time."

He experiences "up and down" fluctuations daily. There is also a noticeable waxing and waning of the symptoms over a 3-4 month period which he does not attach to any particular demands or actions in his life.

> "...I have no clue as to what the frequency or what causes the frequencies of the up and down. It varies wildly and doesn't seem to respond to any kind of external stimulus at all and so just when it comes on, it just comes on."

The longer cycle of "up and down" ultimately results in the "lows get lower" and the "highs are not as high" reflecting a general sense of well being. Both cycles (daily and longer cycle) he attributed to the effectiveness/ineffectiveness of Sinemet.

> "I think it mostly has to do with how effective the Sinemet is. Initially, when the Sinemet really kicks in you feel very good, everything is almost

> back to normal. But over a period of time, the length of the effectiveness of the Sinemet decreases."

Understanding the experience of these "up and down" and "high and low" cycles requires understanding what Dave experiences when the Sinemet is working versus not working:

> "When I make a fist with my left hand and then I start to roll my toes with my left foot. So 30 seconds of when toes seem to want to start rolling like that. Then the onset of the Sinemet happens and everything changes. All of a sudden I can move, my back is flexible. I kind of gauge how I'm doing by moving the toes around. If I can easily just make the toes move, then I know the medicine is effective and as the medicine wears off the toes get slower and slower and pretty soon I can't move at all. It has a slower decay."

As noted earlier when the Sinemet was working Dave felt basically normal referencing pre-Parkinson's disease.

> D: "And then when the Sinemet comes on everything changes dramatically in a couple of minutes where I can flip all around and move normally instead of being like stiff and walk like that. Everything is loose again. And it seems like more than just a psychological relief. It seems like my personal nature kind of comes back to me where I'll feel aggressive again and I feel like pushing things and trying."
>
> I: "Do you feel more like yourself?"
>
> D: "Yeah."

He spoke of his "personal nature" being restored and feeling like himself. His way of being in the world was influenced by whether Sinemet was working or not. His identity and how he related to others was experienced in the lived body, the body that moves, pushes and grasps. His embodied being rested in a body with normal movement and flexibility. When Sinemet was working, he felt "aggressive", "like pushing".

He emphasized how Sinemet dramatically and rapidly changed how he felt.

> "When it works it works really well. And it's really a dramatic change...For me, it's definitely a threshold thing that causes this incredibly dramatic change. Sometimes I can be feeling really bad and within 10 seconds I can feel almost perfectly normal...All of a sudden I can move."

He contrasted this to when the Sinemet was not working, providing a physical description of what he looks like:

> "Well, before the Sinemet turns on I would be, if I was walking, I'd be sort of shuffling along. My neck doesn't turn very well when the Sinemet isn't working so I'd be looking straight ahead. Maybe, look like a little old man, you know, kind of shuffling down the street. And usually I'd look like I'm trying to avoid situations...When the Sinemet is not working I feel like I've been robbed of more than the physiological but also sort of robbed of my basic nature because I have to withdraw into this sort of like emergency mode."

When Sinemet was ineffective Dave experienced a loss of his way of being and getting around in the world. He needed to "withdraw" and just get by. Sinemet ineffectiveness involved a decline in physical functioning but even more important a loss of his "basic nature" and sense of self.

> "Accompanying this is also sort of a psychological effect that kind of makes me--I kind of diminish along with my physical capacities. I feel like I feel more timid. I have to focus my mental attention on just getting by until the medicine starts to work again..."

Dave acknowledged the differences in his appearance and physical mobility when Sinemet was effective versus not were noticeable to others but misunderstood.

> "I think a lot of it can be noticed but misinterpreted. As the medicine starts to decay I think you could be misinterpreted as being angry or

> upset or something like that. Sort of a mood thing. And it isn't like that at all. It's just that you're in that state. It has nothing to do with your mood. On the one hand, I wish other people could understand what's going on better, but I would not like to kind of share the unpleasant experience of what's happening either. I think you can only realize what was happening by really experiencing it yourself."

His experiences when Sinemet was ineffective were untranslatable because their physical nature cannot be captured in words. The disease had privatized his embodied self. He withdrew into an emergency mode <u>not</u> from embarrassment but because these experiences could not be understood. It involved his basic way of being and getting around in the world.

> "...people think of it as you have a shaky hand or a shaky leg or something like that. If that's the only thing that happened, it would be a lot easier to deal with but my experience it's a total neurological defect. When the medicine is at it's least effective stage I experience this kind of narrowing of all my facilities. It isn't like I loose the ability to think or feel or--but those abilities become stressed...My threshold for all kinds of emotional response is very much narrowing. I feel like an eggshell covering that doesn't take much to affect an emotional change. That's definitely a difference. And when the Parkinson's is at it's worse--I call it neurological strangulation. I feel like I'm suffocating neurologically. I just have to sit down and everything sort of pulls inside, pulls back. It's a difficult sensation to describe. There's certainly a weakness associated with it. There's certain muscular weakness, loss of coordination and things like that. But the more affected part is this kind of overall sickening feeling, neurologically."

Dave's experience of "neurological strangulation" was similar to Mary's "dead in the water" and Ed's description of his brain being "waterlogged". The experience was not purely physical but involved how they were able to think and their sense of how they felt.

The "neurological strangulation" was experienced at the low points of the longer cycles but also at the down times on any given day. As he continued to describe this experience, he provided non-verbal clues such as grimacing and physical clues which indicated what an encompassing experience it was.

D: "...the illness has kind of sine curve to it where it's up and it takes a big path where it it'll change over 2 or 3 weeks or 4 or 5 weeks where things are up and then there down and then up. And with the progression of the illness the highs have not been quite as high and the downs have been deeper, so that in the worst case scenario, that's when the big sine curve is at it's low point and the medicine is also at it's low point during the day and I'm most fatigued. I'm in a very distressed and uncomfortable situation where sometimes I just have to lay on the floor just because it's the most comfortable position I can think of. Even sitting in a hot bath is uncomfortable."

I: "Uncomfortable, is there pain associated for you?"

D: "It's not exactly associated with any kind of pain. It's kind of an internal sensation that something is happening throughout the entire neurological transmission path. It's like I can't communicate with my body. But there's spurious communication back like noise and I don't know how to interpret it. And it isn't like pain which is a very distinct kind of signal back. It's a very sharp signal. This is kind of like a noisy signal that I'm getting back."

I: "Kind of nebulous, fuzzy?"

D: "Yeah. But it has enough spikes in it that it will--it makes your whole body kind of uncomfortable. It's that I have to regroup all my thoughts and energy and what facilities I have left to kind of just put myself at ease to minimize the uncomfortableness of the noise coming back. And the bad part is that if I'm in some sort of situation where I am around people when that

> happens, I cannot concentrate to communicate with them. I don't want to talk to anybody. I just want to totally pull back, and it's not because I'm embarrassed or anything like that. It's just because physically or somewhat like physically I have to defend myself from the illness. It's a very difficult thing to describe what the sensation is. I call it neurological strangulation. It's like things are not--it's like you're not getting a full, full flow back and forth of information."

When he was at his worst in terms of the cycles, he was non-functional. On a daily basis he described times in the day when all he could do was to lie down and rest. This helped minimize the "noise". He also experienced this relative to the low points on the longer cycle. One of his examples of a difficult situation was having this experience recently at a party with friends.

> "And I was really looking forward to it because a lot of my friends were going to be there and I wanted to talk to them and there were interesting people. When I got to the party, after that day and a half of real hard work, I wasn't feeling very well. And I thought well, I'll just sit outside and I'll just, you know, at some point the medicine will kick in and I'll be feeling much better and what happened was time kept rolling by and I kept feeling worse and worse and worse...And I had to lie down. So I told the host that I was going to go and lie down for awhile. And the only place where I could lie down, unfortunately, was where they left their coats and bags and things. So I mean for about an half an hour people kept coming in and seeing me lying there, you know, in my worse condition."

When Dave discussed these low points or his "worst condition", his body indicated tension, tightening and arching as he sat. He spoke with facial grimacing and apparent bodily distress. When he experienced these sensations, he was not at home or comfortable in his own body. As he stated, "I can't communicate with my body." His body was not the body he once knew.

Fighting the Parkinson's

Throughout his narrative, the theme of fighting the Parkinson's or defending yourself from the illness was consistent. Intrinsic to this theme was the notion of being robbed by the illness. An example:

> "You don't know what you're going to be robbed of by the Parkinson's. You don't know what it's going to take away from you as well as you're motor functions and that's kind of a scary situation."

Parkinson's was a threat, something he lived with in an adversarial relationship. Parkinson's was something to defend yourself against so you would not be robbed of such things as your "basic nature". Benner has described this type of relationship to an illness in her research of people with asthma. A significant number of participants in her study understood their illness as something to be fought with, to relate to in an adversarial, controlling manner (Benner, Graduate seminar, Fall, 1990).

As he stated in the first quote provided in this chapter, he had told no one except his girlfriend he had Parkinson's disease. For six years he lived with this secret. In the interim, he had stopped working because of difficulty with fine motor skills but also because he did not want to explain to people what was going on with him.

I: "Looking back on it, why didn't you tell people?"

D: "Well, I've always been a private person and I've always had a great fear of people treating me with any kind of special treatment or special way and I was really afraid of--First, I felt it was my business, it was my problem, I was going to have to deal with it, it was nobody else's problem and I didn't want to be treated in some kind of special way...But in retrospect that was a big mistake. If I had been clued into anything from the beginning, I wish I had been clued into the fact that it was very important to let people know from the onset what's happening, for a number of reasons. But the most important thing is the longer you keep it to yourself, the more difficult it becomes to share with other people. And what happens is you not only end up fighting the Parkinson's but you end up fighting with yourself as far as letting any symptoms show that you have Parkinson's. You know, like you are fighting the Parkinson's and you're fighting this fear that you have it as well. And that makes it twice as difficult."

He described an awareness of depression during the years, such that he discussed it with his physician and was prescribed anti-depressant therapy.

D: "I think it builds up (depression) and it was pretty paralleled with the progression of the illness. As things got worse with the illness, the depression changed as well...Before I had to be hospitalized I had gotten these like these suicidal impulses that I didn't know where they came from. One happened to me while I was down here working, just working away and all of a sudden I got this impulse that said, why don't you do it now. You know. And I thought, where did that come from? How did that pop into my mind? There's nothing that's bothering me. I'm just down here working. And the second time it happened I was at home working on a film and when I'm working on films I'm really involved and very happy, and that's when I realized that something was happening. It was sort of out of my control."

I: "Did you share that with anybody?"

D: "Yeah. I did. I went to see my neurologist and told him about that because he had mentioned to me the importance of being aware of depression. And so I started to be treated with antidepressants at that point. But I decided I didn't want to be

> taking them and took myself of off them and then a couple of years lapsed and that's when things got really bad and I wasn't even aware that they were getting bad."

> I: "Did Cathy sense, did she think something was going on?"

> D: "Yeah. She knew that I was depressed. She thought that I was probably was laying there in a pool of blood or something...Even though she recognized that there was something going on, I was stubborn enough to resist anybody's advice because I thought I was in control. I thought I knew what I was doing. But I wasn't."

Dave could not give up his belief that he was in control because then the Parkinson's would have robbed him of one more thing:

> "It's like giving up more of yourself, conceding more of an illness. I'm sure people with Parkinson's disease kind of cling to what they've got left as far as any positive attributes and giving them up like admitting that your mental health might be in danger or affected is something you do with great reluctance."

Ultimately, the depression resulted in a suicide attempt involving an overdose of Valium. He was discovered two days later by his girlfriend. She had been unable to reach him by telephone so had the apartment manager unlock his apartment.

> "Up until that point I was not really facing the reality of the illness and also I had done a lot of stupid things, like I hadn't really looked into what the possibilities were to be progressive and have Parkinson's disease. I thought it was just that I was trapped in this deep dark pit, you know, with no way out...that there was no way out and it seemed to be everything was--that everything for the rest of my life was predetermined because of my illness. I didn't see any open space in front of me at all...I felt I couldn't make changes in my life and that was the worst part."

Six years of hiding his disease, believing that his future was predetermined, fighting to maintain control and not be robbed of who he was, compounded by depression and hopelessness; led to a suicide attempt. For Dave, the failed suicide attempt was a turning point.

"I can still be in control": Creating a Future

> "I was still in the hospital, I kind of got up in the morning and I had to put my socks on and I had this very difficult time getting my socks on. But then I said, I'm going to sit here, if it takes me all day, I'm going to put these socks on. I eventually got my socks on, and that was a real positive experience because it told me that, you know, even though all this stuff had happened that I still had my determination and the Parkinson's and the depression and everything else had not robbed me of that. And I knew that as long as I had the determination that I was going to be alright, that everything would work out alright."

This was a response to being questioned about a positive event or situation since being diagnosed. The realization he had not been totally robbed of his nature by the Parkinson's allowed choices and a potential future. He explained the most significant result of his suicide attempt was an adoption of a "correct attitude".

> "The whole thing requires a correct attitude that I only have recently developed, and that attitude has to do with the ability to change, to change internally, whatever you're experiencing at the moment, even though it's the worst possible situation, there is always a possibility of change. And I don't mean that one day I'll be cured or something. That's kind of my external existence and that may never change at all. But you can change your outlook on things. So, that gives me hope at all times, that even when I'm feeling bad think, well just hang in there and work at it you've got the ability to make things better. You can put yourself in a really good place to get your head feeling really good."

The belief one's attitude can change things provided options and control. Changing his attitude restored his sense of control over his life and of a future which he previously felt he had lost to the disease. Hopelessness had been replaced by having control, having control over your attitude, what you think and your personal meanings.

> "I'm really inspired by the realization that amazing changes can happen inside of people and they can make them happen. They're the only people who can. No matter how horrible your situation, you still have that inside which is totally in your control and if you work at it you can make amazing changes. And I feel there are no hopeless situations. There are just people that have lost hope. And I think that's been the most beneficial is that realization that even though I can't control what happens with my body a lot of the time, I can still be in control and make amazing changes in my attitude."

Dave had invested in a control paradigm which rested upon positive thinking it will make it possible to overcome the illness. Throughout his narrative he asserted that the correct attitude provided the ability to control one's situations and experiences. This was what he learned as a result of this disease and the message he wanted to share with others.

> "The message that I'd like to get across is the idea that although things look bad and you might be upset right now, real large changes in your attitude and outlook are possible. You can make them happen and it would be a shame to waste that opportunity. And that with a lot of hard work you'll find that out and then you'll see how dumb you were when you thought that all hope was lost."

He made a swing from a position of hopelessness to control, which in many ways was not a surprising swing. Prior to his suicide attempt he was overcome by hopelessness, depression and a perceived loss of control of his basic nature, abilities, and options for his life and future. From Dave's perspective, the only pathways open were to continue in his hopelessness or to take control. How he took control was influenced by his vision of self-mastery and mind over matter. He fully recognized many aspects of his "external existence" could not be changed. He could not be cured nor could he control how his medications worked or the trajectory of his disease.

> "I always try to be cognizant of how the illness works and what affects it, but that's real frustrating because to this day it's still a complete mystery to me. I mean, I know certain things that would make it much worse, but I don't know anything really that consistently makes it even stay at a constant level."

Thus the only perceived option Dave had to overcome this hopelessness was create his "attitude", his mental and emotional responses.

> "I was locked into this deep dark pit and I didn't see any way out at all. I thought well, the only way I can get out of this deep dark pit is maybe climbing out, you know, inch by inch; and I was not up to that kind of approach because I was, I'm involved in just the opposite ability level and getting lower and lower. So I needed a way of dispelling the whole situation, of dissolving the deep dark pit. And that came through, externally it came through people being supportive, and internally it came about by viewing the sense that large changes could be made in my own thinking, my perception, and that was something that I could control. It wasn't going to be taken away from me."

The potential influence of health care professionals and pharmacological therapy for his depression cannot be ignored.

Prior to his suicide attempt, he saw only a neurologist about every 3-6 months. This is the standard way people with Parkinson's disease are managed in the health care system. While hospitalized on the psychiatric ward he connected with a team of professionals. One of the key people he identified was a new neurologist.

> "And he came around every single day and I thought, who is this guy? He's not a psychologist or a psychiatrist. He's the head of the neurology department. He approaches a lot of neurological illnesses as having a psychiatric component that is part of the illness. And so he was there every day to see who was there and who had neurological illness in a psychiatric sense. He didn't think like you had a weakness, you know, you became crazy, and all that kind of stuff. It's his viewpoint the symptoms of Parkinson's disease are tremor and whatever and a psychiatric component which is depression. So he treats it as a symptom of the neurological illness."

The neurologist's approach to depression as an integral part of the disease process provided Dave an option. Treating depression as one of the commonplace symptoms of the disease was an explanation which freed him. Prior to this, acknowledging the depression meant he had failed to fight the disease and allowed the alien disease to rob him of his mental health thus implying a weakness. The neurologist provided an alternative explanation which absolved him of his guilt and sense of failure.

> "A major symptom that also the illness is depression and it is likely to occur in a large number of Parkinson's patients regardless of what activities they pursue, regardless of what their attitude is like. It's purely a chemical change that takes place...Antidepressant medication allows me to be psychiatrically and psychologically in control to the extent that then the things that

> environmentally occur with the illness I have a fighting chance to deal with."

Nothing about him (i.e., his essential nature, personhood or moral character) had caused the depression, it was <u>purely</u> chemistry. The moral burdens of shame and blame had been removed. This view made anti-depressant therapy a reasonable intervention. His depression was the result of a chemical imbalance that was part of the disease process, not a human weakness or character flaw.

It should be noted the etiology of depression in Parkinson's remains controversial in the literature (Habermann-Little, 1991). Current research indicates a neurochemical imbalance exists in depressed people with Parkinson's (Mayeux et al, 1987). Whether or not it is the sole or primary etiology has not been established. He has continued ongoing care with several professionals after discharge:

> "I go to see a rehabilitation psychologist once a week and she's probably the most important medical person. I see my neurologist about once a month or once every two months. His involvement is really key. I see a psychiatrist just mainly to prescribe the nortriptyline...Seeing my psychologist, I work really hard on that. I like do mental homework all the time. I take that meeting real seriously when I meet with the psychologist."

He described his relationship with these professionals as "part of the team that's managing the illness". This represented a cognitive change in how he approached his illness.

> "I have a second chance to deal with the illness and I feel like I've been able to make a decision

> on my own as far as whether I wanted to or not to deal with the illness. I can make a big change in my thinking and that even though I may not immediately change the outside world I can make this big change on the inside which is going to affect how I benefit from the outside world...I was talking to a friend of mine the other day and I explained that the illness I feel is my illness. It isn't like some kind of foreign like the Asian flu or something. It's something that I have. It's part of me, and that I try to deal with. Looking at it that way is a lot easier than if I think of it as something that has happened to me. Because of that I need to be real aware and involved with the management of it. It isn't like these doctors take care of me. It's their part--I sought them out to help me manage what I've got."

His language indicated he had changed from seeing the illness as "something that had happened to me" to "my illness, it's a part of me". While he verbalized this dramatic change, his narrative was inconsistent with this transformation at times. Even during the last interview his narrative remained adversarial at times. Throughout the interview he vacillated between a stance "not fighting the illness" to a stance of "fight every single day" and it's "a battle every single day". He did acknowledge the transformation of not fighting the illness was difficult.

> "But the biggest thing is, even though this is hard to do sometimes, is to not fight the illness. You can't think of the illness as being something that is, had been forced upon you."

Although he perceived possibilities and restored hope for the future, his relationship to the illness continued to be an adversarial or a "fighting" relationship. The transformation which occurred was not one of integrating the illness into who he was but rather a "thinking makes it so" stance. That is, by thinking positively about situations he believes he can transform them into positive situations. He could give a situation whatever meaning he chose. On a day-to-day basis he continued to fight the illness.

> "It's just a matter of being able to deal with it every day, fighting it every day, getting as much done as I can. As long as I feel like I'm getting something done, then every day makes sense. If I'm just going to get through the day and fight this horrible fight and it's painful and uncomfortable and unpleasant that doesn't make any sense. But if I feel like I fight real hard, I can probably get stuff done...And if I can succeed in doing some things while I'm fighting this illness, other things should be easy. I try not to worry about things. I try not to be afraid of things because I think about my illness as being the thing most frightening and upsetting."

Prior to his suicide attempt battling his illness was the central project and organizing narrative of his life. The theme of fighting the illness continued in his narrative. But fighting the illness relativized all his other battles. He had faced and survived the worst in his illness (a suicide attempt) and everything else paled in comparison. Nothing was as frightening and as difficult as his illness. This coping strategy worked well to provide possibilities for the future. He had already survived the worst.

Transcending the illness:

> D: "And also the Parkinson's in a way, in a strange and perverse way, simplifies your existence. You have to give up certain things. You are a little less able to do certain things. But you can't dwell on that. You have to dwell on all the new things that are coming into your life."
>
> I: "What are some of the new things for you?"

D: "Going to school. Recently I've gone to these advocates here in the city, and they told me about this self-support program that I never knew existed, that going to make my life really easier. It's through SSI and you have to be on 2 forms of income. You have to have SSI and another form. What they will do is they will, if you present a plan that will get you into a self-employed mode, or an employment mode, off of SSI like in 2 or 3 years, they will match the amount of funds per month that you receive with the second amount of funds. Like they will match my federal disability payments each month."

I: "Because you have a plan now, for school and career?"

D: "Right. So virtually they would pay for all my education, like a computer and stuff like that."

At the time of our last interview, Dave had been accepted into a graduate program in rehabilitation counseling. He had enrolled in summer session and was about 4 weeks into one course when we met. He reported everything was going "pretty well". He spoke with a sense of relief:

> "Sometimes you can doubt or you might question what you're losing with the illness. Are you going to lose creativity? You don't know where these things come from exactly, so you don't know what's going to be affected, you know. And it's nice to know with school I haven't felt the loss of creativity. The Parkinson's hasn't caused creativity to be damaged or anything."

More than the immediate sense of relief, school provided access to a future.

> "Even though I'm not a religious person I've always had the hope that if there was some work for me to do, that was kind of predetermined, that I would be smart enough to recognize that and be strong enough to do that. And I know for a long time the things that I have been doing certainly aren't that and so I sort of want--the only thing I'm focused on, that I'm focusing on entirely, and that is I feel that this is the new direction of work I'm going into to is--I'm hopeful that that's going to be, if there

> is such a thing, the kind of thing I've been meant to work with, meant to do...So it helps to have a big plan that you have a big overview, then it helps to be working real hard toward that plan, day by day. Because then when I'm fatigued and when I realize that that's going to be about it, I'm much happier then going to sleep at night. But if I hadn't been working toward something, if I hadn't accomplished much during the day, then I would look at the time remaining as a big scary piece of existence."

School provided a new direction and hope for a future rather than a "big scary piece of existence". There was hope for a new direction, a new project that he was meant to do. Dave saw developing a second career as essential due to his young age and because of declining federal and state funding for the disabled.

What he had chosen to study was significant, to train as a rehabilitation counselor. He believed being disabled was an asset.

> "And now I feel like I have an added insight into disability, by having a disability myself."

Because of his frustration with the splintering and bureaucracy of services for the disabled, he wanted to enter the field professionally. In each interview there was discussion related to how difficult it was to get support and services because of the system. Many examples existed. He had experienced an eight month delay receiving SSI. He had been canceled for MediCal for a month due to a technical processing error. His frustration was not limited to the federal or state systems but included services for the disabled at the college.

> "It's still an extremely aggravating situation to see how dispersed all of the resources are and how--I can't imagine that there's isn't a better kind of system for handling it. For instance, they have a whole building, this little temporary building, but they have a whole building for the Disabled Students Association, and they have this big organization with all these people and stuff, and yet they seem to be missing the most basic kind of elements. I called them up at one point and I said, what kind of special financial avenues exist for disabled people going to college? And they said they didn't know and they had no input to any kind of financial aspect. I mean, they're doing stuff like helping you gain access or having a sign, a person do the sign language and stuff, but you've got to get into college first, you've got to pay the tuition, you've got to overcome that first. And they're disconnected from that whole thing."

One of his goals was that he would be able to inform "people as fully as possible what benefits are available and where they can go for help."

Most significant, training to become a rehabilitation counselor made sense of the last seven years of his life. It provided him an explanation as to why he was disabled. There was something "he was meant to do, it was predetermined".

The Vulnerability

Dave's liberation from hopelessness and concurrent treatment for depression steered him away from a destructive or suicidal path. Dave's hopes for the future were tied to getting into a new line of work, one he was meant to do. The only hopes he expressed were related to this. When asked if he had fears or concerns about the future:

> "Yeah, I certainly do. I hope that I'm strong enough to handle it. That's all I can say. I have doubts everyday: Can I really handle this? Can I

> stand one more day? You know. And that's the battle you fight every single day. I say I hope I'm strong enough but I'm not sure. I'll just have to wait and see...When I get worried about stuff like that I tell myself to shut up and keep going and everything is going to be alright, that I can make it and it will be okay."

Dave continued to vacillate between a sense of control by having the correct attitude versus feelings of powerlessness and questioning if he had the strength to continue "the battle" with his illness.

Benner and Wrubel (1989) noted one problem with people who take up the "thinking makes it so" view is they will vacillate between complete autonomy and freedom and the opposite, powerlessness. Glass (1977) in studying Type A behavior has noted when the limits of control are reached people tend to give up and experience apathy or helplessness, thus vacillating between control and helplessness.

Dave's vulnerability and how precarious he feels was evident in the above quote. He had invested heavily in a "thinking can make it so" view which provided his sense of control. The experience of Parkinson's disease may be such that it lends itself to this view. The body becomes resistant and the mind (or thinking) and planning by taking medication can make the body work. But the limitations of this approach were evident in Dave's case. Missing from his narrative was an acknowledgement of the limits of control and the notion control is not achievable in all situations. Particularly related to the future there was a glaring absence of any narrative of disease progression and future limitations he might experience. When specifically asked if he was concerned about physical limitations, he replied negatively.

> "I think I'm at the stage now where it's just a matter of execution, that I need to execute as well as possible with the illness. I don't think a lot of things will change from this point on. Either as far as treatment modalities or I don't expect major changes are going to happen with me. It's just a matter of dealing with it everyday, fighting it everyday."

Although on one hand he was cognizant of his disease progression (earlier discussion of the lows get lower, the high are not as high), he did not have a narrative about disease progression in the future. Unlike most other participants who acknowledged future limitations (and concerns about this), this was missing from his narrative. Rather his discussion was limited to new found hope and possibilities.

> "It's good to have the feeling of things happening and coming up in the future, that there are positive things to think about."

His vulnerability was evident when he reached the limits of control. For example his loss of control at a party was "upsetting and very humiliating".

> "It has to do with control and feeling in control and to a certain extent the illness has a mind of it's own. I know that some of it is--I can help to control my routine and by doing certain things and I suspect some of it is psychologically triggered but to a larger extent the overall effect is not very predictable. And that means a loss of control, and that to me, that's very upsetting."

Whether he will be able ultimately to deal with losses of control as his disease progresses cannot be known. To lose control in a particular situation undermines the belief that control can be grasped by attitude or thinking. The illness having "a mind of it's own" weakens his faith in his ability to be in control. When control fails Dave feels vulnerable both in the present and the future.

CHAPTER 6

Paradigm Case: Live Life Now

> "We all think of ourselves as a little bit, at least a little bit immortal and at least a little bit invincible and I guess I've always viewed myself that way, too. And I've had life tell me, no, that's not, you better start thinking about enjoying life now."

Gary Miller had been diagnosed with Parkinson's for approximately 18 months. His disease by objective scales was mild, only involving his left side (Hoehn & Yahr, Stage 1). His own account was consistent; he perceived his disease to be fairly mild.

> "I'm fairly lucky, my symptoms are fairly mild, they don't seem, they're progressing faster than I would ever like to see them progress, in as much as I can tell there are differences. But they seem to be progressing slower than I believe is the norm. So my situation is not as severe as others experience."

But yet being diagnosed with Parkinson's had changed his experience of temporality. The importance of the present and living now was a common theme throughout his narrative. His story was one of "get on with living and enjoying my life".

Background

Gary was a native Californian having lived in the state for all of his 44 years except for two years while in graduate school. He had married shortly after college.

> "Right after graduation I got married. Shortly thereafter my wife became pregnant and we had our son who is now 21, you know, very soon after our marriage. So by the time I was not quite 23 I was a daddy already. And I worked in the insurance business for a couple of years, not because I

> particularly wanted to but rather because I was staring military service in the face and it was very difficult to find a job doing something that I was interested in doing. So I worked in insurance for a couple of years and decided early on that I didn't enjoy that and I decided to go back to school to pursue a field that interested me more."

He studied public policy and has been employed in related areas for approximately 15 years.

His first wife and he divorced in the mid-1980's on "fairly amicable" terms both wanting custody of their son, who was teenager at the time.

> "We decided the best way to handle that was to split the custody about half, 50/50, and he would live with me from the middle of summer through the end of the first semester of school and would live with my ex-wife the other half of the year. And we also agreed we would both stay in town until he was out of high school so that he could continue to have some continuity. And so he could finish up middle school and then go to high school where he had grown up and all his friends and so forth."

At the time of his participation in this study, Gary was in the midst of personal and professional changes in his life. Two months previously he had left his job.

> "I'd been I guess considering moving on from the kind of work that I have done for the last 15 years to something quite different but I've never quite been able to and still haven't quite put my finger on exactly what I want to do next. But I decided when I was given the opportunity to leave the company with a generous separation package I did a lot of soul searching and I decided what I really needed to be able to do or to be able to make the transition to something very different I had to put some distance between me and the work day environment that I had existed in for so many years...So I decided I needed some distance and this afforded some security in being able to do it."

He had recently remarried. He explained the many changes occurring in their lives.

> "Kathy and I are doing all the things that you are not supposed to do in trying--we're changing several things in our lives all at the same time. We've gotten married. I left my job planning to change careers and we've decided to leave the Bay Area and move to another area. Our place is on the market. We just had an offer this morning which we countered. So it's possible we could be in escrow soon on all of this, and of course we're faced with the situation that we don't have jobs there, we maybe have the house sold and all that but frankly it's a great adventure. And neither of us consider it terribly dramatic. So it's a little unconventional but we feel that we're at a point in our lives we can do that sort of thing. Kathy and I are the same age, she was married as well before, but she has no children, I have one child who's grown and on his own. We don't plan to have any more children. Neither of us has any debt to speak of except for a mortgage on the house."

By the third interview, the changes were becoming realized. The influence of Parkinson's disease on the changes he was making in his life was acknowledged by Gary.

> "And we felt now is the time to make some changes in our lives and slow down the pace and perhaps live in an environment that's a bit less expensive and a little slower and so forth. I would have to say that it wasn't the major reason, but having Parkinson's and so forth kind of prompted some of my thinking along these lines. I mean, I was considering it for a long time anyway, the notion of perhaps living in a less stressful environment and living in a little bit slower pace, the fact that I have Parkinson's disease kind of contributed to or, it was just one more plus in the direction of saying that maybe that is the way to go."

Getting Diagnosed

> "I was a runner for years, and probably 14 years, 12, 14 years ran religiously virtually every day. And about a year before I was diagnosed as having Parkinson's disease I noticed I was running during my daily run I'd typically run about 5 or 6 miles at noon time. And about, every once in a while,

> not every day but periodically I would notice I would about 3 or 4 miles into my run, my left leg would kind of stiffen up on me...The overall effect was that I would end up kind of--it would throw my gait all off, my stride, and I would be uncoordinated, not to the point of falling down but to the point that my gait was all off and I'd be ratcheting along. I'd lose my stride, and have to stop and walk for maybe 10, 20 yards and then I could start up and run again and maybe a mile or two and then the same thing would occur."

The changes in his stride, noticed over a six month period gradually increasing in frequency, sent him to his internist who was unable to detect any abnormalities on examination. After several visits to a chiropractor, for a possible "back problem", he noticed the leg was "a little bit worse but not dramatically worse", and requested a referral to a neurologist.

> "It took me literally six months to get from the time that I said I wanted to see a neurologist until I was able to see one. And in the meantime, the internist that I had seen before left the HMO and it was a comedy of errors which was very very frustrating but I finally persevered and raised hell and finally was able to see a neurologist. And after 2 or 3 visits with him, he did an MRI and I guess an X-ray too, I think of my head and could find no other thing and subsequently diagnosed the problem as being Parkinson's. Something that I skipped is in this probably this last 6 month period I developed-my running problem continued. And also during that time, I noticed a tremor, or the beginning of the tremor in my left leg."

In retrospect, he recalled the possibility of Parkinson's had occurred to him. He recounted the incident.

> "I guess it occurred to me, it had occurred to me that was one of the possibilities that it might be. A short time-I can't remember exactly, 2, 3, maybe 4 months before the diagnosis was actually made, I remember being in the shower at the athletic club that I belong to and what was happening was I'd get done running, at that point exercising, whatever I

> was doing, I'd shake a lot. And I thought, "Holy shit I--" you know, I thought of Parkinson's disease but to some extent, from what I knew, it's not supposed to be hereditary necessarily or anything like that. But I thought about it."

His father has Parkinson's disease.

> "And he was diagnosed as having Parkinson's, you know I really don't remember. He's 76, 76 years of age and he was diagnosed perhaps maybe 10 years ago. And he has a pretty pronounced tremor I think on his right side. Sometimes it affects both sides but I think it's predominately in his right side. And he has the more classic Parkinson's symptoms where he tends to pitch forward some. He's doing pretty well for somebody 76 years of age. He can still get around and so forth and but he does kind of shuffle and pitches forward some and is not as stable as he, certainly as he used to be."

His immediate reaction to his diagnosis was influenced by his father having the disease. He described his response, crying as he spoke.

> G: "I began to cry and I still don't know why exactly. I mean I'm feeling a lot of emotion about that right now. But I don't really know why. (long pause) I guess that I do know why. I don't know how the disease will progress. I know how frightening it was for my mom when my dad was diagnosed because my mom's an RN and she saw the changes in my dad's patterns of movement and it just never really dawned on her that that's what was wrong because I guess it started off subtly like it does with most people. And it never really occurred to her that's what was wrong. But she is an RN and she knew, not necessarily kept up with Parkinson's per se and the treatment with L-dopa and so forth. She knew about it peripherally but not much. But what her recollection was and what scared the hell out of her was that she had spent 10-15 years working at the state hospital and for several of those years on geriatric wards. And this was back in the middle 50's and 60's when there effectively wasn't treatments for the disease and she saw what basket cases people became and that scared the hell out of her. That's what I harkened back to."

> I: "When you were given the diagnosis?"

> G: "Yeah. And I guess that's what still kind of (crying). I don't dwell on it but it bothers me because you know for all I know, I mean, the Sinemet I take helps the tremor a bit, but it doesn't make it go away. Entirely. It certainly helps and when I'm relaxed and have kept up with my medication the tremor's not visible. But it's never completely gone. My doctor has told me that there's no way to predict the course of the disease."

His initial response of fear related to disease progression was compounded by anger.

> "So it's frightening and I guess I was pissed off too. I mean, you know I'm not supposed to get Parkinson's disease at 43 or 42, or whatever I was at the time. So it was some, both of these aspects of it."

The fear and anger he initially experienced when diagnosed still remains to some degree 18 months later though he doesn't allow himself to dwell in these feelings. His initial response to the diagnosis (and then as he described this in the interview) was an emotional time.

> "The only time I've ever really been emotional about it is when I was first diagnosed. Sometimes I'll, like quiet moments to myself I'll be a bit angry about it but I don't get emotional like I'm going to cry or get tearful about it. And I guess the way that I've dealt with it for the most part is not to deal with it. I mean, I deal with it by knowing as much as I can and doing the things the doctor suggests and doing other things to me make sense, like exercise, and you know, trying to reduce the stress that I'm under and I guess I figure I'm doing what I can do and there's no sense in worrying about what's going to happen. There's nothing I can do other than what I am doing."

Gary had been open with others about being diagnosed.

> "I don't advertise it but I don't hide it either. If there's a reason to mention it or discuss it, I do. I'd say most of my good friends and many of my acquaintances and some of my coworkers were all aware. So it's nothing I have made an attempt to

> hide...I think I notice my tremor much more than others do. I mean, I notice it immediately and I know I've mentioned it to friends and associates at different points in time and they'll say to me and I don't think they are simply being polite, they'll simply say, I haven't noticed it. And I think most people are being genuine and truly haven't noticed it. But I'm aware of it."

His consciousness of his tremor partly explains why he has chosen to share his diagnosis.

> "I brought it up with my boss before I left the company I worked for. I mentioned it to my boss and to my secretary and I mentioned it to my boss for a couple of reasons. One, he's a good friend of mine, and secondly because I thought it must be noticeable, that at least on some occasions I shake a lot, or at least I feel like I do. I don't really remember when I mentioned it that he said he noticed it or not. Just recently, yesterday, I was working with a placement firm to help pull together my resume and develop a job search strategy and so forth. Actually it wasn't yesterday. It was last week. I noticed a video camera in the room and I said "are we going to do some video taping of the interview" you know mock interview sessions and so forth, and he said, "yeah, we probably will." And I said, "Well, this is probably a good time to ask this question but you probably notice I tend to rather be at ease in talking and interview situations and even public speaking," but I said, "You may have noticed that tend to fidget around a lot and I move around quite a bit and so forth." And I said, "the reason for that is because I have Parkinson's disease and I have this tremor and what I find is that when the tremor starts to cause me to shake, I get some relief from it by changing positions."

Gaining Experiential Knowledge

Although having had his diagnosis for less than two years, Gary had a fairly in-depth formal understanding of Parkinson's disease. He articulated the underlying neurochemical imbalance, the proposed mechanism of action of

Sinemet and Eldepryl therapy, the common symptoms and other information he had gained from reading. Whereas he had acquired formal knowledge about the disease, he was developing a practical knowledge or an experiential know-how as he lived day by day. The two other participants in the study who had the disease for comparable time frames were also very engaged in this adaptive task. The areas of their questioning and learning were similar to Gary's. However gaining of experiential knowledge was not limited to those recently diagnosed. It was an ongoing experience for almost all participants whenever new symptoms, changes in medication regimes or new experiences presented.

A major area of questioning Gary had in common with others newly diagnosed (defined as less than 2 years for this discussion) concerned what symptoms were directly attributable to the disease versus a side effect of medication versus his "reaction to some of the symptoms".

> "The thing that's so interesting about it is it's all been so subtle and so slow in developing, I mean, relatively speaking, that I can't ever pinpoint what's related or what's not-other than the tremor I can't pinpoint what's related to the disease."

Central to this questioning was an increased awareness and close monitoring of bodily changes. He explained this relative to a recent backpacking trip.

> "I found myself not so sure of foot and not really, a little bit clumsy I guess, not uncoordinated, I didn't fall down or anything, but I just didn't feel sure of foot as I have in the past. I guess I believe it's related to the Parkinson's."

He discussed further:

> G: "It's a subtle difference, I was just a little bit more tentative than I have been in the past."
>
> I: "Describe being more tentative. What do you do?"
>
> G: "I think I'm more aware. I may move slower. I'm not consciously slowing down in order to negotiate better. I'm just more aware and probably, a slight bit more cautious."
>
> I: "Before was there an awareness?"
>
> G: "Not even a thought about it...I noticed right at first, it was a hesitancy so much, again all of these are very very subtle, the difference I use to bound down stairs and when I started noticing some changes, I still go down stairs quickly but I grab the handrail when I do. It's not because I'll stumble it's just because I feel a little bit unsure. And it's ever so slight but it's a change. I know it's a change from before."

Gary was very aware of the slightest changes in his body. His athletic background may have conditioned him to have this increased awareness of his bodily states. Several times during the study he referred to his tremor being present (i.e., he could feel it) although not visible. He was keenly attentive to subtle changes:

> "Maybe there's a little bit of difference in my left arm as well. When I make a fist sometimes, like right now, I can kind of feel the muscles twitch. It doesn't show visibly but I can feel it being different from what I recall it being before."

He spoke of this during our first interview and continued to be aware of a different feeling in his left arm throughout the remainder of our interviews, although there was never a visible tremor detected by myself or Gary. I interviewed his wife approximately two months later and she confirmed a slight visible tremor had begun in his left arm.

Part of his questioning centered on if what he was experiencing was a disease symptom or his response to the symptom. He had experienced subtle differences in his memory and mental acuity.

> "I do know that I've noticed some changes but I don't know if they're a result of the disease or my reaction to some of the symptoms. I certainly notice that before I left my job that when I would get into a stressful situation, the tremor would really act up and I did sometimes feel like my leg was just hopping up and down. I sometimes felt quite rattled and I don't know if that's rattled because the Parkinson's is causing me to be rattled or rattled because I'm distracted by the tremor. I hope it's because I'm distracted by the tremor but I don't know."
>
> "I tend to be a verbal communicator. That's what I basically do for a living, and if I get rattled as a result of the Parkinson's whether it's because of the Parkinson's affecting my brain and my cognitive power or if because the tremor is distracting me and that's causing me to get rattled, that causes me to be a little bit concerned because that affects what I do and how good I am at what I do. I seemed to get a little rattled at work, and otherwise too, and I'm not sure whether that's a reaction to the physical manifestations of the symptoms that I have, distracting me, or if it's really that I'm getting mentally rattled."

Accompanying his questions about the relative impact of the disease or his response to the disease on his thinking was a question about the effects of medications.

> G: "I've also noticed that in some ways my mental acuity is not the same. I don't know that it's deteriorated or anything like that but it's not the same. And it may be the disease or it may be the medication and I don't know which. But there's a difference and the difference is my memory isn't as quick. I've always been very quick at recall of things and that seems to be less the case now. The information that I'm looking for in my head is still there, and it comes out, but it's not as

> instantaneous as it's been in the past. I suspect it's related to the disease or the medication or both. But it may not be. I don't know, it's hard to know. But I think that it's more related to the medication than it is to the disease."
>
> I: "Because?"
>
> G: "Well, I wasn't taking as much Sinemet, in fact, I just kind of started on my current regime shortly before I quit working, maybe 2 months before and I was taking less of it, 3 instead of 4, and so it seems the memory isn't as quick recently. So it, I can't help but think that it is related to increasing the medication."

This area of questioning was not one where Gary had definitive answers possibly because those answers don't exist. This questioning was most common in newly diagnosed participants but emerged in other participants who were experiencing changes in physical or cognitive functioning. This questioning of what is a symptom versus a side effect of medication was a common occurrence among clients I had cared for as a clinician.

Another area of experiential learning for Gary involved ways to manage his tremor with medication dosaging.

> G: "The fourth one (dose of Sinemet) tends to be the most difficult one for me to remember to take later in the evening, because the tremor isn't bothering me as much, but I believe it's quite helpful for me to take it, because I think there's some residual in the morning, it's still acting upon me."
>
> I: "Do you notice a difference in the morning when you have taken it the night before versus if you forgot to take it?"
>
> G: "It's having less tremor. The tremors are almost always there whether I'm taking the medication or not it's just more pronounced if I haven't taken it regularly. It really helps me much more when I consistently take it four times a day."

Other interventions to manage the tremor:

> "What I find is that when the tremor starts to cause me to shake, I get some relief from it by changing positions. And when I change positions for a few seconds or maybe a couple of minutes depending on the situation I don't shake."

Unlike participants who had their disease longer, Gary did not have an account of medication working versus not working nor an on/off cycle account. But evident in his narrative was a developing language related to the sensations and subtleties he experienced. Being newly diagnosed Gary was gaining experiential knowledge of his disease, dosaging of medication related to symptoms and the recognition of subtle changes in his body.

Enjoy Life Today

Having Parkinson's disease reshaped Gary's experience of temporality. His sense of the future and mortality was questioned in light of a progressive disease whose exact course was unpredictable.

Benner and Wrubel (1989) noted life threatening illnesses such as cancer confront the person with their finitude, temporality and perception of the future. While Parkinson's is not life threatening in the same sense, for Gary it was life changing as he realized his mortality and finitude.

> "We all think of ourselves as a little bit, at least a little bit immortal and at least a little bit invincible and I guess I've always viewed myself that way, too. And I've had life tell me, no..."

> "It's similar to the thing some people sometimes do

> when they're diagnosed as having cancer or having some major life-threatening problem, immediately life-threatening problem. They go well, geez, I may as well live my life as well as I can cause they're ain't going to be that much of it. I hopefully will have quite a lot of my life left. I don't view this as immediately life-threatening. It could be over a very long period of time. I'm hoping not. But at the same time I've thought well, it's time to get on with living and enjoying my life...There aren't any guarantees what's going to happen with me and I may as well go ahead, not worry about it, and just go ahead and live. "

Realization of the uncertainty of the future made the present most important.

> "I feel that I've learned about life, is that you've got savor it right now while it's here and while you are able to enjoy it. Because you may not have that opportunity sometime in the future. And I feel very fortunate that this is kind of awakened that kind of thinking in me and it's not the kind of crisis situation that a lot of other people face with medical problems. It's not cancer, I'm not looking at something that's life threatening in two or five years, in all likelihood. Or in six months, you know, when the typical situation being people who say, who have planned all their lives for their retirement and so forth to enjoy themselves when they've retired and then they find they have cancer, that they have six months to live or whatever. And then you know, they're saying I've really got to live my life a day at a time and enjoy what time I have left. I've got that message, but I've got a much longer lead time to implement all of that."

In order to live his life, enjoying it now he was making many changes in his life. He attributed the magnitude of the changes he was undertaking not only to his disease but to Kathy (he met Kathy and became diagnosed within months of each other). He explained what was most important was enjoying their life together today.

> G: "I guess providing for ourselves and a comfortable life, one that's is a little bit more stress free

> than has been the case in the past, and just leading a comfortable pleasant life. I don't have major career goals to achieve any longer. I'm not sure that I ever did, but if I did I'm not so concerned about those kind of things today. I'm just more concerned about leading a happy life. Where we can enjoy ourselves, I never been terribly career oriented but I guess I have felt that there are certain standards of living that I have to maintain. I think it was there, and in contrast to the way I'm looking at it now. I think that certainly is less important than it was."

I: "And what do you attribute that to?"

G: "I attribute it to, primarily to two things,the fact that Kathy is an important part of my life and I want to share that and I want to have more time available to be with her and to enjoy our life together. And the other part is the Parkinson's. Ah, that I don't know, I don't expect to be an invalid as a result of it, but I might. And so I'm interested in enjoying life today, while I know that I, I know that I can do things today, so I'm going to enjoy them to the maximum extent I can."

He discussed how in the last six months to a year they had focused on enjoying life. They had traveled more taking an extensive trip to the Middle East because "we wanted to do something that we haven't done." He, along with friends, had done a backpacking trip and a fishing trip in the last two months.

As mentioned they were moving shortly. Gary was utilizing the move as a time to make a career change, something he had been considering for awhile. What his job would be was unknown. His exact job was not his priority but rather a less stressful employment situation which could support him in his central priority of enjoying life.

> "We want to get settled there and both get employed so that we can buy a house, qualify for the mortgage that we can handle, buy a house, and then

> start looking at how we might earn a living otherwise. We're very interested in exploring other things that we can do with our lives in terms of career that will allow us a great deal of more freedom and flexibility so that we can travel and we can choose not to work if we want and so forth."

He was approaching the relocation with enthusiasm mixed with some anxiety. He expressed some concerns related to health insurance.

> "With the notion of quitting my job, the only reluctance I had about that was the notion, well I could have a problem with health insurance at some point. I don't know. I don't in the near future because I'm going to continue my existing medical coverage throughout a cohort plan for a minimum of 18 months. But I suppose it's conceivable that I may in my next job end up with health insurance which says you have Parkinson's disease, you have a pre-existing condition, we're not going to cover it. I've decided not to worry about. If I can't get the insurance, the medication isn't cheap. A lot of people spend a lot of money on things that are less important. If I have to spend it on my own, I guess I will. And the other part is there's no guarantees even if I stayed put where I was that my health insurance would be good forever, or that I would have that job. I couldn't think of a much worse reason to stay doing something I didn't want to do because I have health insurance."

As the time of their move got closer, he experienced anxiety related to not having a job as of yet.

> G: "And I'm starting to feel a little bit of anxiety associated with, geez, we're going to be up there soon and I haven't done anything effectively as far as networking, or any pursuit of a job for myself. And that's starting to bother me a little bit. And so that's caused me some unhappy moments. Not seriously unhappy, but second thoughts about what if I can't find a job, and so forth."
>
> I: "This is probably the longest period in your adult life that you haven't been working?"
>
> G: "Yes, that's right. Plus the fact when I get up there, it's not the best time of year, of course you never know when something is going to pop up,

> but it's not traditionally the best time of year to be looking for a job...I've got a brief window to find something in all likelihood anyway, careerwise, a very brief window of probably six weeks and then after that it's going to be part time work or nothing at all. I'm kind of anxious about that a little bit not knowing how I'm going to react to it. If it takes me a good deal longer."

The Future: "I don't focus on it"

> "I don't have a lot of concerns about it (his future), partly because I don't focus on it, I don't want to focus on it. But I guess on some occasions and some moments I'll stop and think, and I'll think about, out maybe 20 years. And I'll think God, I'm only 44, in twenty years I'll only be sixty, I'll be 64 which is not that old any more especially. And I expect to be a vital person at that point, but that will, I will have had Parkinson's for over 20 years then, and I don't know. Maybe I won't be vital at all. Maybe I'll be fairly limited in what I can do, either physically or mentally or both. And that concerns me. But I don't think about it much, I just, you know, every once in awhile I'll think about it, but I'll think about in that context. In 20 years I'll still not be an old man, but in 20 years I could be severely limited in what I can do, and that's troubling. But I don't really focus on it."

That Gary did not focus on the future was evident throughout his narrative. His story was one of living and enjoying the present. But this did not mean that he was unaware of the potential, future limitations. He realized these but yet his hopes rested on the limitations not being too severe.

> G: "...that I won't be too limited in what I can do, or not severely limited. That I can continue relatively well physically and mentally, and that's about the extent of it. I mean it's no more specific than that for me."

> I: "You've shared at times you feel that your train of thought isn't quite as sharp. Are the mental

> concerns more than the physical or is it both?"
>
> G: "I think it is more of a concern than the physical part of it, from the stand point, I mean it would be very difficult for me to be physically limited, because I've always been very physically active. But the notion of being mentally slow, or whatever, having a difficult time, either mentally or in terms of being able to express myself verbally, that's quite troubling to me. That's more troubling to me, because to be it connotes more dependency upon other people. And perhaps being more of a burden on other people."

He acknowledged his fears of future limitations. But yet he did not focus on this. He hoped his disease would be a "relatively minor one for years". He referred to it as "denying the disease".

> "I plan to continue to deny (laughter) the disease. I mean, I think I'm realistic about the fact that it may have dramatic effects on me over time, but I'm not willing to accept that it is going to have those kinds of effects upon me. As far as I'm concerned it's my intention to overcome it to the extent I can. And if it turns out over time that there are certain aspects that I can't overcome, that it is going to change my life in those ways, well then that's fine, there are other things why let yourself be limited, if there's ten things you can't do there's still a thousand things you can do that are different, my effort is going to be to keep that kind of an attitude about it and if that's denial, I'm not sure it is, but I plan to deny the disease will get the better of me."

Gary was coping with his Parkinson's by living in the now, not focusing on the future and doing whatever he could do to help manage his symptoms. But he did acknowledge the dramatic changes which may well occur in the future. His father provided an example of how the disease might progress.

> "I've definitely noticed some behavioral changes, he's very much more dependent upon my mom than he's ever been. He gets rattled very easily, and he has a tough time making decisions, and he's kind of

> gotten cantankerous, and so forth, which some of it is just age, too, I suppose. I also noticed that he has a lot more of the sort of characteristic blank look on his face from time to time, and so yeah, some of it's based upon just seeing my dad and seeing what's happening with him."

His father also provided an example of coping.

> "I'm a lot more like my dad than I ever thought I was. By that I don't mean the fact that we both have the disease, but rather, something I've always admired and hated about my dad at the same time, was the fact that he's very stubborn, and when he sets his mind to something , that's the bad side the stubbornness about it, but the good side is he doesn't let things bother him much. He gets past them, there are almost elements of denial there, and there are almost, but that's not all bad, because it allows him to cope. And I find that, I've always known that I was a little bit that way anyway, and with this, I find that's my method of dealing with this, too. But again I look at my dad and it served him awfully well, he's had a couple bouts with cancer many years ago, and he has been in remission for like 16 years and I think, an awful lot of it is just his strength of his will. And I find I'm remarkably similar. I'm pretty good dealing with things day-to-day and week to week, and so forth, and I guess when I stop and think about it, is that whatever my circumstances are in 20 years I'll probably be able to deal with it."

His approach to the future was it was largely unknown. He was doing everything he could today to help manage his disease and that was all he could do.

> "I'm slowing down the lifestyle, a little bit less stressful environment, and perhaps work and so forth, I don't know if it will help in the long run as far as the progress of the disease but it seems to make good sense in terms of managing the symptoms that I experience. So that's one thing. Maybe it's just because it's part of me anyway. I feel that lots of physical exercise is important to me. It seems to me that Parkinson's disease has a tendency to cause atrophy of muscles and tightening of muscles and things like that, it only makes sense to me that I exercise--I don't know that it will help but it can't hurt. So I figure I'm doing what I can do and that's all I can do."

Unlike participants who were frustrated with the lack of definitive answers to progression timetable questions, the very fact there were no definitive answers provided room for hope and possibilities for Gary.

> "But again coming back to one point, it doesn't progress the same way in each and every patient and nor do patients respond to the medication in the same way...You know, 10 years or 20 years from now I could be, my symptoms could not be much worse than they are today or I can be disabled. And I don't know which way that's going to go and, or any place in between as well of course. But from what I understand there's an awful lot of research being done and Parkinson's disease is receiving a lot of attention and there's a lot of hope for either more effective treatment of the symptoms and hopefully even perhaps they'll be able to figure out exactly what in the hell it's all about and come up with some kind of cure. So there's hope on the horizon."

Gary accepted he had Parkinson's and there would be disease progression. But he had hope for the future. Hope that his disease progression would be slow and hope for research efforts to be successful. He acknowledged in the future he might be disabled but rather than dwell on this he utilized positive thinking and believed that he might not be disabled. The unpredictability of <u>his</u> disease trajectory allowed this possibility. Thus enjoying life now and being engaged in the present, freed him from dwelling in the unknown future.

He believed whatever his circumstances would be "I'll probably be able to deal with it", much as he saw his dad coping. He was concerned for Kathy and the potential long term impact of the disease on her. At this time, he did not believe it had impacted their relationship.

> "No, other than it means that there could be differences in our future. It's the old dilemma of what is this disease going to do (to) me? And in that sense, it may change or have an effect on our relationship...It's changed I guess our outlook, but it hasn't changed our relationship and in some ways it's kind of made it closer and there's a big issue to share there, I guess is the point."

He acknowledged part of how he deals with his disease day-by-day was by "talking it out" with Kathy. At times, he was reluctant to do this though.

> "It concerns me that if I talk about it, I'm not afraid she's going to leave me or anything, but I don't like to worry her. I'm concerned that if I say, I really do notice some differences and I think it's attributal to the Parkinson's and so on, it will worry her, and of course that's not my intention at all. She doesn't want to not hear it or anything like that, but I can tell sometimes when I'll say that something has really bothered me, or that some of the symptoms seem to be getting worse at various times and stuff, I can just sort of read expressions on her face that show she's concerned and I don't like to do that terribly. But at the same time, we're there to share things."

His future concerns for Kathy related to if he became mentally impaired.

> "If I'm restricted in what I can do physically, that's more of a problem for me, sure it impinges upon other people, you know in terms of what I can do with Kathy, the kinds of things, activities we can engage in and so forth, would be different, but she can do stuff on her own, too. She doesn't have to do her thing with me. But if I was slipping mentally, then I would be more dependent on her and more of a burden and that's hard to deal with."

The future was not something Kathy and Gary discussed in any depth.

> "We don't talk much about it. Maybe because our lives are too much in disarray right now. Or not disarray, but, there are too many question marks about the future to really seriously do a lot of that. When we do talk about the future, primarily

> it's in terms of fun, frankly and it's short term future. What we want to be doing in two to five years at the most. But as far as looking out, fifteen, twenty years, we don' talk about that."

In Transition

Evident at the time of Gary's participation in the study, was the transitional place of relocating and embarking on a new, yet undecided career. While he was making major changes partially as a result of his diagnosis, the changes were his focus. He was living in the present and occupied with the activities of the present (such as the move, finding a new job and housing). He described his relationship to his illness:

> "It's tangential. It (Parkinson's) affects my life, but it's kind of in the margin, and kind of on the tangent, instead of my life going ahead in the absence of the problem, in a vector, it's kind of perhaps deflected slightly but not ah, not dramatically."

Perhaps the disease being tangential or in "the margin" was possible due to the mildness of his symptoms. In reviewing all participant's narratives, Gary was the only person who had never had anyone inquire or acknowledge the visibility of his symptoms. It was not until our second interview that I observed tremor and detected rigidity (and it was ever so slight). The mildness of his symptoms combined with the "disarray" of their lives may have made it possible for the disease to be "in the margin".

One can not speculate if his stance will change with time as he experiences more symptoms. He expressed a confidence in being able to deal with whatever he encountered.

> "My attitude is just work through it and that's the way things are and just deal with it."

He reiterated that message as one he felt would help other newly diagnosed people.

> "It's a frightening prospect in a way to be diagnosed as having a long-term illness, that can be, that is degenerative, and it can be ultimately fatal, I suppose in some circumstances. That's frightening to have that, to realize that that's the situation. But, I guess the comfort that I would suggest to them is, you've got time to deal with the problems you are going to encounter. And they're going to be difficult, they're going to be aggravating, but you can do an awful lot of living while you're in the process of experiencing the symptoms of your disease...I think the encouragement I would give them is that, it's not like you are going to fall off the end of the Earth in six months, you can learn to deal with the problems, it comes along slowly enough that you can deal with the changes that are going to be facing you, fairly easily."

He has found a stance of situated possibility and a way not to allow the illness to take over or totalize his life. His narrative is one of living in the present, having hope and "denial". His world remains intact and the illness at the margin.

CHAPTER 7

The Demands of Parkinson's Disease

This chapter discusses what the major challenges in coping are for the study's participants. Before discussing how one copes with their illness, it is imperative to know what they are "coping with". This chapter presents the major demands of the illness from the person's perspective. The following chapter will discuss coping patterns and ways of experiencing the illness. While stress and coping are obviously linked, the discussion is divided into two chapters to allow full, rich description of the adaptive demands and the coping patterns.

View of Stress and Coping

A phenomenological view of stress and coping was utilized in this research. Stress is defined as "a disruption of meanings, understanding and smooth functioning so that harm, loss or challenge are experienced, and sorrow, interpretation or new skill acquisition is required" (Benner & Wrubel, 1989, p.59). Coping is what one does or does not do in response to this disruption or breakdown in meaning, understandings or smooth functioning. These definitions sanction studying Parkinson's disease as a disruption; of personal meanings, smooth functioning and an ongoing life course (Benner & Wrubel, 1989). Thus, I sought to understand what aspects of Parkinson's were stressful on a day-to-day basis and over the trajectory. For the participants, what aspects of their situation involved loss, suffering, changed hopes and plans and disrupted personal meanings? What are the major challenges and the specific realities the person with Parkinson's in middle life must face?

An underlying assumption of mine which resulted from years of clinical practice must be stated. Parkinson's disease, by it's chronic and progressive nature, must be viewed as a process. It is a continually changing condition. To think of having this disease as a single event would be a mistake. It must be viewed as an illness which requires ongoing attention, management and intervention. In my clinical experience I noted that health professionals always emphasized the slowness of the disease progression. Implicit in the discussion was the notion that because it progressed slowly it was easier to deal with and manage. I entered into this research questioning that notion. The fact that it is a slow but never ceasing progression may well be one of the unarticulated challenges people face.

Parkinson's disease likely presents similar challenges as other chronic illnesses, but the specific and unique demands of this illness have not been articulated in the literature. While several of the adaptive tasks common to chronic illness have been outlined (Moos, 1977, Strauss et al.,1984; Moos & Schaefer, 1984), it is essential that the unique aspects and challenges as well as the common, shared challenges of this illness be understood. In this chapter I describe the demands of Parkinson's disease as presented by participants. I am using the construct demands as articulated by Moos (1977) and recently discussed in chronic illness research (Woods, Haberman, Packard, 1993; Packard, Haberman, & Woods, 1991; Benner, personal communication, 1993; Chesla, 1988). Demands involves both the difficulties or breakdown and the challenges experienced as a result of the illness. The discussion will be divided into (1) demands of the illness itself, and (2) demands about roles, relationships, and identity. While demands will be discussed in categories for an in-depth description, the nature of the demands is such that they do not occur in isolation but are intrinsically linked.

Demands of the illness

Demands of the illness itself included: (1) acknowledging symptoms and seeking medical help, (2) balancing emotional responses to the illness, (3) dealing with a changing body/self, (4) gaining formal and practical knowledge, and (5) dealing with ambiguity and unpredictability. Each of these demands was experienced to some degree by all participants. Some demands were more salient at certain times, situations and contexts. But the commonalities amongst participants were striking. The issues, demands and adaptive tasks occur within the context of the disease, the person and the world.

Acknowledging Symptoms/Seeking Medical Help

The first adaptive task the illness creates involves recognizing and acknowledging something is going on. The "what is going on" or the symptoms experienced varied greatly. Classic texts in neurology and patient education materials almost always cite tremor, rigidity and/or bradykinesia as the early presenting symptom(s). While several participants did notice either "stiffness" or "shaking" first, just as many described subtle changes in doing a specific activity or a different presenting symptom. Some examples:

> "My writing started to cramp. I've always had nice penmanship and big handwriting because in grammar school that's what you're taught and my penmanship was excellent. And it just started to get real small and close together."
>
> "My left foot, toes curled under, kind of making it uncomfortable to walk. And then I got a callous, I think because I was walking weird because of my toes curled."
>
> "I couldn't brush my teeth effectively, I was having difficulty brushing my teeth. And I couldn't get hand lotion out of the bottle."

Participant's demonstrated an awareness of changes. However, for most participant's who experienced this sense of "something being different" this was not affirmed by the health care providers. Consider the two paradigm cases of Mary Hampton and Gary Miller. Both discussed with their primary physician what they were experiencing, however their physician negated their experiences by suggesting they were insignificant.

Mages and Mendelsohn (1979) stated the first adaptive task for patients with cancer was to appraise the significance of symptoms and initiate appropriate treatment. Appraisal of the significance of Parkinsonian symptoms is particularly difficult because of ambiguity. The presenting symptoms vary as illustrated by the three previous quotes. Participant's initial appraisal was to seek medical advice because they knew "something significant was happening". However their practitioners negated what the person was concerned about. It was not uncommon to have to experience further or worsening symptoms before they gained the attention of their primary physicians.

> "It took a couple of years. It was very subtle. I'd go to the doctor and he said it wasn't anything. He really negated, he said no, you're okay. So then I let more time go by and I was getting worse and then my husband and I said there is something really wrong."

Several participant's shared that they were deeply concerned by the time their physicians acknowledged there was a problem. They had begun to diagnose what they thought they had.

> "I thought I had a stroke or something."

> "...I was afraid it was a brain tumor."

For a few it took extreme persistence to get the appropriate medical attention.

> "The next six months I spent losing my hair from pulling it out, damn near, not literally but I had such a bad experience trying to be able to get in to see a neurologist and actually get an appointment."

In some cases even after receiving a referral from the primary physician to a neurologist, getting a definitive diagnosis was impossible. Anne had been experiencing symptoms for about three years and had discussed this with her internist on at least two occasions. After she insisted "something is really wrong", she saw a neurologist.

> "Around October, we went to Dr. R. and he looked at me and shook my arm and made me jump in place and all these kind of physical movements and we went back in his office and he said I have good news and bad. It's not a brain tumor but I think maybe you have Parkinson's disease. But I'd like you to get a second opinion."

He referred her to one of the top specialists in the area.

> "And Dr. M. did the same routine, checking me over and I brought an MRI with me and he said it's too early to diagnose...I felt strange because I felt the symptoms within me and I was surprised that Dr. M. didn't see it."

Getting a definitive diagnosis was essential for participants. The power of naming the disease enabled them to legitimize their ambiguous bodily changes. It rescued them from their worst fears of brain tumors and other neurological disorders. Getting a diagnosis helped to socially construct their new identity for better or worse.

Balancing emotional responses

Being diagnosed with a chronic illness such as Parkinson's disease requires an acknowledgement and an acceptance of the illness to some degree. While some participants expressed an immediate sense of relief that it was Parkinson's versus some other neurologic disease (examples: Mary Hampton, Dave Smith), this sense of relief did not preclude them from experiencing feelings of anger and denial.

> "I guess I was pissed off too. I mean, you know, I'm not supposed to get Parkinson's disease at 43, or 42."

> "I knew about Parkinson's but I thought it was an old folks disease. And associated it as being that of the aged. The thought of my having it didn't make an awful lot of sense. I think I went into a real long denial process. Denial that I don't want it. Put it that way. I knew I had it. But I didn't want it."

> "I was really angry because I felt like my life was getting better, I was really upset. I just didn't want it to happen. The thing was I didn't want to lose control of my left hand because I like to use it, I like to sew and I used to do graphic arts and stuff."

The fact participants had a disease which normally affected people much older contributed to feelings of anger and "why me?". Most participants were deeply involved in their careers and family life. Several stated they were in the prime of their lives. Thus to be diagnosed with a chronic illness they would have "to deal with the rest of my life" was the reality they had to acknowledge.

> "It took me that long, 6 months to a year, to even begin to be close to accepting. I just sat around, a mummy in my chair and I never moved hardly or did anything, why me? I thought I was in the prime of my career and I was doing real good in my job and it just seemed the whole road caved in."

Participants experienced different emotional responses to their diagnoses and the demands of their illness. Anger and/or the experience of "why me" presented in the majority of cases. Others acknowledged a depression resulted. Recall Mary Hampton's retrospective analysis of feeling burdened and overwhelmed. This was also fairly common with several participants acknowledging these feelings lasting for a couple of years.

> "The first two years that was all I could think

> about. A long time. I wouldn't have expected it to last that long, 2 to 3 years. That's all I could think about. My whole thinking was not only colored by but it was always there to think about."

The adaptive challenge participants' faced was balancing their emotional responses and integrating the illness into their daily lives and their self-understanding. Moving from feelings of being overwhelmed or anger to acknowledgement of the illness as their own was a major demand they faced.

Dealing with a Changing Body/Self

With Parkinson's disease, the smooth functioning body ceases to be. Movement, which once was taken for granted, becomes visible often requiring concentration and instruction from the mind. Mary Hampton spoke of thinking movement or reminding herself how to do something. Two examples:

> "I would put my hand up to wave goodbye and I'd put it up and it wouldn't wave. And that was a peculiar feeling, I could lift it and it wouldn't automatic--and I'd think wave. Oh yeah, I had to consciously do it. Scrambling eggs for some reason, "How do you do this?" and then I could think it through and do it."

> "...where I'll just be moving along and the unable to. Often like sitting, than to get going, I have to think movement."

Some additional examples from different participants of what once was pre-reflective now required conscious effort.

> "And when I'm walking I have to remember to lift my feet, to swing my arms, when I'm talking I have to think talk louder and enunciate better..."

> "It is like everything seems like an obstacle course and how's the best way I can get over it, whereas before I never even thought about it. I didn't think about getting dressed, I just did it."

> "My muscles, I have to tell them what to do. Your muscles do things automatically. Something simple as brushing teeth gets to be something I have to tell myself how to do it. I have to tell myself sometimes to put weight on my right side if I'm going to move to the left, or put weight on the left side if I'm going to move to the right, how to get in and out of a car."

> "If I notice myself dragging or if I trip, I'll make a mental note, pick your foot up, pick your foot up."

Simple activities such as walking, talking on the phone or brushing one's teeth were now visible. Activities which once occurred without any awareness, required thought and instruction. Automaticity was lost.

Many began to view their body as "uncooperative". They began to talk to their body or parts of their body as objects.

> "I was having difficulty with my right arm and my hand would grasp the wheel (driving) and not let go. And I just could not tolerate that. It just didn't seem to want to cooperate with me."

> "The legs just do not want to walk up hill. They're stiff and they feel painful. They just don't want to cooperate."

In these cases the hand or the legs wouldn't do what they were supposed to do. The mind or the brain was unaffected but the body would not cooperate. There was a loss of bodily wholeness and bodily integration.

> "Because your mind is still driving on and wanting to be productive and you've got the horrible body that you're trying to drag along behind you."

> "It's like learning something over. You've got to really concentrate. Sometimes your body is willing to shift (driving a car) but, the signals from your brain are not getting to the muscles telling it, hey, do this, put your foot in and out when you put the clutch in...The mind is telling you what to do but the muscles aren't getting the signals."

> "The mind was going like crazy and had all these plans, and then to begin moving the muscles to execute them just was unreal."

> "It's an interesting thing as to what you can do and what you can't do...I just can't move sideways (ordering food cafeteria style) for that length of time or even a short time. Many times I'll stand there with the leg up in the air and it won't go any further. I can tell it all I want. I have to wait for it to release. Sometimes I tell it what to do and it works and sometimes it doesn't. Sometimes it just won't do it."

Participants viewed the problem as one of the body or the muscles. The mind was intact, "driving on" and "going like crazy", but the body either wasn't getting the message or was uncooperative. These quotes exemplify a breakdown in bodily continuity. The body no longer functions in a smooth, skilled, habitual way. Rather the mind was in control of the body, instructing <u>it</u>, trying to get the body to cooperate.

With Parkinson's the body can no longer be taken for granted. The body and it's abilities come into question. The body as a skilled knower and negotiator of the world is lost (Heidegger, 1962). Rather there is a body-mind separation consistent with the Cartesian model. Parkinson's disease is such that people experience further loss of bodily integration as the disease progresses and new symptoms are experienced. Concentration, instructing one's body and finding new ways of doing activities are the demands of a changing body.

> "I've been trying to make things easier for myself, you know, what's the simplest way I can do this? To try new ways of doing things."

Gaining Formal and Practical Knowledge

Almost all participants had heard of Parkinson's disease when diagnosed. But their understanding was limited, many having knowledge of the disease because of a memory from their past or because of a distant acquaintance.

> "When I was a real little kid we had a little old lady who used to come to church once a month for communion, all rolled up in a ball. This was back in the 40's. So Parkinson's was this little old lady cause I would always ask my dad what's wrong with this little old lady. She'd come up there and she was shaking really bad."

> "And I remember seeing pictures of people stooped over and Parkinson, the guy, and he had it that's why they named the disease after him. I remember seeing a picture of Parkinson walking stooped. In a medical book or something, a school text book or something."

There were two participants who had a parent with the disease prior to their being diagnosed (Miss Ryan, Mr. Miller). In both cases though, the parent lived quite a distance and was seen only periodically. Though their knowledge base was broader, it was limited to the changes or symptoms they observed in their parents. Neither participant had done any formal reading as result of the parent being diagnosed.

Upon diagnosis participants identified a need to know what Parkinson's disease was. Information provided at diagnosis was difficult to ascertain in most participants. By their own descriptions, they were "in shock" and didn't recall the dialogue between themselves and the physician. There were a few exceptions to this, people who clearly recalled being given a diagnosis and then very little information.

> "And I began to ask questions. He said, well it's a noncurable disease. Told me the classic symptoms and these kind of things. I really did have the classic symptoms. I agreed with him that that's probably was the problem. And after about 5 minutes he abruptly stood up and said, well that's all the time I have today and obviously this is a complex discussion and you won't remember this anyway so you'll just have to come back another time. I was shocked in maybe 12 minutes in his total time seeing me, he diagnosis me with an illness and gave me no hope, told me here take some medicine period. And then dismissed me."

> "Well, I went back and talked to the doctor about it. I said, look you know, this looks to me like that's what I have (had a book about Parkinson's disease). He says, yeah, I think you do. And you should take some Sinemet. And he put me on 25/250's about 4 a day. And said, so long, goodbye. The diagnostic process is over. You're on chemicals the rest of your life."

The human significance of the illness was passed over and objectified by what is known about the disease and treatment. The human response was all but ignored by health care providers. Self-care and day-to-day coping with the illness were trivialized and ignored. Only two participants described their physicians in a healing and caring role. For an example, see the discussion of the neurologist who visited Dave Smith after his suicide attempt on p. 102.

Many of the informants embarked on learning everything they could about the disease. Recall Mary Hampton's strong need to know.

> "I wanted anything I could get my hands on because I didn't want anybody knowing something about Parkinson's that I didn't know..."

Others had the same need.

> "I got most of my information through support groups and through reading whatever I could get my

> hands on."
>
> "Well, the thing that strikes me at first is just the initial period of reality when I read everything I could possibly get my hands on in order to understand what was happening...Uh, so there was this period of intense examination of the illness from the medical point of view."

During the interviews, participants were asked to describe their understanding of what Parkinson's disease was. The majority as part of their response discussed the underlying neurochemical disorder in the brain. A formal understanding existed possibly as a result of their intensive efforts to gain information. Gaining a theoretical understanding of the disease, how to obtain a definitive diagnosis and treatment, are the first adaptive demands. Participants in this study had a least a beginning theoretical understanding of what the pathophysiology was and how the most commonly used drugs worked. It may well be this is a level of knowledge everyone needs to have and this information is readily available. No one in this study had been diagnosed for less than a year. It is possible that gaining a certain theoretical knowledge level is one of the most central demands people face during the first year.

While the first months to a year was often spent reading whatever "I could get my hands on", participants confronted the limits of formal knowledge (Benner, 1984a). They began to acknowledge their experiences mattered and that they knew what was best for themselves.

> "I mean, it's my body and I would know better than a doctor would know." (discussing taking more

> Sinemet) "After all you're the one that's got the illness. The doctors are looking at it from book knowledge and from their own eyes, a healthy perspective. So you have to help educate them because some of them are woefully uneducated, they don't seem to understand little nuances."

> "Text book information isn't very helpful because it can be so broad. Have you ever read contraindications for any medications from hair loss to everything, you know. So reading has not been-it's only been marginally kind of helpful...I'm more interested in specifically what works for me. The only gauge of it is it's effectiveness for me. I don't care if some swami has an idea that sitting in a certain position will help. If it helps me I'm going to use it. I don't care how valid it seems in the medical profession."

Participants came to see the limits of "book knowledge" and began developing experiential knowledge or a practical "know-how". Practical knowledge was evident in several areas. Two related areas, learning about their response to and dosaging of medications and diet and lifestyle effects on their medications and functional abilities, will be discussed as examples of gaining practical knowledge.

Responses to and Dosaging of Medications

For the person with Parkinson's, medications are the main therapeutic option available. All participants took at least two anti-parkinsonian medications with some taking 3-4 different medications. Each of the drugs was usually taken several times a day. Taking medications as part of one's daily routine was one of the first adaptive tasks.

> "...I feel as though I'm on a treadmill and I just have to take them for the rest of my life. And so I better get used to it. I take a pill, or 2 pills, eight times a day."

> "I think of having to take all that medication the rest of my life is very annoying, more than annoying. It makes me dependent on medications. Addicted in a sense, in a sense that you can't live without it or it makes a big change if you forget."

For one gentleman, his most positive experience was when he discovered he could take his Sinemet without water.

> "The biggest thing about taking medication I discovered the day of the earthquake was-it was coincidence that it happened the same day. I'd been out at a meeting some place and was driving back to my office and I ran into traffic. It was time for my medication and I thought can I take this without water. So I tried it and it worked and I thought this is great. It really opened up a lot of possibilities."

This gentleman was fortunate as many participants expressed the need to take their pills with food in order to avoid nausea. One participant described how he learned to either eat before or take food with his pills.

> "One time I got sick on the airplane and got nauseated about 45 minutes after I took the pills. And I threw up and passed out at the time. I've done it a couple of times driving the car, I've always been able to get off the road or get out of the car. If I'm in a place where I can lay down as soon as I feel like I'm getting nauseated, then I'm generally alright. But if I'm on an airplane, it's better for me to skip a dose than to take the pills and not eat."

Generally, participants who experienced a significant improvement in functioning with medications were not as frustrated about having to take them. When medications made a difference in what they were able to do, they were very willing to take medications as they needed them. Recall Mary Hampton's description of "panting".

> "I am just panting to take medication in the sense when I'm not functioning I'm dead, and therefore it

> is such a dramatic difference from taking the medication that I could never not take the medication or not know it was time to take the medication."

Many participants spoke positively about medications, particularly about Sinemet when they began drug therapy.

> "And it was so sudden. I came roaring home. And I said I can write, I can write."

> "Initially when the Sinemet kicks in you feel very good, everything is almost back to normal...the Sinemet is a terrific medication. Because it isn't like being drugged or it isn't like these-it's like being, taking you back to normal."

> "I started walking better, talking better, the whole thing. I mean, I was in control."

> "Oh, it was a miracle drug. I'm not exaggerating. I mean, I felt human again."

Thus for participants who experienced a dramatic response from medications, while they still had to deal with fitting medications into their daily routine, there was more of an acceptance of medications. Because of the experience of positive effects, they took medications willingly.

> "I know that I have to take the pills. So why get upset about it. I mean, I feel bad that it's something I'm going to have to do the rest of my life but then I figure, thank God I have the pills. They help. I mean, I have to take the pills. There's no question about it. It's part of my life to take pills. I guess like someone who has diabetes and has to take insulin."

For as many participants who spoke of the positive benefits, there was a relatively equal number who spoke of problems with drug therapy.

> "And they give other things like in my right arm have involuntary arm movement and I have dystonia and that's brought on by the Sinemet that I have to take. And so I get rid of the tremor but so in

> doing I destroy my right arm."

> "...I think that medications are kind of like a bandage on a big wound, they help a little bit sometimes, but they don't cure things. And medications can like a bandage get dirty and cause infection as well, medications can be the problem sometimes too."

> "...the medication I take keeps me in a constant state of agitation. I'm in a constant state pretty much because I feel like I'm spaced out. And I've never had trouble thinking when I'm talking. I've never had trouble with the written word when I sit down and sometimes I have to think. I do things like misspell a word. I mean, I'm a great speller...I think it's the side effects of the drugs that I take. The medicine does help me move physically. Mentally I think it slows me down and I get frustrated."

An area of extensive practical knowledge involved dosaging of medication; the timing of the effective relief, side effects versus symptoms, loss of effects of the medication, and the actual physical sensations and capacities created by the medicine. This can best be explained by using an exemplar. Tom Brown was a 50 year-old man who had Parkinson's for seven years. He took 4 different anti-Parkinsonian medications. Other than the paradigm case of Mary Hampton, he experienced the most marked fluctuations in functioning. Despite these dramatic fluctuations, he continued working full time. Describing Sinemet's effect for him:

> "All of a sudden I loosen up, I mean, it's like a flow through your system. When it happens all of a sudden the tightness goes away. All of a sudden there's a little bit of movement, loose movement and you just kind of feel it happening...But the medication has different effects depending on my emotional state. I find the medication is great if I can have a steady emotional state. But I can't

> though. Stress eliminates the medication so the problem is how to have a stress-free day. Otherwise the medication works erratically."

He describes how he knows when it is time to take medication:

> "I have my pills, I use a pill box which goes every 2 hours. So it reminds me every 2 hours. And then I try to make a judgement whether I want the medication at that time or not. I might reset the pill timer for another 15 to 20 minutes just because I don't feel I want it right away."

I: "How do you make that decision?"

> "I'll go into a dyskinesia near the end of a cycle. I am on the medication but as it starts to wear off I go into dyskinesia. Now I have the dyskinesia for about 15 minutes and it gets worse and worse until all of a sudden the medication cuts out in which case I almost within a matter of minutes almost seconds, I get stiff. I go from the dyskinesia to a bradykinesia state. So it's a sign that it's time to take the medication when the dyskinesia starts because I'll be bradykinetic soon."

Sequencing and timing as well as typical responses are learned over time. Tom felt his dosaging of his medications had worked "relatively well" for a number of years. He was able to continue working including having customer contact as needed.

> "I try to plan for things that I know I am going to do. If I'm expecting something that I know requires that I handle myself reasonably well physically, I adjust my medication a little bit so I'm not at the end or beginning of a cycle and be in the middle or the best time cycle when I'm with a customer...If I plan for it, I can do a good job."

During the last year, however he began to experience more "erratic" responses to his medications. Because of this and his strong need and desire to continue working (has 2 sons in college that he helps financially), he, at the advice of his neurologist began participation in an experimental study which involved continuous Sinemet infusion. At the time of our last interview, he had been on the infusion approximately 2 weeks. When asked how things were going with this new way of taking medications, he shared:

> "Yesterday I couldn't get turned on. I went to work with the pump on. But I couldn't get on. I couldn't get enough medication. It just wasn't working. I was shaking, I had a terrible tremor. I got on the phone and called Dr. S. and he called back in about 20 minutes and I said I just can't get on today. What am I doing wrong? And we talked and he had some suggestions which I did. And I was expecting within 10-15 minutes it should help. And it didn't. Nothing happened. I waited an hour and a half and nothing happened...So I have to learn how to adjust this when I'm under pressure. I have to figure how it works with stress and anxiety."

The practical "know-how" that Tom must learn includes the management of time pressures and anxiety associated with new technology and relating drug effects with the practical demands of his life. Learning how to dosage and regulate the continuous infusion was a new demand for Tom. Whereas he had developed an extensive and detailed practical "know-how" about his previous medication regime, with the new regime he was a novice. As a beginner relative to the continuous infusion, he had to rely on his neurologist. This was of particular interest because when speaking about dosaging medications in earlier interviews, he shared he never discussed what he did with his neurologist in any detail.

> "Well, they like to be quite mechanical about it. They like to know do you start everyday at 6 o'clock in the morning with a pill and take one every two hours so you have one at 6, one at 8, one at 10, one at 12 and so on. And I finally

> breakdown and say yes, I do it that way everyday. But I don't do it that way. They understand it that way. They count it and figure out how many, whether you're taking 800 or 900 and so on."

As one experienced with self-adjusting medication, Tom would regulate his dosages based on how he was functioning and what he was experiencing. Now on an unfamiliar regime, he needed to rely on his neurologist to regulate the dosage until he gained experiential knowledge. Gaining practical, experiential knowledge about how one responds to medications and becoming skilled in dosaging one's medication were key demands for the participants.

Diet and Lifestyle

Equally important as gaining practical "know-how" about responses to and dosaging of medication, was learning how diet and lifestyle influenced functioning. Two of the paradigm cases demonstrated practical knowledge about the role of diet in how they felt and how their medications worked. Dave Smith explained:

> "I think what happens a lot of times when I have trouble getting the Sinemet to come on or when I miss a dose completely is that some kind of digestive problem is not letting the Sinemet get through into the intestine. I think what you eat is as important as when you eat it, how much you eat. I've tried to improve Sinemet's absorption by eating less, eating more lightly..."

Dave ate only one regular meal a day. He felt by not eating breakfast or lunch, he had the best chance of absorbing and "getting the maximum" out of his Sinemet.

> "Dinner is the only real meal I have all day and I

> have to be real careful when I eat dinner and what I eat at that meal. I make sure I eat dead in the middle of my Sinemet dosage so that the last dose has absorbed as much as it can at that time and I have as much time as possible before the next dose is ingested. So right at an hour and a half is when I eat...And what I eat is real important too. I can't eat high protein stuff and I also find that the amount I eat is as important as the type of food I eat. So I try to eat as small amount as possible and that's the reason why I just eat one meal. I operate better during the day if I haven't eaten anything."

Ed Suyigami also was very aware of the influence of what he ate on how he felt and functioned.

> "Sometimes the breakfast will shorten the on period. In the morning I only have a dry cereal with less than 2 grams of protein. So this leaves me with Corn Flakes, Rice Krispies and a few others. But if I'm going to drive, I skip breakfast so that I get the full on period."

While other participants did not speak directly about protein or eliminating meals, they discussed the importance of a balanced diet to how they felt.

> "I think I've learned to manage them (his cycles) and it has to do with eating and sleeping and eating regularly. If I eat a balanced meal, you know sort of eat something in the morning and eat a fairly good lunch and eat a decent dinner and get somewhere between 6 and 8 hours sleep a night, it really--I feel different the next day. Things like coffee really affect me. It tastes good but it seems like the next day I really, even decaf, I pay for it, with a lot of shaking the next day."

Lifestyle and trying to balance activities were areas of experiential learning. Several participants spoke of needing to slow down a bit.

> "It does slow me down. I've learned how to take care of myself in terms of trying not to overdo it. At first I ended up abusing myself getting so tired that I have to climb into bed and rest for a couple days. So now I plan a schedule that's flexible so

> that if I have a tired day I can postpone things a little."
>
> "I think it comes down to the point that I just got to take it slow and do what I can do. I can't do everything maybe I want to do. I don't want to be sitting around. But I think I have to do things on a limited basis. I have to be careful and not over extend myself."
>
> "And the Parkinson's, in a way, in a strange and perverse way, simplifies your existence. You have to give up certain things. You're less able to do certain things...You get up and eat and do certain things. And with the Parkinson's that utility becomes a bigger part of your life. It takes longer to do all those utility things."

For participants who experienced fluctuations in functioning on a daily basis, learning how to balance and plan activities was a central demand. Tom (presented earlier in this chapter) was a vivid example of this. For him balancing activities around functional levels included the additional demands of his job. He worked as a computer programmer for a firm located about an hour from his home. He explained how he managed his activities and job requirements around his fluctuations.

> T: "So what I have found is that I have, my ability, for the times of day when I feel that I can really be productive have become shorter and shorter. When I'm really on which may be about 2 hours a day when I feel both my arms are working properly and I can be a ten finger typist."
>
> I: "Does that dramatically change day-to-day?"
>
> T: "Oh yes. Very much so. It might occur in the morning, it might occur in the afternoon, it might occur in the evening. I don't know when it's going to happen. And I try to set aside projects that I need, things that I want to do and when it happens then I try to do it at that time. If I have a lot of typing or letters or something like that I'll try to set up those activities so when that happens

> hopefully I can do it. The office people know that I have these kind of situations and there a little more tolerant of it. We may schedule a time during the day for something and I'll see how I am at the time, if it's okay and for some reason or another I'm really bad I just ask them to wait an half an hour or something like that for a meeting. And they can."
>
> I: "Do you find yourself, when you have those hours or that stretch of time, just doing things as fast as you can to get much..."
>
> T: "No. I try to prioritize, I try to do things that are most important at that time. Trying to do things fast doesn't work. It might cause stress, in which case I'll just immediately go into the dyskinesias and not get anything done. So I try to hold down the stress. I just try to pick the things that are most important and get as much of that done as I can in that time."

He has discovered that managing anxiety and pacing activities can alter his response to medication. He has had to develop the social skills to negotiate alterations in schedules to accommodate his illness.

Setting aside projects or activities which can only be done when one is functioning at a certain level, was a common way participants dealt with how to balance activities. For Ed Suyigami, shopping and driving were the activities which were done when he was at his best. For Mary Hampton, projects which required mental effort were set aside till she was "on". Thus how to balance and plan activities in light of variations in functioning was an area of experiential learning for participants.

People with Parkinson's gain experiential "know how" and expertise in many areas of day-to-day living. Dosaging of medications, planning diet and activities; are two examples.

The knowledge these participants had in these areas was far more advanced than any formal explanation could provide and incorporated coping, symptom and diet management as well as a host of practical knowledge about alterations in self-care.

Dealing with Unpredictability

Dealing with unpredictability was both a daily demand and a trajectory demand. On a day-to-day basis, many participants were faced with unpredictability relative to how well they would function at any given moment. While they strategized and planned in an effort to maximize their functioning (by regulating their medications, watching their diet etc...), there were limits to the control they had. A key adaptive demand was acknowledging these limits.

> "It's just that everyday turns up a challenge. One day I move pretty well and the next day I find I'm not moving well at all. And I can't figure out why. It gets frustrating. It's just every day turns out different and it's all in how you function. Whether your medication works or not that day."

> "I lucked out. My medication didn't come on too hard for whatever reason, whether I was tired from the day before or what, there is no way to know. Just luck sometimes."

> "Because I can't guarantee that I'll have two hours of on time during a certain period of time. Because it changes from day-to-day. Even when I watch what I eat and so forth I just can't control it."

> "I can help by doing certain things and taking care of myself which puts me more into control but there's a lot that's not very predictable."

Dealing with unpredictability on a day-to-day basis was an adaptive need of participants who experienced fluctuations. However, all participants faced unpredictability related to the course and progression of their own disease. Participants were keenly aware of subtle changes which indicated progression. The changes were different from one individual to another but ongoing monitoring was common to all. Some examples:

> "Well, I feel weaker now during the off phase. When I'm in the off phase I notice that I don't have as much strength as I used to. I notice that I'm having trouble turning in bed, for instance, flipping stomach to my back or whatever."
>
> "I would say that in the last year I went downhill in that I'm having more on/off effects. I find it takes me longer to get going in the morning, to get the medication started and the process working where I feel I'm ready to go."
>
> "It's kind of an ongoing thing that one must always examine one's life because there is that progression so it's challenging all the time. It's not that you're getting use to what it's going to be like and what it's been like or what it is like, it's changing every day. Even though you may only be able to slightly feel the progression you know that the progression is there."

It was usually in the context of the progression they were experiencing that participants raised the issue of the future and it's unpredictability.

> "I don't really have a true sense of what the course will be. I don't think anyone can tell me what I'm going to be like in a year."
>
> "No one can tell you how your disease is going to progress. You don't know. Nobody knows. And so I have no idea."
>
> "When you have a chronic illness that's progressive like this it really cuts down your ability to plan cause you don't know how bad it's going to progress."

Whereas participants acknowledged the course of their disease was unpredictable, how they coped with this varied. Different ways of dealing with an uncertain future will be discussed in the next chapter.

Parkinson's disease presents with many different challenges which are directly attributable to the illness itself. This chapter thus far has discussed these adaptive demands. The focus will now shift to demands about one's roles and relationships.

Demands Created by Roles, Relationships and Identity

Work as a Role and an Identity

All participants in this study except for one was employed outside of the home at the time of their diagnosis. While at various work stages; some entering new careers while others were in the "prime" of their careers, no one spoke of being close to retirement. However nine of the participants had stopped working because of the illness. The effect of this chronic illness on work life and identity were significant.

Particularly for the men in their 50's, the decision to stop working was not an easy one. Several stopped only when they realized it was a question of "safety". An example:

> "In about the middle of June I noticed it. I couldn't tell for sure but I was having problems with my left hand then. But I thought well, it was windy that day and maybe that was partly the reason. Sometime during the trip on the 10th (July) and the 11th I thought, gee this is not right because I couldn't make very good landings

> and I couldn't control the plane like I should. And I thought well maybe I'm going to have to give this up. So I flew the next trip, the 12th and 13th and it was the same trip and so I could fly everything but I couldn't make any of the landings and then I thought I better get on the sick list. So that's when I quit working. I think I was probably depressed from then on until 2 or 3 months ago (about 4 years). I've been not so depressed because I've come to the regular retirement age. That helps a little bit, the fact that I wouldn't have been flying now anyway."

Another gentleman stopped because he could not physically do his job with the speed it required. Three years later, he still struggles with not working.

> "And when I was working I used to feel pretty free with my money. I'm not free with money anymore. Sometimes I wish I could work, you know, do something. But I don't know what to do is my problem. It bugs me being restricted. I wish I could make a little money. It's hard having your wife make all the money. I'm glad she has a good job but it's hard not to contribute some money."

Even though this gentleman received medical disability, he did not consider himself as contributing.

Going on disability was not an easy decision for any participant. But for the men in their 50's, even though they acknowledged it was necessary, they struggled with issues related to not being a productive member of society, financial dependence on their spouse, and loss of their identity as a working person. By many of their own definitions, they had been "workaholics", thus no longer being employed left them struggling for other ways to be productive and making contributions. Work was a source of identity. These men had invested over 30 years in their jobs or careers. Often it had been the central project in their lives. These participants demonstrate the centrality of work to identity in this culture.

One gentleman who had not worked for three years, took a temporary position for a few months to "see if he could do it".

> "It wasn't a lot of money. I was just-it was just self-satisfaction to see if I could do anything to make myself useful. I didn't know if I could stand the pressure of lifting or just being there on my feet for 4 or 5 hours. So I did it for 2 and 1/2 months. On my feet quite a bit. I got tired, but it was a good kind of tired feeling...It was an opportunity for me to prove to myself that I could still work and I could be of use to anybody."

Work was seen as a measure of usefulness to society. And work was also experienced as a measure of independence.

> "I think independence, still having my independence and still be able to work and make an income."

Thus not working meant losing one's independence and often experiencing financial limitations. This was commonly discussed among both men and women participants.

> "I found out that I don't get social security checks until I'm 65 or 62 and that was discouraging. I would like to be earning some money and I don't know how I can do that. Today I had to write a check for $550 for my daughter's college housing. So I wrote this check and just the volume of it hit me. I'd like to be bringing in a little money, contributing something."

> "It's depleted my savings pretty good because my insurance ran out. I had insurance for a year after I left my company and then it lapsed. And so I was forced to pay on all my doctor bills with my savings and I went through almost $20,000 worth of my personal savings, just about depleted all my savings to keep afloat."

Even for participants who remained employed, the approach to work life changed.

> "You know, I would like to do more, I'd like a better job title. I'd like more responsibility. I'd like to be able not to have to do the grunt work and just do the think work. But that is not the reality at this stage. I'm treating this more as a job as opposed to a career. That's been a very very difficult change to make because I've identified a lot of my personal self with my work. But the disease has forced me to look at that. I can't go for better jobs anymore. I need to keep working as long as I can to have money to live on."

A central concern was how long they could continue to work and ways of keeping themselves employed.

> "Because they realized it's getting more and more difficult for me to drive into work. They are going to run the computer network out to my house. Which will give me about 3 days of work here at home and 2 days probably in the office. So hopefully that will keep it that I will continue working for awhile still."

> "Work has always been a big thing. I've worked since I was probably 16. That's just always been a big part of my life. The way I attack work is different but the value of work hasn't changed. I guess I've sort of always known that I'd like to do something a lot different but I can't put my finger on it. But this has pushed me into trying to figure that out. I would like to be able to stay at home and work. And I think if this continues to deteriorate, I may really be pushed into that. It may become more of a necessity. I'm concerned about how we're going to retire. We probably haven't done as much planning as we should to prepare for that. I'm concerned about the quality of life, where we are going to live, can we afford to live here, how will we live financially?"

Parkinson's disease resulted in needing to end work careers for many. Those who continued working, needed to make changes in how they approached and were able to do in their jobs. A central demand was to accept the changes in their work lives as a result of their illness.

Driving as a Measure

Much as work was a measure of independence for those employed, for those no longer able to work driving was equated with independence.

> "It's bad enough when you are in the prime of your career and you can't work anymore and all of a sudden your driving is a little bit screwy. You start thinking am I going to be trapped in my house or can't get out cause I can't rely on family or friends to come and get me. So I get kind of scared. Maybe someday I won't be able to drive. I'll be here all alone or whatever."

> "As long as I can still drive a car, I still have my independence."

> "I quit driving because of my last wreck and I decided then that it was time to quit. Because of giving up on my driving, I'm deprived of my independence. So I've had to rely on my kids."

Being unable to drive was equated with dependence. Not only in the sense of no longer being able to do for one's self but having to ask for help.

Soliciting Support

As participant's experienced disease progression, the changes in roles were not limited to work alone. Changes in the family and how responsibilities at home were re-negotiated and re-interpreted were aspects of the challenges faced.

Some of those married spoke of their spouses taking care of things that they had typically been responsible for particularly in relation to home and family life. For example, Tom Brown noted although he was able to continue working, his wife took on more responsibilities at home.

> "And Anne has taken over more, a lot of things that I used to do in a sense. She handles more things

> about the house and everything and just makes sure things get done."

Tom noted his wife taking a more active role "just happened", and that it was never formally discussed.

While in some cases spouses assuming additional responsibilities and accepting changes in roles seem to occur relatively smoothly, in other cases the need for help or increased dependence caused much strain in the relationship. Two examples will be briefly presented.

Mr. Ray Timmons was a 59 year-old participant who had been married about 30 years with two grown, married children. He readily identified his wife as his primary support system but described a painful, strained relationship.

> I: "Tell me a little bit about your wife. From your perspective, how does she support you?"
>
> R: "Well, she used to teach school and so sometimes she treats me like a kid in one of her classrooms and I resent that."
>
> I: "Did she teach grammar school?"
>
> R: "No, the mentally retarded and the physically handicapped. Sometimes she talks to me like she's talking to one of those kids and I resent it deeply."
>
> I: "I'm trying to get a sense of the interaction. Is it, do you feel, what makes you feel like she's treating you like a child? Is it because she tell you what to do or..."
>
> R: "Yeah. And no matter whether there's 10,000 different ways to do something, if it isn't her way, it's wrong. And I don't know."
>
> I: "Is this something you felt prior to having this disease or it didn't come up before?"
>
> R: "It seems like more often since then. Well, nowadays if I have trouble doing something and she

> comes along she will finish it for me which is alright sometimes but she does in such a way that kind of bothers me. Like get out of the way and let me do it. She makes it sound like she could do it better and easier herself so I don't bother anymore."

Mr. Timmons had stopped doing many things around the house and yard when his wife was at home.

Another participant, Mrs. Julie Carroll, had separated from her husband about six months previously. She had Parkinson's for only four years but her disease had rapidly progressed to the point of needing a wheelchair at times. She acknowledged they had been having problems for several years but felt the disease had contributed to their ultimate separation.

> "He still cares for me but he can not live with me. He can not physically live with me and see me deteriorate like I do or have done, you know the day in and day out."

She lived with her three teenage daughters and was dependent on them for much assistance. She discussed how their relationships have changed.

J: "And my kids are now treating me like one of them rather than their mother."

I: "So your relationship has changed?"

J: "Yes."

I: "Why do you think?"

J: "Because they have to do things for me. So therefore they sort of tell me how and when it will get done. And I have to remind them I'm the mother and I decide."

Learning to ask for help, having assistance and support provided and being able to receive the support were key adaptive tasks. Julie, who had difficulty getting the quality of support from her family that she needed, shared a paradigm story of soliciting help when traveling on an airplane.

> J: "And I let them do everything. I let them get me to my seat. I let them haul me to the bathroom. I let them do everything. And because I just didn't feel that I would be able to do it. And those close quarters, you know, how I am in my own house. I knew with those close quarters I'd never be able to do it myself. So I let them do everything. On the way back I ran into a snag. They got me a wheelchair and the guy pushed me into the area where the plane was supposed to leave. But it had been moved to another gate. And I had to figure out how am I going to get there because I can't move the wheelchair with my right hand. So I looked around pleadingly to another fellow traveller and this woman picked up my sign and she said do you need help. And I said, yes, ma'am, I do. And she wheeled me down there...And then they couldn't get me back to coach so I was treated to 1st class. And they came out with this menu and the guy said which one would you like to have? And I told him, I'd have any of them but I would require somebody cut up my meat. And he said sure and he did it."
>
> I: "What did you learn from this experience?"
>
> J: "Well, that I can do and I can get help. It is out there. It's knowing to ask." How help is provided was often key to people's ability to accept it. "My assistant is very, that type of person, and my roommate is not that helpful. I have to really ask her, whereas my assistant is, she's ready to do anything that is physical and there's just a difference. I don't know how to explain it. Some people help you, help me, and it's a natural thing for them to help. It's easier for me to ask and get help from people that are comfortable giving help."

When it's difficult to ask and receive help:

> "I'm pretty independent. But sometimes you don't get favorable responses from people when you ask them to help you with something...They say they'll be right over to help but they never show up. So I end up struggling to do it myself or just letting go. After a couple of times asking I never ask

anymore."

For some, the type of help which was most welcomed involved allowing them to do things when they could and at their own pace.

As Tom Brown explained about his wife:

> "She let's me do things at my pace. She doesn't baby me or anything like that. She gives me a little more space. She let's it happen. If it takes me longer fine, it takes me longer. She would never say I can do it better or faster or anything like that."

Learning to solicit support when needed, defining what type is most helpful and receiving support, are all adaptive demands.

Summary

This chapter has discussed the demands experienced by the person with Parkinson's disease. The demands have included those presented by the illness itself such as changes in one's body and functioning, learning to dosage medication and accepting unpredictability as something which can not be changed. The illness demands required a gaining of practical knowledge. Participants quickly recognized the limitations of formal medical knowledge of the disease and had to learn how *they* could manage their illness on a day-to-day basis. Their level of expertise was evident; they knew what had the best chance of working for them. But in learning how to live with their illness they also encountered the limits of control and predictability. No matter how well they planned, how closely they monitored their functioning, what they ate and when they ate; there were times their body or their medication didn't work the way they expected.

Demands related to roles, relationships and identity were discussed. Having to stop working and ultimately for a few no longer being able to drive physically and symbolically meant dependence. The changes experienced were central to their identity as productive, contributing members of society. Changes were also experienced in relationships with spouses, children and friends.

The demands of this illness are numerous. While greatly influenced by the nature of the disease itself, adaptive demands were also formed by the participant's stage in the life cycle. The issues they were dealing with was very much influenced by their work and family stages.

This chapter has attempted to discuss the demands participants experienced in their day-to-day lives. The next chapter will discuss different ways of coping with these specific demands. I will suggest how one copes is shaped by how one understands and experiences their illness.

CHAPTER 8

Ways of Coping with Parkinson's Disease

The focus of this chapter is how different participants coped with their illness. Participants demonstrated both commonalities and differences in coping that were shaped by the nature of the disease, the bodily experiences associated with symptoms and medications, personal and cultural meanings of the illness and self and professional care practices. Specifically, in this chapter I will discuss how participants coped with (1) challenges to their sense of self and (2) a future of limited horizons. Both of these challenges have to do with temporality. The challenge to the sense of identity is a threat to continuity with one's past life. The challenge to the future is a threat to one's sense of possibility and continuity in the future. Both challenges and coping responses are shaped by the person's concerns, relationships, habits, practices and their world (Dreyfus, 1990; Benner & Wrubel, 1989). Participants ways of coping with the challenges to their sense of self and future were guided by their background meanings, concerns and their self-understandings along with the embodied experience of the illness.

Coping with a Changing Identity: Maintaining an Intact Self

Parkinson's disease presents many challenges to the person which threaten their sense of self. For example, bodily capacities come into questioning. The body and it's pre-reflective way of negotiating the world ceases to be. In addition, because of their disease people often experience changes in roles which are intricately linked to their identity. Many participants stopped working because of the disease's impact on physical functioning. They experienced changes in relationships and roles which brought into examination key aspects of their identity as a partner, a parent and a contributing member of society.

Participants were faced with the challenge of maintaining a sense of self in the context of these many, encompassing changes. The demands they faced involved integrating the illness into their self understanding and sustaining a sense of continuity with their pre-Parkinson's self. How they did this was shaped by their background meanings and concerns and the actual, specific illness demands they encountered. It must be noted not all demands presented equally to all participants. For example some participants experienced marked fluctuations in physical functioning throughout the day while other participants did not have this bodily experience. The specific realities of their illness influenced what possibilities showed up for coping and maintaining a sense of self. Three of the paradigm (Mary, Ed, and Dave) cases will be discussed as common ways among participants of coping and maintaining or reshaping an identity. These cases exemplify broad illness experiences and coping patterns related to and dealing with temporality.

Ed Suyigami's identity rested in his view of himself as a scientist. Being a scientist was not just limited to his work but was an integral aspect of who he was and how he understood and experienced the world. While no longer able to work, he maintained his scientific identity by keeping abreast of discoveries in the scientific world (reading journals, attending professional society meetings) and by approaching his illness with a scientific, objective stance. His training and career had ingrained in him the importance of rational approaches; precise, empirical data; and control of extraneous factors which might otherwise influence the data. These practices and ways of understanding were deeply rooted in his identity as a scientist and extended to his most general ways of being in the world. Being objective and rational were deeply established in his habits and practices. His objective, scientific stance to his illness kept him anchored in his identity. He approached his illness utilizing "scientific techniques". For example, he kept accurate, precise, detailed diaries relative to his bodily functioning and responses to medication. He sought empirical data to substantiate; he had the disease, was experiencing certain symptoms and side effects, and to measure disease progression.

Thus his way of coping was in part set up by his identity as a scientist. In turn his coping pattern reinforced and maintained his identity and ways of being in the world.

Having a sense of control and looking normal were key to his identity and way of coping. Both daily and in anticipating his future disease trajectory, he strived to be in control of his body and situations. He planned his activities around his medications so as to appear normal. To be seen shaking was to "look abnormal" and resulted in feelings of shame and inadequacy.

Parkinson's disease, despite his in-depth knowledge of neurochemistry, was viewed as a deficiency or weakness and thus a source of stigma and shame. Without a scientifically proven explanation for the etiology of the neurochemical imbalances, Ed Suyigami felt inadequately absolved from somehow causing the disease. He felt personally flawed and experienced the illness as a source of shame. His central way of coping was to avoid situations which would allow his differences to be seen. At all costs he wanted to avoid appearing abnormal in public.

While for many participants, to avoid these situations would be impossible, for Ed Suyigami it was achievable. After he went on disability, his social contacts were limited. His identity was not defined by his relationships nor was his sense of enjoyment the result of activities that involved others.

On a day-to-day basis he was successful in his coping strategies. He avoided being seen shaking by carefully planning and executing his days around medications and his responses to them.

Control related to his future however was more difficult. He approached the future with the same desire for control and predictability. The inability to know how his disease would progress frustrated him. He was frustrated with the medicine for being an "imperfect" science and with his own ability despite his scientific approach to predict his future symptoms including the severity and timing of these symptoms.

Mary Hampton's self-understanding was embedded in her roles and practices as a wife, a mother and an active, involved person. She held strong notions of good relative to being a wife and good parent. Central to her identity was her taking on meaningful activities and "giving something" to people. Her traditions including her upbringing and her parental influences contributed to these self understandings. These well developed understandings along with her husband's support have been strong resources in maintaining an unspoiled identity and a sense of continuity with her pre-disease self.

Mary's concerns and personal meanings determined what she perceived as possibilities given the limitations of having Parkinson's disease. To withdraw or disengage was not a possibility she could easily choose. To remain "emotionally alive", as physically active as she could, and involved in meaningful activities organized Mrs. Hampton's coping responses. While her activities had to change over the years due to increasing physical limitations and more frequent periods of being "dead in the water", she did not stop doing and being involved. She continued to take on meaningful activities where she could "give something" much as she had done in the earlier, pre-Parkinson's times of her life. For example, when her husband began his academic career being a faculty wife did not provide the sense of "community" she was anticipating. She took on other activities such as becoming involved with the League of Women Voters and being a school board member. These activities supported her identity of giving and being involved. As the Parkinson's disease impacted more and more on her <u>abilities</u> to do certain activities at particular times, she either replaced the activities with other meaningful ones or found ways to renegotiate her level of involvement during these particular times. But she did not withdraw as her sense of self was linked to her activities and relationships with people.

She experienced possibilities in "too much" or thrashing. What was perceived by the researcher as an exhausting, uncontrollable and uncomfortable experience for Mary was experienced as being "emotionally alive" and functioning. "Too much" allowed her to think, talk, function, remain engaged and active. Her ability to go with her body rather than attempt to prevent these experiences freed her to maintain her sense of self as an active person. She did not fight "too much", but was solicited by her body. This solicitation opened up the possibility of walking, hiking with her husband, doing household chores and self-care activities.

She copes by staying active and engaged in meaningful, defining activities and maintaining her relationships with her husband and family. She has strived to hold unto her pre-illness identity maintaining a continuous self despite the radical body changes she has experienced.

Dave Smith experienced Parkinson's disease as a threat to his embodied self. His being rested in a body that moved freely, loosely and normally. He lived in the world through his skilled, physical capacities. Parkinson's was not experienced solely as a body insult but as a threat to his being and "basic nature".

When his Sinemet worked, his body was a known, familiar body that he could communicate with. His sense of self as an "aggressive" and "pushing" person remained intact. The effectiveness of Sinemet helped maintain a continuity with his pre-disease self.

When his medication decayed, the experience was distressing and encompassing. When he experienced "neurological strangulation", an experience which occurred more frequently as the years passed, he was physically uncomfortable, overwhelmed and unable to maintain activities, interactions or communication. Along with his diminished bodily capacities, he experienced a diminishing of his being. The sensation he experienced and the "feeling" ("overall sickening") were intertwined. His embodied being could not reside in this "suffocating" body. His basic nature and sense of self was lost. His physical, emotional and mental being had been taken from him, he had been robbed of his most general ways of being in the world.

Surviving his suicide attempt and the depression that followed meant he had successfully confronted his illness and through his <u>determination</u> he had won. Still having his determination provided him a connectedness with his previous sense of self. He had not been robbed permanently of his pushing, aggressive, determined self.

Following the suicide attempt, he experienced his illness in a new way. He took up his illness as the central focus of his identity. Who he was had been reshaped by this illness experience especially the most recent events. His perceptions and how he viewed his situations were his new found ways of gaining control and coping with his illness. He could create his personal meanings and assign positive meanings to situations which previously had been experienced as overwhelming. His sense of self and continuity were experienced in creating new personal meanings.

These participants coped and strived to maintain a sense of self in ways that made sense and showed up as possibilities for each of them. The possibilities for keeping their sense of self unharmed were bounded by personal, cultural and illness meanings. What made sense and worked successfully for one participant because of their personal meanings and illness understandings did not necessarily show up for another participant with different concerns and understandings. For example, Ed coping's patterns and ways of protecting his sense of self worked for him. His central identity as a scientist was maintained and he avoided situations which would produce shame by limiting his activities and social contacts. This worked for him because his identity and meanings were not tied to activities or relationships. Mary could not limit her activities in the same way because her sense of self involved an active, engaged self. But on the other hand, shame was not something she experienced. Mary was able to "go with", be solicited by her body. She experienced possibilities in her body even when she was in her worst physical state of "too much". These experienced possibilities reinforced her identity as "emotionally alive". Dave did not experience his body in the same way. When he experienced "neurological strangulation" (his worst state) he had to "withdraw". Of the three participants discussed, he experienced the most insult and challenges to maintaining an intact identity. The role of depression in this can not be overlooked. His situation was compounded by the hopelessness he experienced. He had to find new ways of coping and protecting his identity from being harmed. His ways of dealing with his illness were not working. His sense of self was violated. Having the ability to assign meanings to situations offered a way of dispelling hopelessness, a second chance to deal with his illness, and a way of regaining a sense of an intact self.

Coping with Limited Horizons: Keeping Possibilities Open

As an outsider to Parkinson's disease and as a person who lives in this culture, I perceived the notion of living with a future that included a downhill trajectory in terms of functioning and capabilities was as overwhelmingly negative. I could not understand how persons lived and faced this future. I was only able to see the worst possible outcome as a result of the disease. Though participants live in this common culture which anticipates a future of promise and greater possibilities, they were not outsiders to their lived experiences. Much as they experienced possibilities within their current illness and physical limitations, they still perceived possibilities within the context of a progressive illness.

One predominate way of dealing with a limited future was to keep open a range of possibilities for the future. Participants who took up this way of considering the future saw both "best scenarios" and "worst scenarios" along with many other potential options as viable possibilities. As Gary Miller stated:

> "It doesn't progress the same in each and every patient...my symptoms could not be worse than than they are today or I can be disabled. And I don't know which way it's going to go or any place in between as well..."

The fact that neither participant's nor professionals knew how their symptoms would progress allowed a range of possibilities to be imagined. Most participants had a "best scenario" as one of the possibilities. The specifics of this scenario were influenced by the current nature of the disease and the severity of the symptoms they were experiencing. For example, for Gary Miller the best option would be not to experience a worsening of his symptoms. For Mary Hampton who had experienced more new symptoms recently, her best option was "a progression of the disease that is as slow as possible". Best options usually centered around no further progression, minimal or slow progression and for some participants involved development of treatment options which had fewer side effects associated with them. It is worth noting while participants occasionally spoke of a "cure", they explained a cure would mean a "halting" or "stabilizing" of their symptoms. They did not conceive of a "cure" taking them back to their pre-Parkinson's level of functioning.

Along with the best options, participants had a sense of what would be most difficult for them to deal with in the future. Again, these were influenced by the symptoms and limitations they were experiencing along with their personal meanings and concerns. For example, Ed Suyigami enjoyed reading and reinforced his identity by reading professional journals. His "fear" related to the future was that he might reach a stage where he wouldn't be able to read. Some examples from different participants:

> "I'm afraid of all the physical limitations, the incontinence..."
>
> "My only real fear is the loss of cognitive ability. Everything else I can kind of deal with..."
>
> "The thing I fear most is probably losing mental capacity."
>
> "Every night when I say my prayers I say "please don't make me be a burden on my family". I don't want to ever get to the point where I can't take care of myself."
>
> "My biggest fear is that I would end up in a convalescent home. I don't want that to happen."

While the participants knew these fears were possibilities, they did not accept them as the only outcome possible. They acknowledged their worst fears and terrors but did not perceive their outcome as determined or established. To live investing on the worst possible end would be terrorizing and immobilizing, making life in the present unlivable. Rather by acknowledging their worst fears, they were able to keep these in the background to a certain degree. They lived in their present concerns, enjoying their current possibilities and capacities, and did only essential planning for the future. For example, several participants spoke of planning for the "future financially" with "the Parkinson's in the back of my mind". The planning centered around issues such as work, living on a limited income, costs of living including costs associated with additional support they may require. They considered their options in light of the range of possibilities they perceived possible with their illness.

> "Well, I have been thinking about my options. If I go out on disability in the few years, I will have to make some changes. My kids have offered to help which is nice and I know they mean it. But I'm not sure that's the best way to go. I could also get another roommate to help with costs. But I'm thinking maybe to move into a smaller place, like in a retirement community. Where they would take care of the outside. I'm paying a lot of money to get the outside stuff done plus then all the repairs and maintenance work. And maybe then I won't need my car because they have to take you around. I think that might be best for me financially."

Mary Hampton provided another example. She and her husband had recently been given a sum of money by her parents (she described as "a pre-inheritance gift for tax purposes").

> "...as we are doing financial planning, this is one of the things that we've been--the fact that there

> may be a time when certainly housekeeping will become a necessity. Who knows whether wheelchairs, mechanical devices; whatever help. I just don't know what the future is so in a sense you hate to plan everything for the future when you don't know it's going pan because you want to give yourself enough cushion. And so its partly setting up finances with an eye to future needs..."

The majority of participants did not try to predict or second-guess what their future held. They believed it was not graspable and perceived a sense of hope in keeping a range of possibilities open.

Ed Suyigami approached his future with some commonalities but with notable differences from the rest of the participants. He perceived more limited future possibilities than other participants. He was "convinced" he would reach a point where he could no longer care for himself. He became "convinced" because he had experienced (empirical evidence existed) a time when he was ill when he could not roll or twist out of bed and had to crawl to the bathroom. He believed his only hope for not becoming dependent rested on experimental research efforts, such as fetal cell transplants, being successful in "stabilizing" his disease progression. The chance that this might occur in the next few years, left a glimpse of the possibilities other than being wheelchair bound open. Of all participants, he had given the most consideration to the future. For example he had visited several board and care facilities. He felt this was necessary as he did not have a network of social resources to call upon and would be dependent on professional care resources. This, coupled with his belief unless there was a scientific breakthrough within the near future, he would require institutionalized care. He spoke in "when" I need care in contrast to other participants whose language was "if" or "may" need. He approached the issue of institutionalized care as he approached every other issue, in a rational, logical and somewhat detached manner. It seemed as if he accepted this outcome, as the known end result of having Parkinson's disease.

Dave Smith's way of coping with the future stood out from other participants. Missing from his narrative was any discussion of disease progression occurring in the future even when directly asked. He did not have a story of his "worst fears" possibly because he perceived he had confronted the worst in his illness with his suicide attempt. Rather his present concerns centered around having the strength to deal with his illness on a daily basis. Perhaps because of the vulnerability of his present and his vacillating feelings of powerlessness, a narrative of future concerns including diminishing physical capacities was not possible. The precariousness of the present was what he was dealing with.

Summary

Changing identity and a future of limited horizons called forth the most challenges to one's sense of temporality. The magnitude of changes experienced by participants as a result of their illness brings into questioning one's basic sense of self and general ways of being in the world. Strategies for maintaining an intact self were discussed using three contrasting paradigm cases as prototypes for how participants coped.

The trajectory of Parkinson's disease proposes a future of limited functioning and decreasing capacities. The way participants took up this issue was presented. Being able to experience a range of possibilities within the framework of disease and future promise of new treatments offered hope and a way of coping.

CHAPTER 9

Implications

In this research I have attempted to provide a fuller understanding of the experience of Parkinson's disease from the perspective of the persons who have this illness. My aim was to change the dialogue from one of disease and outcome to a discourse of illness meanings and the daily self-care and coping required by this illness.

In this chapter I will discuss how this work links with the current literature related to depression and psychological adjustment in Parkinson's disease. I will attempt to point out ways it differs and enriches our understandings and ways it questions the implications which might be drawn from existent literature. I will conclude with the implications of this work both for people who have Parkinson's disease and for health care professionals who encounter people with this illness.

Another Perspective

The depression and the psychological adjustment literature have been dominated by research which has taken a disease approach to Parkinson's. Missing from this body of literature is the illness experience with the context of the disease process.

The literature on depression has primarily attempted to address why some people experience depression with Parkinson's and others do not. The underlying purpose to this body of research appears to be identifying who are at risk for developing depression. Identification of a specific variable or a combination of variables might help alert practitioners to "patients" who are at high risk. Possibly this would lead to closer monitoring of certain individuals for depressive symptoms and consideration of anti-depressant therapy as an aid. While such information could be very helpful to those persons who truly do suffer from depression, it fails to look at the context of the illness and what the person is dealing with on a day-to-day basis. Offering anti-depressant therapy as the sole treatment for the problem may help alter neurochemical imbalances (just as Sinemet does with dopamine deficiency) but overestimates medication's potential efficacy and fails to deal with self-understandings and illness meanings and self-care practices that exacerbate the problem of depression. The literature on psychological adjustment has widened the dialogue to include psychological and social factors such as self-confidence, and social roles. Still underlying this research was the attempt to "identify variables" which predict people's adaptation to the disease (Dakof & Mendelsohn, 1989). While researchers have claimed to be utilizing a "person" rather than a disease approach, the person has been studied solely from psychological and social perspectives. The cultural context of illness and the embodied experience of illness have been overlooked. Implicit in this research has been the notion there is an "effective" or successful way to adapt. What this sets up is a judgement of coping patterns with those which do not result in "effective" adaptation, being seen as a negative outcome and often the failure of the person. For example, Dakof and Mendelsohn (1989) in describing depressed and worried participants emphasized they <u>allowed</u> the disease to dominate their lives. Participants they found to be "passive and resigned" had <u>surrendered</u> to the illness. This leaves one to conclude these participants have failed to achieve successful adaptation because of a personality or a character weakness. Also problematic in this research are conclusions or recommendations for the person with Parkinson's. For example, one study concluded with the following recommendations: (1) to exert extra efforts to have a normal life so as to minimize the disease's influence, (2) to not <u>allow</u> the disease to dominate their identity , and (3) concern oneself with how they can work around their limitations (Dakof & Mendelsohn, 1989). General recommendations of this nature may not be helpful to the person who has this illness. Certainly it does not suggest strategies or ways to deal with the illness on a day-to-day basis. When a person is "dead in the water" or experiencing "neurological strangulation", neither extra efforts nor working around limitations will make these bodily experiences any easier to cope with. Any recommendation must start with an understanding of the experience from the person's perspective, with their personal meanings, concerns, illness understandings and perceived possibilities for coping. Without this understanding, not only will suggestions be of limited value but may potentially have negative effects. Participants in this study clearly demonstrated at times that "minimizing" their illness was not an option. For example, becoming skilled knowers and expert managers of their medication dosaging, timing and sequencing required intense bodily monitoring.

In summary, the current dialogue in the literature has centered around predictive variables relative to two outcomes, the presence or absence of depression and "effective" adaptation. This project has shown coping is shaped by personal meanings, concerns, illness understandings, and demands experienced. Persons cope in ways that are available to them. They do not "choose" their ways of coping but rather deal with their illness in a way that makes sense and is intelligible to them. This project broadens the dialogue relative to Parkinson's disease. The embodied experiences, with the exception of Sack's (1983) descriptions of bodily experiences associated with Sinemet, have been ignored. For these participants bodily experiences intrinsically shaped how people coped and the possibilities they perceived for encountering and negotiating their world.

Implications for Professionals

The Embodiedment of the Illness

Participants experienced their illness as an embodied experience. The manifestations of the disease which clinicians speak about such as tremor and bradykinesia are not experienced as "a little shaking" nor "difficulty in moving". But rather are experienced as a way of being and encountering the world. In Chapter 3 and 5, two vivid examples were presented. Dave Smith's "neurological strangulation" left him incapacitated, whereas all he could do was "lie down to decrease the noise". Communication, movement and interaction were impossible. Mary Hampton's "dead in the water" was not experienced as difficulty in moving but rather as an encompassing experience involving the self which affected all aspects of bodily movement and the ability to think and respond. "Dead in the water" resulted in the body losing it's ability to grasp the world in a meaningful way. In contrast, Mary experience of "too much" provided a re-connection and access to the world. She could move, do activities, think, be engaged and regain access to the world.

Understanding bodily experiences as connections or ways of accessing (and in turn losing access to) the world is a very different understanding than seeing symptoms as disease manifestations to regulate or minimize. This view of symptoms as manifestations fails to understand the bodily experiences as general ways of being in the world. The meaning of bodily experiences and responses by participants were shaped by their self and illness understandings. Several understandings existed thus the clinician must begin with what the person's understanding is. For example, are "too much" or dyskinesias understood as a loss of control and experienced as shame or as a way of staying connected and engaged in the world? Without an understanding of the meaning of bodily sensations and experiences for the person, practitioners will reinforce the experience as a privatized one. Practitioners need to elicit information from patients that will facilitate understanding the bodily experiences. For example, if the person's goal is to have periods of time when they appear "normal" and the trade off they accept is experiencing fluctuations in functioning, the practitioner's efforts to have the person's functioning "even keel" will be unsuccessful. These efforts would fail to acknowledge the personal meaning of appearing normal. Rather, the person and practitioner could work together to achieve a medication regimen which would provide some periods of time when one appeared "normal".

Creating Caring Practices

Missing from most participants narratives were any stories of caring, nurturing practices by physicians or health care practitioners. Beginning with the diagnostic phase and continuing through the years of managing and coping with the illness, there was a glaring absence of healing practices by professionals.

With the exception of one person, participants saw a neurologist, or in a few cases an internist, as the sole practitioner relative to their Parkinson's. The main function this person had was to provide anti-parkinson medication and to suggest new medications as time passed. Their interactions with these professionals were centered around the scheduling and amount of medications they should take. Despite the well-established limitations of drug therapy for this disease, little acknowledgement of this was ever imparted to the person with this illness. While it was clear participants experientially knew the limitations of drug therapy, there was not open dialogue about this nor was there discussion of how to deal with this. Physicians continued to offer medications and experimental options as the sole strategies for managing the illness. This approach was not surprising as it is congruent with the model of cure and treatment which exists in the health care system. Despite the inability to provide such a promise, interventions were limited to this.

A "cure" model does not fit for a chronic illness such as Parkinson's. This illness requires an abandonment of this approach and development of practices which offer medications as a palliative treatment but also respect the habits and practices developed by the person to manage their illness. How can this occur?

First, health professionals must have an open dialogue with the person beginning with the diagnostic phase. There must be an acknowledgement that the person who is experiencing symptoms knows their body. Participants were aware of very subtle bodily changes and knew something was wrong. Practitioners need to pay attention to the subtle and often ambiguous bodily changes the person is experiencing. Once a diagnosis is made there must be an honest dialogue with the person about what is known and unknown about this disease.

This dialogue should include what can be offered in terms of medications but the limitations must also be discussed. Selling medications as a cure or a treatment without discussing the "trade-offs" is unfair and unethical.

Second, we must create a relationship between the professional and person which encourages and supports coping being discussed. Many participants perceived their physicians solely as medication prescribers. Persons with Parkinson's were left to learn ways of managing their illness. They experientially learned how to self-dose their medications, balance diet and activities and ways of dealing with their bodily experiences. While some sharing of this occurs to a limited degree in support group forums, there is little knowledge about or acknowledgement of these practical ways of coping by practitioners. Professionals need to listen and learn from the persons who have gained experiential knowledge. Listening to persons means acknowledging as health professionals there is a limit to the knowledge we have and what we can offer to persons with this chronic illness. Also listening involves acknowledging and legitimizing their experientially gained expertise. This would end practices where the person perceives they have to "cheat" or lie to their practitioners about medication dosaging. These would be replaced by practices which respect the lived experiences and accept practical strategies for coping.

Third, a clinical ethnography such as this provides practitioners with the tools or background to begin to understand their patient's personal meanings, the powerful demands they face, and their ways of coping and being with this illness. The contrasting paradigm cases articulate different illness understandings and possibilities for coping. While the cases presented were contrasting, they were not unique cases. They were strong examples of different understandings, demands and coping possibilities which were common to other participants. The cases provide practitioners a way to initiate dialogue and gain access to the worlds of their patients.

Fourth, we must create a relationship between practitioners and patients which allows vulnerability to be expressed. Parkinson's challenges one's identity and ways of being in the most basic ways. Participants in this research often did not discuss this with anyone. They coped with their feelings and fears related to the future and their sense of self in isolation.

Practices which nurture and support people who have this illness are desperately needed. Abandonment of a framework which offers only medication and experimental procedures is overdue. Practices that affirm experientially gained expertise, that legitimize the lived experience, that support coping strategies and that acknowledge human vulnerability are needed.

Implications for those who have Parkinson's

This work has attempted to interpret the world and lived realities of having this illness. Participants in this project were committed to having their stories told, they wanted people to understand what it is like to have this illness. The goal of this research was to provide an access to understanding participant's worlds. This understanding should never be underestimated. Understanding is the starting place for healing, and developing compassionate, caring practices. Understanding forms the basis for decreasing isolation and assists in the development of effective interventions. Interventions must have understanding as a foundation.

The power of understanding the participant's experiences and world, frees them from privatized, isolated experiences. This can happen on two levels. This work demonstrated commonalities in understandings, concerns and illness demands. Participants can recognize themselves in the paradigm cases and receive validation in the common demands and ways of coping. That in itself, can help decrease one's feelings of isolation, to know there are others who have shared understanding and experiences. But also the power of understanding makes caring practices by professionals a possibility.

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Appendix A

Mini-Mental Status Questionnaire

1. Where are you now?
2. Where is that place located?
3. What day of the month is it today?
4. What day of the week is it?
5. What year is it?
6. How old are you?
7. When is your birthday?
8. In what year were you born?
9. What is the name of the President?
10. Who was the President before this one?

Appendix B

Demographic Questionnaire

NAME______________________________ ID#__________

ADDRESS____

TELEPHONE____

AGE____________ BIRTHDATE_____________

Are You Married?________

If yes, for how long?__________________

Who is your primary support system or caregiver?

____

What is the relationship of that person to you?__________

Are you presently employed? YES____ NO____
Full-time______
Part-time______

What is your occupation?_________________________________

How long have you been in this occupation?______________

If not presently employed, where you previously employed?
YES____ NO____

If YES, when did you stop working?_______________________

Why?
Retired_____________
Disabled____________
Voluntary__________
Compulsory_________
Comments_______________________________________
____

Economic Status (Check all that apply)

_________ Employed
_________ Disability Benefits
_________ Veteran Benefits
_________ Private Pension Plan
_________ Public Assistance
_________ Annuities, Investments, Savings
_________ Family Income
_________ Other

Residence (check)

_________House (own___ rent____) _______Condominium
_________Apartment _________Retirement Community
________________________Other

What is your ethnic or cultural background?______________

Do you consider yourself a spiritual person?_____________

Religious Affiliation, if any_____________________________

Are you involved in a church or synagogue?_______________

Have you been involved currently or previously in any organization or group which has been important or influential to you?

____
____

Are you involved with a Parkinson's support group?

____

HEALTH INFORMATION

When were you diagnosed with Parkinson's disease?

____

Medications you take for PD:

Sinemet__________________________

Bromocriptine or Parlodel___________

Eldepryl________________________

Anticholinergics_________________

Others__________________________

Other medical problems/medications you take?____
____
____
____

Appendix C

Hoehn and Yahr Staging (Modified)

Stage 0 = No signs of disease

Stage 1 = Unilateral disease

Stage 1.5 = Unilateral plus axial involvement

Stage 2 = Bilateral disease without impairment of balance

Stage 2.5 = Mild bilateral disease with recovery on pull test

Stage 3 = Mild to moderate bilateral disease; some postural instability; physically independent

Stage 4 = Severe disability; still able to walk or stand unassisted

Stage 5 = Wheelchair-bound or bedridden unless aided

Appendix D

Schwab and England Activities of Daily Living Scale

100% = Completely independent; able to do all chores without slowness, difficulty, or impairment; essentially normal; unaware of any difficulty

90% = Completely independent; able to do all chores with some degree of slowness, difficulty, and impairment; may take twice as long as normal; beginning to be aware of difficulty

80% = Completely independent in most chores; takes twice as long as normal; conscious of difficulty and slowness

70% = Not completely independent; more difficulty with some chores; takes three to four times as long as normal in some; must spend a large part of the day with chores

60% = Some dependency; can do most chores, but exceedingly slow and with considerable effort and errors; some chores impossible

50% = More dependent; needs help with half the chores, slower, etc.; difficulty with everything

40% = Very dependent; can assist with all chores but does few alone

30% = With effort, now and then does a few chores alone or begins alone; much help needed

20% = Does nothing alone; can be a slight help with some chores; severe invalid

10% = Totally dependent and helpless; complete invalid

0% = Vegetative functions such as swallowing, bladder and bowel functions are not functioning; bedridden

Appendix E

HISTORY AND ILLNESS MODEL INTERVIEW (Time 1)

1. Where were you born & raised?

2. Tell me about your family (parents, siblings)?

3. Education: How many years? Where did you go to school?

4. Are you married currently or previously?
   If not other significant relationships?
   Children?
   Who is the closest person to you in your life now?

5. Employment:
   Tell me about you job (Present or most recent)
   How did you get to this point?
   What kinds of responsibilities you have/had?
   How important is your work to you?
   How do you think your work has influenced who you are?
   Is there anything about your work that is difficult or stressful? Describe.

6. Think about events in your life which stand out as important in shaping who you are. Tell me about those.

7. I am interested in your understanding of your illness.
   a. Could you describe the first things you noticed about yourself that made you suspect there was something different or that there was a problem? Why do you think it started when it did?
   b. What do you think might have caused these problems or differences?
   c. Could you describe in your own words, what you think Parkinson's disease really is? How does it work?
   Probes: What does it look like?
   Is there something different about how your body, mind or emotions work?
   d. How severe is your disease? What do you think the course of the illness will be?
   e. What kinds of treatment should you receive?
   Probes: Medications
   Other treatments (Get them to be specific)
   Other options?
   f. What are the most important results you hope to receive from this treatment?

8. What were you told about PD? By who? Have you ever known anyone with PD prior to you being diagnosed?

9. Describe how you felt when you were given the diagnosis? How did that change over time?

10. Describe a situation when you had to explain to someone (friend, acquaintance, etc) that you had PD. What did you tell them?

11. Since being diagnosed can you describe an event or situation that stands out as positive or having gone very well?
    a. In general, tell me what happened. (Get narrative)
    Probes: How did this come to be?
    What did you think about it?
    How did you feel?
    Tell me about your first response.
    Other responses.
    How do you feel about your responses?
    Would you handle it the same way?
    Does this remind you of other situations?
    Was it handled in a similar or dissimilar fashion?
    Do you think there were any changes in you as a result of this situation? What were those changes?

12. Since being diagnosed can you describe a situation or event which stands out as being difficult or stressful.
    a. In general, tell me what happened (Get narrative) If not addressed ask:
    Probes: How did this come to be?
    What did you think about it?
    How did you feel?
    Tell me about your first response.
    Other responses.
    How do you feel about your responses?
    Would you handle it the same way?
    Does this remind you of other situations?
    Was it handled in a similar or dissimilar fashion?
    Were there any changes in you as a result of this situation? What were those changes?

Appendix F

LIVED EXPERIENCE, MEANING & COPING INTERVIEW (Time 2)

1. Do you feel your PD has progressed since diagnosis? How so? Describe your current symptoms?

2. How has your life changed over this period of time? Probe: work, relationships, interests, leisure. Is this related to disease progression?

3. How has your body changed? Is there any particular activity that you enjoy? How is that now?

4. Tell me about your typical day. Start at the beginning and trace a day for me. (elicit details regarding activities, length of time it takes, difficulty etc)

5. From this day you described, what was the hardest thing that arose for you during the day? What did you do? How did you deal with that?

6. Since we last spoke, can you describe an event or situation that stands out as being difficult or stressful.
   a. In general, tell me what happened (get narrative) If needed use probes that accompany this question in first interview.

7. Since we last spoke, can you describe a situation or event that stands out as positive or having gone very well for you?
   a. In general, tell me what happened (get narrative) If needed use probes that accompany this question in first interview.

8. What about taking medications? How is that for you?

9. Describe how you deal with your medications? When do you take them and how does that relate to what you can do or not do?

10. How do changes in your medication regime happen?

11. Other people talk about learning to adjust and alter their medications over time? Have you done this? Has this caused problems with your partner (caregiver) or your physician?

12. Who is of the most support to you? Tell me about that person?

13. Is it easy or hard for you to ask for help?

14. What kinds of help feel helpful to you? What kind of help isn't really helpful?
    Probe: If you could make any changes in the help you receive what would they be?

Appendix G

COPING INTERVIEW (Time 3)

1. Since we last spoke, can you describe a situation that went well for you or stands out as positive?
   In general, tell me what happened.
   Probes as needed.
2. Since we last spoke, can you describe a situation which stands out as being difficult or stressful for you?
   In general, tell me what happened.
   Probes as needed.
3. Has the way you understand and deal with your PD changed as time has passed. How so? How did this change occur?
4. What helps you the most to deal or cope with your PD now?
5. What is important to you currently?
   Has this changed since having PD? How so?
6. What are the chief problems that Parkinson's disease has caused for you?
7. What do you fear most about your future?
8. What are your hopes and desires for your future?
9. What do you think the circumstances of your life will be in 3-5 years?
10. Do you ever talk to anyone about your fears, your hopes for the future? Who is that person?
11. What have you learned from having PD?
12. Do you have any thought or advice to share with others who have PD?
    With health professionals?
    With the public?

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For reference

Not to be taken from the room.

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