

**DESCRIPTIONS AND PRESCRIPTIONS:
HEALTHCARE PROFESSIONALS CONSIDER CARE
FOR PEOPLE WITH PARKINSON'S**

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ABSTRACT

Healthcare professionals are at the frontline intersection of the nation's healthcare system and the healthcare of people with Parkinson's. With increasing numbers of people with Parkinson's, and finite healthcare dollars, what are the work experiences of care of healthcare professionals working with people with Parkinson's? In this participatory inquiry, narratives of work experiences of care of six healthcare professionals of people with Parkinson's were elicited. The healthcare professionals included a general practitioner, a Parkinson's specialist neurologist, a gastroenterologist, a nurse, a social worker, and a physiotherapist. The objective of the inquiry was to describe and understand the work experiences of these healthcare professionals through their descriptions of work experiences of care and their prescriptions for ideal work experiences of care. The interviews with the healthcare professionals were audio recorded, transcribed *verbatim*, and analyzed. The theoretical framing of the empirical material outlined medicalization and medical frameworks, a 'whole person' approach, and theories of care. Three overlapping primary themes emerged from the interviews which were verified by both the literature review and personal reflections. Firstly, Parkinson's is a difficult, complex and multifaceted disorder; secondly, due to the complexity of this disorder, a multidisciplinary team approach by healthcare professionals is needed; and thirdly, more funding or a change in organization of funding, is needed in order to support this model of healthcare. In describing multidisciplinary care, these healthcare professionals questioned the current funding approach of the healthcare system. This was a noteworthy finding of this inquiry. Metaphors for present and ideal work experiences of care as given by the healthcare professionals worked to bridge the stated quantitative present healthcare situation of increasing numbers of people

with Parkinson's and finite healthcare dollars, and the qualitative descriptions of present and ideal work experiences of care of healthcare professionals of people with Parkinson's. Implications for further inquiry included determining effectiveness and costs of multidisciplinary care for people with Parkinson's, and investigating models of care for people with Parkinson's as suggested by the healthcare professionals in the inquiry.

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My family is key to me
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*This inquiry is dedicated to all people with Parkinson's
And especially in memory of my three beloved family members
Who lived with Parkinson's for so many years with such grace*

*Inez Cromie
Greetje Gray
Rienk de Boer*

CHAPTER 1: INTRODUCTION: THE BEGINNINGS

1.1 Personal interest

I sometimes wonder if my lifelong interest in elderly people is in part due to the fact that I grew up without grandparents simply because all four of my grandparents passed away before I was born. The topic of my inquiry is of particular significance to me as three members of my family had Parkinson's with accompanying Lewy Body dementia. My understanding of these two disorders is based on my perspective of having multiple roles in being an involved family member and friend of people with Parkinson's, and having been a volunteer and board member with Parkinson Society British Columbia (hereinafter P.S.B.C.) for five years. These relationships have permitted me to gain *entrée* to the Parkinson's community. The fact that I am neither a person with Parkinson's nor a healthcare professional affords me the opportunity to view the situation from the perspective of an informed outsider.

My familial Parkinson's experiences and ongoing socialization and extended friendships with people in the Parkinson's community have provided me with ample opportunity for sensitivity to understanding the Parkinson's experience, although less experience with understanding the views of the healthcare professionals of people with Parkinson's. From my experience and my perspective, the care of people with Parkinson's is inadequate, disjointed and incomplete. There is a lack of continuity resulting in a 'lottery of care' with great variability in the level and type of care from date of diagnosis of Parkinson's to end-of-life. I know both from personal experience and

from talking with people with Parkinson's and their caregivers that there is a high level of frustration with many aspects of healthcare for people with Parkinson's.

I understand that a primary purpose of inquiry is knowledge. "For us, the exclusive, immediate goal of all research is, and must remain, the production of knowledge" (Hammersley & Atkinson, 2007, p. 15). However I remain connected and accountable to the Parkinson's community. I believe that there is a need and a responsibility for sharing knowledge and developing new knowledge and new ideas in the interest of supporting people with Parkinson's until the day when a cure is found. There is a need to understand and make sense of the present in order to turn that understanding into action for the future. I know that I want better conditions for people with Parkinson's. Presently, I am a member of a 'Big Idea' committee which is exploring the idea of a dedicated British Columbia Parkinson's Centre. Although this inquiry set out to produce new knowledge about work experiences of care of healthcare professionals of people with Parkinson's it gained an *action research* component as a result of that new knowledge leading to recommendations for change in these work experiences of care.

1.2 Background

The British Columbia (hereinafter B.C.) Ministry of Health calculates that there are approximately 11,000 people in British Columbia currently living with Parkinson's, with the number of people affected by the disorder multiple times more when family members are included (Parkinson Society British Columbia and Pacific Parkinson's Research Centre, 2008 (hereinafter P.S.B.C. & P.P.R.C., 2008)). Approximately one in three hundred people in Canada has Parkinson's which translates to a total of 100,000

affected persons for the entire country (P.S.B.C. & P.P.R.C., 2008). Statistics Canada projects that the population of Canada will increase by approximately 30% by 2031, with a doubling of people aged 65 and over by 2031 (P.S.B.C. & P.P.R.C., 2008). As well, people are now living longer and there is an “epidemiological transition to chronic diseases late in the life course,” resulting in predicted further growth in healthcare costs (Guttman, Slaughter, Theriault, DeBoer, & Naylor, 2003, p. 313). These are all contributing factors for a significant increase in the number of people with Parkinson’s in the near and distant future.

Many factors within the healthcare system in British Columbia directly affect work experiences of care of healthcare professionals of people with Parkinson’s. These factors include lack of continuity of care among the Parkinson’s population; insufficient funding for multifaceted, multidisciplinary treatment; wait times from several months to over a year for specialist physicians; and lack of guaranteed funding of professional positions year-to-year with expectations that additional sources of funding be obtained from outside both the university and the health authority (P.S.B.C. & P.P.R.C., 2008).

But the story of the work experiences of care of healthcare professionals of people with Parkinson’s is part of a much, much bigger story. All across Canada healthcare professionals are at the frontline in a battle to maintain the nation’s healthcare system. With medicine becoming more technological, the population growing older, and a national shortage of doctors and nurses, there has been a rapid increase in spending in healthcare, from \$12.1 billion in 1975 to \$183.1 billion (or \$5,452 per Canadian) in overall spending in 2009 (Howlett, 2010). The costs of healthcare and limited healthcare budgets are bringing about a reshaping of the healthcare system. In Ontario where a \$24.7

billion shortfall is expected this year, the province is launching a restructuring of hospitals, even though there have been no policy statements on what type of system works best (Howlett, 2010). It soon becomes evident that better insight into the workings of the healthcare system is needed and that this inquiry is most timely.

1.3 Rationale

There is a need for better understanding of work experiences of care of healthcare professionals of people with Parkinson's. Healthcare professionals are frontline workers both in the healthcare system and in the care of people with Parkinson's, and yet their narratives have been overlooked. There is a need for a space to be made for the voices, perspectives and narratives of these healthcare professionals. This absence of narratives of the healthcare professionals of people with Parkinson's is in contrast to the plethora of narratives of people with Parkinson's, as well as of their caregivers in both the public domain and in the literature.

1.4 Statement of purpose

This qualitative, narrative inquiry provided a unique opportunity to listen to, and learn from, healthcare professionals of people with Parkinson's. What stories did healthcare professionals of people with Parkinson's have to tell? The general purpose of the inquiry was to record new understandings of these work experiences of care and to fill a gap in the literature.

The specific purpose of this inquiry was to explore, through description and understanding, the work experiences of care of healthcare professionals of people with

Parkinson's. The central question of this inquiry was to determine how healthcare professionals define acceptable, unacceptable and ideal work experiences of care of people with Parkinson's.

The inquiry, involving both descriptions of present work experiences of care and the more abstract prescriptions for ideal care, is important as having a more complete understanding of these experiences could enable planning of future work experiences of care.

[Philosopher Martin] Buber notes that to be an "ethical community" requires being willing to label the shortcomings in a community. Since no community is ideal, persons strive for freedom to engage in critical scrutiny, promotion of egalitarian ideals, and movements between different communities to maintain openness. Freedom involves a tension between critiquing and preserving the structure of a community (Arnett, 1986, in Lashley, 1994, p. 102).

1.5 Significance

Healthcare professionals of people with Parkinson's are positioned as frontline workers in the healthcare system, and as frontline workers in the healthcare of people with Parkinson's. This makes a deeper understanding of their work experiences of care of significance to multiple stakeholders, primarily healthcare professionals themselves, people with Parkinson's and the greater healthcare system. As such the inquiry is grounded in the needs of all three stakeholders.

Specifically the present inquiry is significant on multiple fronts. It is yet another piece of evidence toward: educating healthcare professionals, healthcare administrators and healthcare service providers on best healthcare practices for people with Parkinson's; encouraging the B.C. healthcare administrators and healthcare service providers toward re-examining long range healthcare planning and policy toward a reorganization of

healthcare professionals; making funding decisions in both public and private healthcare services; supporting changes to better meet the needs of people with Parkinson's; and ultimately, determining if there is a case for a British Columbia Parkinson's Centre. "A better understanding of the full impact of Parkinson's will ultimately result in better and more efficient use of the Canadian healthcare system and improved quality of life for people living with Parkinson's" (Health Canada and Parkinson Society Canada, 2003, p. 6).

1.6 Terminology

Terminology for this inquiry is outlined as follows.

Healthcare professionals refers to any of the following professionals who work directly with people with Parkinson's: general practitioner, internist, neurologist, gerontologist, psychiatrist, gastroenterologist, neuro-psychologist, pharmacist, nurse, occupational therapist, physical therapist, speech and language therapist, social worker, exercise specialist, dietitian and pharmacist. The specific healthcare professionals who participated in this inquiry were three physicians - a general practitioner, a Parkinson's specialist neurologist, and a gastroenterologist; and three allied healthcare professionals - a nurse, a social worker, and a physiotherapist.

Care refers to the professional interaction between the healthcare professional and the person with Parkinson's. It encompasses two components: therapeutic psychological care or physical care; and care as in caring for a person in a concerned way in a caring relationship. "The first meaning reflects the patient as a recipient or object of care, that is, technical care. The second meaning is manifested through a caring

relationship between [the healthcare professional and the person with Parkinson's]. The meaning of care and caring is derived through context, a particular situation or experience" (Lashley, Neal, Slunt, Berman, & Hultgren, 1994, p. 108). For purposes of this inquiry, aspects of professional experience such as benefits, job security, professional development, etc. are excluded from this definition of care.

Parkinson's is a progressive, neurological disorder which results from the loss of dopamine, a chemical messenger in the brain (*Taking charge: a guide to living with Parkinson's*, 2008). Cardinal symptoms include tremor, rigidity, *bradykinesia* (slowness or poverty of movement), and postural instability. Parkinson's is not a simple movement disorder but a complex neuro-psychiatric disorder. It can significantly affect a person's physical, mental, emotional and social well being.

... Parkinson's disease patients can gain symptomatic relief through pharmacotherapy. Over time, patients' symptoms may require both higher dosages and polypharmacy, but patients obtain less satisfactory relief with an ever-increasing range of side effects. A combination of disease progression and side effects contributes to sufferers' considerable physical and cognitive limitations, including freezing (momentary inability to move), impaired executive function, gait problems, chronic constipation, drooling, dyskinesia (uncontrollable spasm-like movements), the on/off syndrome (sudden loss of function between medication doses), and hallucinations (Lees, 2002, in Solimeo, 2008, p. 543).

The average age of onset of Parkinson's is 60 years of age, although a few people have been diagnosed before age 20. People with Parkinson's may live with symptoms for thirty years or more, and may be completely dependent on others for more than a decade. Parkinson's can result in long term disability and premature mortality. The complexity of Parkinson's as well as its long term ongoing chronic nature makes this a particularly challenging disorder, both to live with and to treat. There is no cure for Parkinson's, with treatment focused on limiting symptoms, increasing function, and delaying progression

(Chrischilles, Rubenstein, Voelker, Wallace & Rodnitzky, 2002). For the purposes of this inquiry the word ‘disease’ is omitted from the term ‘Parkinson’s disease’ so as not to imply a single known cause as Parkinson’s is considered to have both genetic and environmental causes, depending upon each individual.

Lewy body dementia is a type of dementia often associated with Parkinson’s.

Quality of life, for purposes of this inquiry, is health-related quality of life. For people with Parkinson’s, quality of life is regarded in terms of how their physical, mental, emotional and social life, is affected over time by Parkinson’s.

1.7 Limitations

The choice of a single interview for this inquiry provided limited depth and complexity of findings. The inquiry was limited in scope with the total number of participants being six. This was a select number, with each healthcare professional having limited personal experience and limited exposure to people with Parkinson’s. While the small sample size encouraged depth of understanding and analysis, the inquiry remained focused only on the experiences and interests of a small group of healthcare professionals practising in Vancouver, in other words, within a specific geographic, social, economic, and cultural context. The inquiry was not generalizable to the larger population of healthcare professionals, nor replicable to other settings. In other words, the inquiry could not claim to speak to the experiences, particularly the nuances and intricacies, of healthcare professionals of people with Parkinson’s in general.

My understandings and interpretations were by definition situated and partial. My background ‘expertise’ was as a lay person who once sought the services of

healthcare professionals of people with Parkinson's on behalf of my family members. As a non-healthcare professional undertaking an inquiry on healthcare professionals I was the one with less knowledge, privilege and power in the area of work experiences of care of healthcare professionals, and as such this could have led to misunderstanding and miscommunication. Through undertaking this inquiry I put myself in the position of speaking *for* as well as speaking *about* others when in actuality healthcare professionals of people with Parkinson's are well suited to advance their own experiences of care on their own terms.

For the inquiry a choice was made to refer to each participant by their profession rather than by a pseudonym. This choice allowed for direct association to each participant's profession and aided in gaining a 'picture' of each healthcare professional, even though it had the unintended effect of depersonalizing the professionals as empirical material rather than as individual human beings. Also for clarity of reading, the order of listing the professionals was always the same in the analysis, and likewise in the summary analysis. With the emphasis in qualitative inquiry being on the individual, and on being human, referring only to a person by profession, and always in this ordered fashion, may be considered a limitation.

While recognizing the importance of non-verbal behaviour such as avoiding eye contact, as well as discourse markers such as "you know", "umhmm" and "um", repeated words and pauses for reflection, I chose to focus entirely on a spoken word analysis for the interviews as I felt an analysis of non-verbal behaviour and discourse markers was beyond the scope of this inquiry. This also may be considered a limitation.

It would have been interesting if the inquiry had been more participatory, either by soliciting the reactions of the healthcare professionals to the analysis summary or by including a shared analysis. In looking at the background interests of each healthcare professional it would have been interesting to delve deeper and learn why each of the healthcare professionals had chosen their career, and whether their choice was based around 'care' or not.

1.8 Organization

This chapter opened with my personal background and interest in the topic of work experiences of care of healthcare professionals of people with Parkinson's. The chapter outlined the background, rationale, statement of purpose, significance, terminology, and limitations of the inquiry.

Chapter II: Literature Review: Reading for Argument is a review of the relevant empirical and theoretical literature in order to provide the contextual and conceptual frameworks for the inquiry. The chapter begins with a review of empirical literature highlighting the social, economic, and cultural contexts of Parkinson's, and continues with a review of empirical literature concerning multidisciplinary care for people with Parkinson's. Following this is a review of relevant theoretical literature outlining the concepts of medicalization and medical frameworks, and theories of care. The chapter ends with a discussion of the relevance of the literature review to this inquiry.

Chapter III: Methodology: Making Methodological Choices outlines the choices made in choosing a methodology for this inquiry. The following topics are discussed: choosing a qualitative approach; underlying assumptions; the social constructivist paradigm; underlying epistemological, ontological and axiological assumptions; the site

of inquiry; choice of approach given the questions being explored; specific methods for collection of empirical material, including the use of metaphors; five steps of analysis; and ethical considerations.

Chapter IV: Analysis: Understanding Through Inquiry focuses on describing and understanding work experiences of care of healthcare professionals of people with Parkinson's. The following findings from the interviews are outlined: present and ideal work experiences of care of healthcare professionals of people with Parkinson's, including metaphors; observations on the interview responses; visual cues; and three primary themes. This is followed by a combined analysis of the interviews, the literature review and my personal reflections, in light of the three primary themes, the theoretical construct of care, and the social, economic and cultural contexts as defined by the healthcare professionals. The chapter ends with a description and critique of a multidisciplinary model of care.

Chapter V: Discussion: So Where Do We Go From Here? begins with a summary that reflects new understanding of the work experiences of care of healthcare professionals of people with Parkinson's. This is followed by a discussion of the inquiry's significance, as well as implications and recommendations for further inquiry. The chapter ends with a conclusion.

CHAPTER 2: LITERATURE REVIEW: READING FOR ARGUMENT

2.1 Introduction

Chapter II: Literature Review: Reading for Argument is a review of the relevant empirical and theoretical literature in order to provide the contextual and conceptual frameworks for this inquiry. The chapter begins with a review of empirical literature highlighting the social, economic, and cultural contexts of Parkinson's, and continues with a review of empirical literature concerning multidisciplinary care for people with Parkinson's. Following this is a review of relevant theoretical literature outlining the concepts of medicalization and medical frameworks, and theories of care. The chapter ends with a discussion of the relevance of the literature review to this inquiry.

2.2 Empirical literature

Understanding work experiences of care of healthcare professionals of people with Parkinson's requires understanding the ever-evolving social, economic, and cultural contexts in which these experiences exist. A review of the empirical literature highlights each of these overlapping contexts. Recognizing the reality of underlying contexts creates the space to challenge and make changes (Salmon, 2005). The empirical literature review continues with an outline of multidisciplinary care for people with Parkinson's.

2.3 Social context

Parkinson's is a progressive, degenerative disorder with a social impact which increases over time for people with Parkinson's, their families, the social system, and the

healthcare system (Health Canada and Parkinson Society Canada, 2003). Parkinson's has an increasing impact on a person's physical and mental abilities, and substantial decrease in health related quality of life (Chrischilles, Rubenstein, Voelker, Wallace, & Rodnitzky, 1998), which has been shown to deteriorate with the severity of advancing Parkinson's (Keränen, Kaakkola, Sotaniemi, Laulumaa, Haapaniemi & Jolma, 2003). The toll and challenges of Parkinson's are evident in a comment made by former *C.B.C. Answer Lady* Marg Meikle, "Parkinson's doesn't define me but it is really starting to get in the way ... It is not a death sentence but a life sentence" (Meikle in Gray, 2006, p. 6).

Parkinson's can also have an impact on the caregivers of people with Parkinson's, with both psychosocial issues (increased stress, decreased mood) and physical health issues (insufficient sleep, hypertension) for the caregivers (Lokk, 2007). The impact of Parkinson's has been shown to increase for the caregiver as the Parkinson's progresses, particularly with Parkinson's symptoms of depression, hallucinations, and confusion, as well as with falls (Schrag, Hovris, Morley, Quinn, & Jahanshahi, 2005). It soon becomes apparent that the challenges of Parkinson's affect more than just the person with Parkinson's, and that the healthcare professional has responsibilities toward multiple people in caring for a person with Parkinson's.

In Canada access to healthcare is considered an important human right. As prescribed by the Canada Health Act, healthcare resources are for the whole of Canadian society. The *Canada Health Act* (1984) guarantees "all Canadians access to medically necessary physician and hospital services, free of financial or other barriers, within a system publicly administered on a non-profit basis" (Madore, 2005, Parliamentary Action). Public policy reflects social values and social values are confirmed through

public policy such as the *Canada Health Act*. “The proponents of government intervention (for healthcare in Canada) ... generally cite economic and social equity factors, as well as administrative efficiency” (Madore, 2005, Background Analysis).

2.4 Economic context

In addition to social impacts there are significant economic impacts of Parkinson’s which increase over time for people with Parkinson’s, as well as the healthcare system (Health Canada and Parkinson Society Canada, 2003). The economic cost of Parkinson’s in Canada was outlined by Health Canada in 2003, based on a report titled *Economic Burden of Illness in Canada, 1998* published in 2002. Standard methods used to calculate direct and indirect costs, the two main components of the economic cost of a disease, were used. The total cost of Parkinson’s in Canada in 1998 was \$558.1 million (males 56.3%, females 43.4%, 0.3% unspecified). Direct costs were \$87.8 million (hospital care at \$39.7 million, medications at \$24.1 million, physician care at \$23 million, and research at \$1 million.) The direct costs of Parkinson’s reflected a small portion of the costs, with the hidden, indirect costs in terms of lost wages, informal care, and changing roles being much greater (Whetten-Goldstein, Sloan, Kulas, Cutson & Schenkman, 1997). Indirect costs were calculated at \$470.3 million (premature mortality at \$78.6 million and long-term disability at \$391.7 million). The Health Canada report showed the total cost of Parkinson’s in B.C. in 1998 at \$103.2 million. All costs have likely increased significantly since 1998 due to increased healthcare costs, as well as increased numbers of people with Parkinson’s.

A separate study explored the impact of Parkinson's on the Ontario healthcare system (Guttman *et al*, 2003). From 1992 to 1999 people with Parkinson's were compared with age/sex matched controls and were found to incur 1.4 times higher physician costs, 1.44 times more hospital admissions, 1.19 times longer length of stay in hospital, and 3 times higher medication costs. The significantly higher costs of Parkinson's emphasized substantial direct costs to both the healthcare system and society. "Perhaps the key message from our study is that research into more definitive therapies for Parkinson's Disease should be aggressively pursued by researchers, government agencies, industry, and the voluntary sector internationally, in hopes of reducing the burden of Parkinson's Disease" (Guttman *et al*, 2003, p. 318). At present there are shortfalls in the British Columbia healthcare system for the care of people with Parkinson's with restricted funding for physician access, both primary and specialist; allied healthcare professionals; name brand Parkinson's medications such as Sinemet as well as other medications; and Parkinson's Deep Brain Stimulation (DBS) surgery. Lack of support for the emotional, social and economic challenges of Parkinson's compounds the challenges of Parkinson's (P.P.R.C. & P.S.B.C., 2008).

2.5 Cultural context

The healthcare system is "a *system* that is social and cultural in origin, structure, function, and significance" (Kleinman, 1980, p. 27). The patients and healthcare professionals, illness and healing, are all components of the healthcare system (Kleinman, 1980). "Health care systems are socially and culturally constructed. They are forms of social reality. Social reality signifies the world of human interactions existing outside the

individual and between individuals” (Kleinman, 1980, p. 35). Beliefs about health issues and responses to these health issues by family members and healthcare professionals are components of this social reality. “They (beliefs and responses), like the health care system itself, are cultural constructions, shaped distinctly in different societies and in different social structural settings within those societies” (Kleinman, 1980, p. 38).

In Canada there exists a culture of inclusion in healthcare, as shown by the general support for universal healthcare. This culture of inclusion demonstrates compassion for supporting all people in society. “... [U]niversal long-term [health] care coverage reflects the value ... placed on the concept of solidarity among their citizens (a sense of mutual responsibility), social cohesion and intergenerational reciprocity” (Sokolovsky, 1997, p. 585). Despite having universal healthcare in Canada there is a ‘lottery of care’ for people with Parkinson’s. This state of confusion in care could be partly due to the fact that guidelines in Canada outlining best clinical practices for care of people with Parkinson’s do not exist as yet.

2.6 Multidisciplinary care for people with Parkinson’s

A review of the literature revealed increasing support for the value of allied healthcare professionals providing important benefits to people with Parkinson’s. *Allied health care interventions and complementary therapies in Parkinson’s disease* (Nijkrake, Keus, Kalf, Sturkenboom, Munneke, Kappelle & Bloem, 2007), is a review of ninety papers concerning allied healthcare and complementary therapies in Parkinson’s. This paper estimated that the use of allied healthcare in Parkinson’s in physiotherapy was 7-57%, occupational therapy was 9-25%, and speech therapy was 4-20%. It noted that

multidisciplinary care was increasingly implemented in Parkinson's centres, although there was still debate around increased healthcare costs of multidisciplinary care versus monodisciplinary care of a solitary general practitioner or neurologist, and whether multidisciplinary care reduced costs (for example, by preventing falls and hip fractures, and delaying care home admissions). Three recommendations concerning multidisciplinary care were outlined as: allied healthcare professionals need to employ evidence-based strategies in order to deliver optimal treatment; allied healthcare professionals and physicians need good communication among themselves; and objective criteria for referrals among healthcare professionals are needed to avoid over-treatment and under-treatment.

Short term effectiveness of an intensive multidisciplinary rehabilitation program which examined mobility, functional independence, awareness of speech problems, psychological well being and quality of life was evaluated (Trend, Kaye, Gage, Owen & Wade, 2002). People with Parkinson's (number of participants = 118) attended a day hospital for one day per week for six consecutive weeks. There were immediate improvements in the patients' mobility, speech, depression and quality of life. Those with more advanced disease gained significantly more. "Overall the results suggest that an intensive, co-ordinated intervention that incorporates targeted advice from a range of professionals can provide immediate benefits for people with Parkinson's disease and their carers. The findings reinforce the importance of multidisciplinary clinical teams" (Trend *et al*, 2002, p. 723).

A study on the effectiveness of an inpatient multidisciplinary program for people with Parkinson's (number of participants = 68) revealed significant improvements

in motor and cognitive scores after a period of 21 days (Ellis, Katz, White, DePiero, Hohler, & Saint-Hilaire, 2008). People with Parkinson's participated in a program with a combination of physiotherapy, occupational therapy and speech therapy for a total of 3 hours per day 5 to 7 days per week. Analysis of the data revealed statistically significant improvements across all outcome measures.

Another study showed that although multidisciplinary care was used by some people with Parkinson's, management was usually monodisciplinary, with a focus on using medications to minimize motor symptoms (van der Marck, Kalf, Sturkenboom, Nijkrake, Munneke & Bloem, 2009). "Clinical experience suggests that optimal management requires a multidisciplinary approach, with multifactorial health plans tailored to the needs of each individual patient" (van der Marck *et al*, 2009, S219).

While the neurologist determines disease severity and optimizes medical treatment to reduce symptoms, allied health therapists aim to minimize the impact of the disease process and improve the patient's participation in everyday activities. The underlying working mechanism is also different. Both pharmacotherapy and neurosurgery aim to correct nigrostriatal dysfunction, ... (whereas) allied health therapists try to bypass the defective basal ganglia by engaging alternative neural circuitries that are still intact (cortical pathways and sensory systems)" (van der Marck *et al*, 2009, p. S220).

The importance of the role of multidisciplinary care in Parkinson's was documented in clinical practice guidelines for physiotherapy, occupational therapy and speech and language therapy. Guidelines for physiotherapy for people with Parkinson's were published in the Netherlands in 2004, and guidelines for occupational and speech and language therapy were published in 2008. "Understanding is growing that paramedical therapies, such as occupational therapy, physiotherapy and speech and

language therapy are important in all phases of the disease” (Kalf, Sturkenboom, Thijssen, de Swart, Bloem & Munneke, 2008, p. 12).

In the United Kingdom, N.I.C.E. (The National Institute for Health and Clinical Excellence) Guidelines provide national guidance on promoting good health, and preventing and treating ill health. The expected due date for review of the Parkinson’s guidelines is June 2011. A draft copy of the review includes guidelines for treatment beyond pharmacological and surgical treatments, including recommendation for Parkinson’s specific nursing, physiotherapy and occupational therapy, speech and language therapy, and palliative care.

It is not known which clinical structure or team involvement is most effective, and the N.I.C.E. guidelines give no recommendations as to how to organize the multidisciplinary care ... Important elements of inter-professional team work are, among others, shared goal setting and shared contribution to treatment plans, effective communication and appropriate referrals to other team members. These aspects should all be incorporated when organizing multidisciplinary care for Parkinson’s disease patients (van der Mark *et al*, 2009, p. S221).

There has been worldwide awareness that people with Parkinson’s are not receiving optimal care. In Geneva in 1997 the World Health Organization called on all governments and all healthcare providers “to join us in taking strong and decisive action to meet the objectives and recommendations on the educational management and Public Health implications of Parkinson’s disease ...” (World Health Organization, 1997).

Specifically, two of a total of nine recommendations urged every government to:

- Support the World Charter for people with Parkinson's disease, launched 11 April 1997, which states that:
People with Parkinson's have the right to:
 - Be referred to a doctor with a special interest in Parkinson's disease
 - Receive an accurate diagnosis
 - Have access to support services

- Receive continuous care; and
 - Take part in managing the illness
- Encourage research into Parkinson's disease and the development of multidisciplinary teams to improve its management (World Health Organization, 1997).

At present there is a Parkinson's multidisciplinary clinic, the Pacific Parkinson's Research Centre (hereafter P.P.R.C.), at the University of British Columbia. For one full year, from May 1st 2007 to April 30th 2008, 1,269 people with Parkinson's or Parkinsonian conditions, of a total of 11,000 people with Parkinson's in the province, or approximately 11%, were seen at the centre. There were waitlists of 4-16 months for follow-up care and 7-8 months for new referrals (P.S.B.C. & P.P.R.C., 2008). These wait times have an effect on both people with Parkinson's and the work experiences of care of healthcare professionals of people with Parkinson's.

A Delphi panel examining national needs for neurologists in the U.S.A. estimated that the average patient with Parkinson's Disease would require 140 minutes of a neurologist's time during the first year of illness (50 minutes during the first visit and a total of 90 minutes during subsequent visits) and would require 60 minutes annually during the remaining 9 years of illness" (Programme on Mental Health, 1997, p. 7).

At P.P.R.C. people with Parkinson's are generally seen by the neurologist once every twelve months when there are no waitlists.

There are presently four neurologists, two nurses, a part time (50%) physiotherapist and a part time (40%) social worker at P.P.R.C. (P.S.B.C. & P.P.R.C., 2008). This likely translates to fewer than half of the 1, 269 people with Parkinson's or Parkinsonian conditions at P.P.R.C. in the 2007-2008 year being seen by the physiotherapist or the social worker. People with Parkinson's who are not seen by the

neurologists at P.P.R.C. do not have access to the nurses, physiotherapist or the social worker at the clinic.

There is a lack of multidisciplinary care to support the neurologists at P.P.R.C. (P.S.B.C. & P.P.R.C., 2008), as well as for the approximately remaining 10,000 people with Parkinson's throughout the province who are not seen at the clinic. The P.P.R.C. proposes a continuity of care framework to meet the needs of more people with Parkinson's in the province through improved multidisciplinary management of Parkinson's, thereby reducing both the challenges and financial costs of Parkinson's (P.S.B.C. & P.P.R.C., 2008).

There are unpublished surveys from across Canada which include questionnaires addressed directly to people with Parkinson's and their caregivers concerning their healthcare needs and recommendations, with gaps found in healthcare services between what was needed and what was available (Parkinson Society Maritime Region Regional 2009 Survey; Knowledge, Service Access, and Needs of Individuals Living With and Affected by Parkinson's Disease, Edmonton Area and Northern Alberta, 2005). A survey of 520 people with Parkinson's and their caregivers in British Columbia concerning their experiences of living with Parkinson's was undertaken in 2009 (Parkinson Society British Columbia Membership Survey, 2009). There were concerns with the healthcare system including limited access and funding for medications, massage therapy, physiotherapy, occupational therapy and exercise. When people with Parkinson's were asked whether they had seen allied healthcare professionals, the responses were as follows: 20% - physical therapist, 19% - massage therapist, 12% - dietician/nutritionist, 12% - speech

and language therapist, and 10% - occupational therapist, as well as 9% had seen a psychiatrist.

A review of the literature using a web search did not reveal narratives of healthcare professionals of people with Parkinson's concerning their work experiences of care. There does exist however both in the literature and in the public domain, narratives of people with Parkinson's and their caregivers about living with Parkinson's. These can be found in the form of poems, quilts, paintings, sculptures, articles, short films, and books. Perhaps the most well known narrative by a person with Parkinson's is *Lucky Man: A Memoir* by Canadian actor Michael J. Fox.

2.7 Theoretical literature

A review of the relevant theoretical literature acts as a conceptual guide for this inquiry. A critique of medicalization and medical frameworks leads to an outline of a 'whole person' approach. With the topic of the inquiry being work experiences of 'care' theories of care provide greater understanding of the concept of care.

2.8 Medicalization, medical frameworks and beyond

The expression 'people with Parkinson's' incorporates Parkinson's as the primary descriptor of a person affected by Parkinson's, implying a distinction from the presumed 'norm' of a non-Parkinson's individual. This invokes medicalization and creates a binary of Parkinson's versus non-Parkinson's, disorder versus order, and abnormal versus 'normal' with a 'normal' human body as being ideological. "The whole medical and rehabilitation enterprise is founded upon an ideology of normality and this

has far reaching implications for treatment. It's (sic) aim is to restore the disabled person to normality, whatever that may mean" (Oliver, 1990, p. 4). Medical frameworks locate impairment "in the individual as someone who lacks the full complement of physical and cognitive elements of true personhood and who must be cured or rehabilitated" (Davidson, 2006, p. 119). Where there is medicalization, medicalized understandings are reified "as naturalized, inherent, and not subject to debate or dispute" (Salmon, 2005, p. 115).

Medicalization refers to a process whereby non-medical problems are defined and treated as medical problems. In the early 1990s, sociologists such as Peter Conrad limited medicalization to the process of "defining a problem in medical terms, using medical language to describe a problem, adopting a medical framework to understand a problem, or using medical intervention to 'treat' it" (Conrad, 1992, p.211).

Medicalization can function "to secure recognition of the realities of ... lived experiences and access to the medical, financial, educational and other supports that are critical to ... well being" (Salmon, 2005, 140). "When you are very ill, you desperately need medical validation of your experience, not only for economic reasons (insurance claims, pensions, welfare and disability benefits all depend upon official diagnosis), but also for social and psychological reasons. People with unrecognized illnesses are often abandoned by their friends and family" (Wendell, 1989, p. 120). For chronic conditions such as Parkinson's where medical advice and intervention are necessary, medicalization holds some currency.

Thus medicalization of a disorder may compromise interests of people with disability by undermining efforts to achieve substantive citizenship rights, and

alternatively, be important in terms of their receiving support and social justice (Salmon, 2005). For multiple reasons it would appear that medicalization can serve to simultaneously dis-able and en-able at the same time (Salmon, 2005).

There are two main concerns with medical frameworks of disability (Salmon, 2005). Firstly, a hegemonic understanding of this framework has been used to justify oppression of people with disabilities. Secondly, medical frameworks are very limiting in that they fail to recognize the role of the environment in creating experiences of disability, as opposed to the impairment creating the disability. "... [M]edical models of disability are limited in their analytical and empirical utility to explain and understand experiences and consequences of disability, and in their application to efforts to address social, political, and economic injustices experienced by people with disabilities" (Salmon, 2005, p. 51).

Moving beyond medical frameworks is a 'whole person' approach with a focus on the integration of biological and psychosocial dimensions of care. "[The medical framework] leaves no room within its framework for the social, psychological, and behavioral dimensions of illness" (Engel, 1977, p. 130).

'Whole person' care has been defined as having two equally important purposes. One purpose is curative, or the 'fixing' part of medicine; and the other purpose is healing, or looking at how to help people live in the best way possible. Curing is something the healthcare professional does, while healing is a process that occurs within the patient (Hutchinson, Hutchinson & Arnaert, 2009). "The emphasis has shifted from the doctor fixing what has gone wrong to what the patient needs to do for himself or herself" (Barbour, 1995, p. 33). This model of care is "based on the premise that in situations in

which treatment is unable to change the disease outcome, it may be possible to create a space in which healing can occur” (Flynn, 2010, McGill).

For care of people with Parkinson’s the whole person approach is supported by multidisciplinary care with the primary role of the physician as assessment and treatment of symptoms, and the primary role of the allied healthcare professionals as minimizing the impact of Parkinson’s and improving participation in everyday activities through different therapies. A synergy of both curing and healing should lead to the best possible outcome (Flynn, 2010).

2.9 Theories of care

In *Caring: A Feminine Approach to Ethics and Moral Education* (1984), American philosopher and educator Nel Noddings, developed a philosophical argument for an ‘ethics of care’ based on what she called natural caring, learned from the care of a mother for her child. Noddings championed the act of caring and relationship as educational goals, and as fundamental aspects of education. Caring was seen as a relation, and was thus “both self-serving and other-serving” (Noddings, 1984, p. 99). Noddings believed caring should be a foundation for ethical decision-making with an ‘ethics of care’ which emphasizes the importance of relationships.

In *Starting at Home: Caring and Social Policy* (2002), Nel Noddings stated that caring and being *cared for* start at home; a person needs to be *cared for* in order to be able to *care for* and *care about* others. In this manner care theory started at home and moved outward. The theory supported relationships, interconnectedness and caring for

others. “Caring-about is empty if it does not culminate in caring relations” (Noddings, 2002, p. 23).

Noddings summarized the three elements of a caring relation or encounter:

- i. A cares for B – that is, A’s consciousness is characterized by attention and motivational displacement, and
- ii. A performs some act in accordance with i), and
- iii. B recognizes that A cares for B (Noddings, 2002, p. 19).

Both the *carer* and the *cared for* had significant roles, with reciprocity in their relationship; they both give and they both gain in the relation or encounter. Without reciprocity, a caring relationship resulted in “disillusionment, fatigue, and eventual burnout” for people in any role such as family members, teachers, and healthcare professionals (Noddings, 2002, p. 19). Noddings acknowledged that “there are many situations where mutuality is not possible; between parent and young child, between teacher and child, between physician and patient. All of these are necessarily asymmetrical, and yet there is reciprocity. The cared-for contributes something essential” (Noddings, 2002, p. 18). Noddings pointed out that this could be something as simple as an “I am cared for” response that showed that caring had been received.

The key to care theory for Noddings was that *caring about* involved a sense of social justice and was instrumental in developing conditions for *caring for*. Noddings’ ‘ethics of care’ was relationally based, as opposed to traditional theories of moral philosophy focusing on rights and justice.

Another book *Being Called to Care* (1994) written by Mary Ellen Lashley, Maggie Neal, Emily Todd Slunt, Louise Berman, and Francine Hultgren, was all about responding to the call to care in nursing, and understanding the foundations upon which care exists. The three themes of responding to care were cited as *authenticity*,

vulnerability, and the *structure* within which caring and being occurred. There was a need seen to foster authenticity and vulnerability to allow caring and being to develop. “Through listening, we come to recognize our interdependence and connectedness with others ... Harkening, then, presupposes an ethics of relatedness, care, and responsibility” (Levin 1989, in Lashley *et al*, 1994, p. 193).

The authors of this book challenged the view that objective medical knowledge was the only foundation for nursing practice. They urged a return to nursing with caring and being as the core to knowing and doing, and argued that caring and being can be learned. The book espoused a fundamental shift in nursing education toward expanding knowledge to include knowledge of care.

In *Being Called to Care* author Francine Hultgren cited four orientations that could be considered for responding to the call of care (Lashley *et al*, 1994). The ‘empirical or instrumental response (control)’ regarded healthcare as technology where “persons are treated as objects; their humanity is denied as they become things determined by natural forces” (Lashley *et al*, 1994, p. 23). In this response, *giving* care through specific skills and problem solving showed a concern for *doing* rather than a concern for keeping the technology within a supportive “human context” (Lashley *et al*, 1994, p. 23). The ‘hermeneutic or understanding response (being)’ questioned what was meant by care and what made it possible to speak, think and act (Smith, 1991 in Lashley *et al*, 1994), with interpretation as “the primordial condition of human self-understanding” (Lashley *et al*, 1994, p. 25). This response began with a need to understand the question itself, and finding out what needed to be questioned. The ‘critical/emancipative response (reason)’ was a reflective and ideology critique of the

“structures and patterns that dehumanize and disempower” (Lashley *et al*, p. 28). This response looked at underlying social and historical factors of nursing and the clinical setting, to be replaced by an altered sense of possibility both for the individual and for society. The ‘radical hermeneutic response (beyond being)’ was a willingness to stay in a constant state of flux, a ‘beyond’ being. Authenticity was part of this with “resisting solid foundations and keeping alive the unrest ... (and in doing so) ... restor(ing) our authentic selfhood and Being-with others” (Lashley *et al*, 1994, p. 32). In relation to being called to care, suffering exposed vulnerability and, “... caring is called forward and nurses are constantly in the flux” (Lashley *et al*, 1994, p. 33). This ‘radical hermeneutic response’ was where there was authenticity, vulnerability and structure in being called to care, or as written as the title of the book, *Being Called to Care*.

2.10 Relationship of literature review to inquiry

The literature review provided the contextual and conceptual frameworks for this inquiry. The reality of the social, economic and cultural contexts of Parkinson’s was evidenced: living with Parkinson’s is difficult, healthcare costs continue to spiral upward, and Canada has a culture of inclusion as shown through its support for universal healthcare. Empirical evidence also included studies on the effectiveness of multidisciplinary care for people with Parkinson’s.

Concepts of medicalization and medical frameworks, and theories of care provided theoretical support for the inquiry. Looking beyond medicalization and medical frameworks identified the multidisciplinary ‘whole person’ approach with its integration of treating/curing and healing. Concepts of care based on *caring for* and *caring about*

emphasized the importance of relationship. Authenticity, vulnerability and structure were seen as essential for developing caring and being as core to knowing and doing. These concepts of care supported the definition of care used for this inquiry, of “therapeutic or technical care, and care as in caring for a person in a concerned way in a caring relationship.”

A review of the literature revealed a gap concerning narratives of work experiences of care of healthcare professionals of people with Parkinson’s. Despite being frontline workers of people with Parkinson’s, the voices, perspectives and narratives of these healthcare professionals were not found in the literature. This review of the literature showed that there were multiple reasons to hear and record the narratives of these healthcare professionals.

CHAPTER 3: METHODOLOGY: MAKING METHODOLOGICAL CHOICES

3.1 Introduction

Chapter III: Methodology: Making Methodological Choices outlines the choices made in choosing a methodology for this inquiry. The following topics are discussed: choosing a qualitative approach; underlying assumptions; the social constructivist paradigm; underlying epistemological, ontological and axiological assumptions; the site of inquiry; choice of approach given the questions being explored; specific methods for collection of empirical material, including the use of metaphors; five steps of analysis; and ethical considerations.

3.2 Choice of the qualitative approach

Why was qualitative approach used for this inquiry? What particular assumptions, worldviews and theoretical lens were employed?

Qualitative research begins with assumptions, a worldview, the possible use of a theoretical lens, and the study of research problems inquiring into the meaning individuals or groups ascribe to a social or human problem. To study this problem, qualitative researchers use an emerging qualitative approach to inquiry, the collection of data in a natural setting sensitive to the people and places under study, and data analysis that is inductive and establishes patterns or themes. (Creswell, 2007, p. 37)

The qualitative approach worked well for this particular inquiry in search of a better understanding of the work experiences of care of healthcare professionals of people with Parkinson's, as the need to understand is a focus of qualitative inquiry. The approach ensured that healthcare professionals of people with Parkinson's remained at the centre of creating their own stories and that they were active participants of knowledge of their

own profession. This inquiry employed an interpretivist approach where reality was subjective and constructed in terms of the individual narratives of the healthcare professionals and the interpretations of the interviewer. This approach “recognizes the self-reflective nature of qualitative research and emphasizes the role of the researcher as an interpreter of data and an individual who represents information” (Creswell, 2007, p. 248).

The focus of this qualitative inquiry was on understanding the phenomenon of the work experiences of care of healthcare professionals of people with Parkinson’s. A qualitative framework created depth of understanding of the issues through *representation* by quoting participants directly, and *legitimization* by the participants double checking for transcription accuracy and being provided with the opportunity for adding their reflections following the interview. The inquiry could be further legitimized by arranging for future conversations about Parkinson’s healthcare with healthcare professionals alone, or a collaboration of healthcare professionals and people with Parkinson’s. *Reciprocity* resulted from the actual interview process as well as the participants double checking their transcriptions for accuracy. Hopefully the inquiry gave the participants opportunity to think about, understand, and re-examine their work experiences of care. The inquiry was *collaborative* as the healthcare professionals participated as active collaborators which was completed ‘with’ rather than ‘on’ or ‘to’ the participants (Creswell. 2007, p. 22). “Conversation for understanding requires being aware of our humanness and meshing as equals rather than through power of one over another” (Lashley, 1994, p. 124).

3.3 Underlying assumptions

An underlying assumption of this inquiry was that healthcare professionals of people with Parkinson's might find meaning in their narratives that would be of benefit to them, their profession and/or the greater Parkinson's community. Another underlying assumption was that people with Parkinson's are dependent on the healthcare profession in order to maintain their highest level of quality of life and in order to remain independent in society for as long as possible.

3.4 Social constructivism paradigm

This inquiry fell within a social constructivist paradigm, supporting the assumption "that absolute realities are unknowable and the objects of inquiry ought to be individual perspectives that are taken to be constructions of reality" (Hatch, 2003, p. 17). The social constructivist paradigm worked well for this inquiry with the paradigm's practical implications including: the inquiry aim of "understanding and reconstruction"; the nature of knowledge as "individual reconstructions coalescing around consensus"; knowledge accumulation as "more informed and sophisticated reconstructions"; and the quality criteria as "trustworthiness and authenticity" (Guba and Lincoln, 1994, p. 112). In this inquiry constructions formed through interactions with the participants (thus social constructivism) were then deconstructed in order to be reconstructed for greater understanding. "Users of this paradigm are oriented to the production of reconstructed understandings of the social world" ((Denzin & Lincoln, 2003, p. 247).

The social constructivist paradigm supported a narrative tradition, both in collecting the empirical materials and in employing an *analysis of narrative*

(Polkinghome, 1995). The narrative tradition was chosen for the importance it placed on the person and the narrative. This tradition worked well for this inquiry as the individual narratives provided depth of understanding of the work experiences of care, and the analysis of narrative in search of themes and patterns provided greater understanding of the narratives. Human beings make sense of their lives through story (Hatch, 2003) and narrative “provides potential insights that are unavailable by other means” (Hatch, 2003, p. 19). “Constructivist narrative work is characterized by involvement by those individuals whose stories are being told and an emphasis on letting the voices of the storytellers be heard in the final report” (Hatch, 2003, p. 17). Philosophical assumptions that led to the choice of social constructivism included epistemology, ontology, and axiology.

3.5 Philosophical assumptions of epistemology, ontology, and axiology

The epistemological assumption of qualitative inquiry addresses the relationship between the participant and the interviewer as being interrelated. My epistemological stance for this inquiry was that the interviewer attempt to lessen the distance between the participant and the interviewer. In practical terms this meant that I attempted to lessen the distance between the participants and myself through collaboration, and by allowing the interviews to flow loosely around the interview questions. Knowledge is formed through interactions with others which in practical terms meant I used open ended questions “so that the participants can construct the meaning of a situation, a meaning typically forged in discussions or interactions with other persons” (Creswell, 2007, p. 21). In this inquiry meaning was co-constructed through the use of the interview, double-checking of the

interview transcription by the participants, and the invitation for further written reflection beyond the interview. The method throughout this inquiry was to rely on the participants' experiences, placing the participants as experts and the interviewer as learner seeking a better understanding. In order to get close to the participants I conducted the interviews in the 'field', either in the participants' workplace office or home office.

The ontological assumption of qualitative inquiry addresses, "When is something real?" (Creswell, 2007, 248). My ontological stance was that reality is subjective and multiple and is real only as constructed in the minds of others. In practical terms, this meant that I ensured that multiple voices, through multiple quotations and multiple perspectives, of the participants were heard. There was co-construction of reality through the use of the interview, the double-checking of the interview transcription by the participants, and the opportunity for further written reflection beyond the interview.

The axiological assumption of qualitative inquiry is based on the fact that inquiry is value laden and includes the values of the interviewer, the theory, and the social and cultural norms of either the interviewer or the participants (Creswell, 2007). My axiological stance was that the interviewer acknowledge the value laden and bias laden nature of the inquiry and report these values and biases. In practical terms this meant that I outlined the value-laden and bias-laden nature of the inquiry. As mentioned previously my own subjectivity includes having three family members who had Parkinson's and accompanying Lewy Body dementia, as well as includes my belief that there is a need to support people with Parkinson's with the best healthcare possible. These value-laden and bias-laden thoughts undoubtedly affected the lens through which I conducted this inquiry.

3.6 Site of inquiry

The site for this inquiry was six healthcare professionals of people with Parkinson's. These were drawn from personal contacts and through my volunteer work in the Parkinson's community. A Letter of Initial Contact (See Appendix A) and Consent Form (See Appendix B) were sent out to ten healthcare professionals of people with Parkinson's in Vancouver, British Columbia. Healthcare professionals who were interested in being part of the inquiry then contacted me by telephone. The six healthcare professionals responding to this inquiry included three physicians - a general practitioner, a Parkinson's specialist neurologist, and a gastroenterologist; and three allied healthcare professionals - a nurse, a social worker, and a physiotherapist. Including physicians from three different specialties and allied healthcare professionals from three different specialties produced a rich diversity of experiences and perspectives.

In the inquiry the healthcare professionals are identified only by their individual profession, *e.g.*, 'the physiotherapist'. The order of their 'appearance' in the inquiry is based on the order a person with Parkinson's is likely to be seen by healthcare professionals, in other words, firstly to the general practitioner for a discussion of new symptoms, then to the neurologist for a diagnosis of Parkinson's, and then depending on their ongoing needs, to the remaining four healthcare professionals. If I had to choose six healthcare professions for the care of a person with Parkinson's I would choose these six healthcare professions.

Three of the participants in this inquiry were female, and three were male. All were between the ages of 45 and 65. With only six participants in the inquiry the

identifiers of gender, age, race, social class and cultural background were not included in the description of each healthcare professional, nor in the analysis. The focus of this inquiry was the spoken word in the interviews, and these identifiers would have added layers of analysis beyond this limited focus.

Three of the healthcare professionals worked full time and three worked part time. Three worked within a multidisciplinary clinic setting, two had their own private practices, and one was self-employed. Five of the six participants reported a family member and/or friend who was diagnosed with Parkinson's.

The inquiry did not examine politics of difference in terms of the selection of participants as the six healthcare professionals were not from a common work environment, nor was the inquiry undertaken over time as in a longitudinal study. Also, the interview was centered on semi-structured questions, and as such the interviewer was not a participant observer as in an ethnographic study; there was no common text; and there was no shared analysis. For all these reasons, politics of difference were not examined in this inquiry.

The type of sampling strategy in this inquiry was *maximum variation* with the purpose to identify and document common themes and patterns as well as variations. This approach involved selecting participants who were quite different from one another based on some differentiating criteria. For this inquiry this included selecting healthcare professionals of people with Parkinson's from various disciplines. "[Maximum variation] is often selected because when a researcher maximizes differences at the beginning of the inquiry, it increases the likelihood that the findings will reflect differences or different perspectives – an ideal in qualitative research" (Creswell, 2007, p 126).

The interviews were conducted at the most convenient, comfortable and private location for the participants, either in their workplace office or home office. The specific site for the interview was the choice of each participant.

3.7 Appropriateness of this approach given the questions being explored

For this inquiry there was a need for research methodology that would accomplish several tasks. Firstly, an important component of this inquiry was to highlight the voices and experiences of healthcare professionals of people with Parkinson's, with a focus on knowledge production, allowing healthcare professionals of people with Parkinson's to be active participants of knowledge of their own profession. Secondly, the methods needed to support developing insight into work experiences of care of healthcare professionals of people with Parkinson's. And thirdly, the methods needed to provide a means for interaction between the participant and the interviewer, which they did through an exploration of the interview questions, as well as through the participants double-checking their transcriptions for accuracy and being given the opportunity for adding further reflections.

The methodology of the inquiry centered heavily on the interview. The interview was employed in order to develop understanding, determine themes that represented responses, and discern underlying theories (Creswell, 2007). "Interviewing can be an extremely important source of data: it may allow one to generate information that it would be very difficult, if not impossible, to obtain otherwise – both about events described and about perspectives and discursive strategies" (Hammersley & Atkinson, 2007, p. 102). The interview method was chosen as the best method for including and

encouraging healthcare professionals of people with Parkinson's to articulate their concerns in their own voices on their own terms. Semi-structured interview questions were chosen as they were practical and helped to maintain focus while being minimally intrusive. The one-on-one interview allowed for greater scope in conversation and was chosen to encourage individual thought. The interview was from an *emic*, or informant, perspective.

Participatory elements in the design of the inquiry included co-constructing meaning with the participants through the interview process and the participants double checking the transcription for accuracy. Through checking for accuracy, the participants were further involved and ensuring accuracy of meaning of the interviews. Encouraging participant involvement led to a greater guarantee of an accurate and deeper understanding of the participants' experiences. Co-construction helped to address misrepresentation and misinterpretation of the participants, as well as address issues of power and privilege in undertaking the inquiry (Salmon, 2005).

Healthcare professionals of people with Parkinson's have unique insights into their own work experiences of care, and also into the needs and interests of people with Parkinson's. The methods chosen acknowledged the importance of encouraging healthcare professionals to exercise their agency in transforming their work experiences of care.

3.8 Collecting empirical material

The focus throughout the inquiry was to explore, through description and understanding, the work experiences of care of healthcare professionals of people with

Parkinson's. The central question of the inquiry was to determine how healthcare professionals defined acceptable, unacceptable and ideal work experiences of care. Discussion beyond the questions was encouraged which hopefully led to an even greater understanding for both the participants and the interviewer. What was encouraged was "detail, elaboration, and reflection without being judgmental or attempting to shape the substance of the stories" (Hatch, 2003, p. 16). "The tension between participant and analytic perspectives is highlighted if we think of the [interviewer] as simultaneously concerned to make the strange familiar, so as to understand it, and to make the familiar strange, so as to avoid misunderstanding it" (Hammersley & Atkinson, 2007, p. 231).

Through conversation, the experiences of "differentness" challenges one's prejudices and provokes critical reflection. Sometimes sharpening those differences is required for our understanding to change. Uncovering truth and discovering meaning is an infinite process. It involves a process of resistance and change that eventually leads one to a refreshing experience or a new view (Lashley, 1994, p. 156).

The interview was conducted and recorded by me, using a palm-size audio recorder. Rapport was established by starting the interview with a discussion around the Interview Protocols and Practicalities Form (See Appendix D) which included the purpose of the inquiry and the central questions. I then obtained the participant's signature for the Consent Form (See Appendix B), and offered to discuss any outstanding issues of the participants. The interview was semi-structured, open-ended and based around 20 guideline questions (See Appendix C). The participants were invited to review the questions prior to the interview (five/six chose to do so), and to read their own copy of the questions during the interview (two/six chose to do so). During the interview I wrote comprehensive notes on an Interview Protocols and Practicalities Form (See

Appendix D) for each of the participants. This served three purposes: to ensure I recorded responses in case the audio recorder did not work for some reason, to allow the recording of visual cues without being suspect, and to allow the participant to respond to the questions without me staring directly at him/her. Immediately following each interview a one page single spaced 'fieldnote' was produced which included the following: pseudonym; date, time, and length of interview; description of interviewee; setting; sounds, taste, smell, and feelings; rhythm or pace; assessment of how interaction proceeded; points of particular interest for further development; and development of theoretical speculations. I transcribed the interviews, recording the length of the interview after each question. Within one week of the interview a copy of the interview transcription was mailed to each participant for double-checking for accuracy, as well as adding further reflections, if desired.

In closing the interview, the healthcare professionals were asked to provide metaphors for present and ideal work experiences of care. The metaphors provided the participants with an opportunity to think more abstractly about their work experiences of care. At the same time the metaphors provided an image for further analyzing the responses to the interview questions, and for looking for support or denial for the themes and patterns of the interview responses already identified. Included in this inquiry are artistic renderings of the metaphors (Figures 1 – 4) drawn by artist Christina Gray, who is my daughter. These artistic renderings were requested by me, and were drawn upon the artist reading the *verbatim* transcriptions of each of the metaphors of the healthcare professionals. They provide a visual interpretation of the metaphors for the reader(s) of the inquiry. "[The use of metaphor] emphasises the great paradox of communication: that

we use a linguistic artifice to communicate the essence of our experience, all the time running the risk that we shall lose this essence in the translation; and might also lose our audience in the process” (Barker, 2000, p. 97).

As a first step toward starting the process of undertaking the interviews I sent the guideline questions to the director of a medical clinic which provided care for people with Parkinson’s. I included a cover email which stated, “I appreciate your feedback and potential approval on my thesis project which I am hoping will be of interest and value to you and others. I send this note to determine your thoughts on my project and how I might proceed as of course I am interested in proceeding as soon as possible.”

In response the director noted that the clinic only had the capacity to provide an “extremely low” sample size of healthcare professionals – less than 10, and that the clinic would need an explicit statement as to how the information from the inquiry would be used. The director stated that due to this potential sensitivity “substantial trimming and re-wording of the questions” would be needed. Specifically the concern was around the phrase about how healthcare professionals “define acceptable, unacceptable and ideal care” which the director thought should be reworded to how healthcare professionals “define optimal care.” In Part One, ‘descriptions of work experiences of care,’ the director suggested bundling questions concerning acceptable care, dislike about care, and unacceptable care into, “What would you regard as optimal care for patients with Parkinson’s disease?” Likewise the director suggested bundling questions concerning limitations of care, significant healthcare policies affecting work experiences, and significant social, economic and cultural conditions into “What challenges do you face in attempting to provide what you regard as optimal care?”

In Part Two, ‘prescriptions for ideal work experiences of care,’ the director thought the questions about defining ideal care and defining ideal healthcare policy to support this care, were redundant given the re-wording of the preceding questions. The two questions concerning the broader social, economic and cultural conditions for ideal care, and the request for an ideal model of care elsewhere in the world were replaced with, “Are you aware of other effective models for care of Parkinson’s patients? Would these models be applicable to B.C.? If so, what are the challenges or drawbacks preventing their application? If not applicable, why not?” The questions: “What was preventing ideal care from happening?” and “Were there ways of overcoming problems that were preventing ideal care from happening in the workplace?” were cited as “redundant, as they are dealt with elsewhere.”

My response to these suggestions from the director was a return email with the following note. “I very much appreciate your interest and feedback on my work, thank you. However, I now realize I made an error in sending the interview questions to you previous to undertaking the study, as the study including the interview questions has already been approved by the Behavioural Research Ethics Board at U.B.C. and must remain as approved.” There was no further correspondence from the director about this issue and the inquiry began as previously determined with the original questions.

There could be different interpretations of this correspondence between the director of the medical clinic and me. The director could have simply been responding to my request for “feedback on my work.” This interpretation was supported by the director’s “Hope this helps” closing of the email containing suggestions for changes. Alternatively the director could have been trying to set limitations, and wanting to direct

the study from a position of power within the hierarchy of the medical clinic. Certainly the 'new' suggested questions would have resulted in a completely different inquiry from the original inquiry. At no time was access denied in any way to the participants in the inquiry, nor was there any further discussion or correspondence concerning the questions of the inquiry following my return email.

3.9 Gaining analysis: five stages to greater understanding

Analysis of the empirical material involved an overlapping spiral of five stages where the different stages were revisited again and again. Constructions from the interviews needed to be deconstructed in order to be reconstructed for greater understanding.

1. Coding the empirical material - Analysis began during transcription of the interviews, when ideas started to form around themes and patterns. A pen was used to make notes and mark codes directly on the transcriptions. Coloured felt pens were used for colour coding the transcriptions: green felt for theme #1 (Parkinson's is a difficult and multifaceted disorder), burgundy felt for theme #2 (Multidisciplinary care is needed for optimal health for people with Parkinson's), and orange felt for theme #3 (Either more funding or a reorganization of funding is needed). The order of the themes reflected their order of appearance in the interview. A separate document was produced, with quotations to support each of the three themes from the healthcare professionals. Throughout the analysis the transcriptions were read and re-read in order to gain new insights and reflections. This was part of the overlapping spiral of analysis.

As stated previously, each participant was asked to participate in an interview of ‘no longer than one hour.’ The length of actual interview and total number of pages of each transcription were recorded as follows: general practitioner (18:22, 5 pages), neurologist (1:14:49, 20 pages), gastroenterologist (40:10, 13 pages), nurse (1:51:57, 37 pages), social worker (37:54, 13 pages), and physiotherapist (1:36:55, 28 pages). From these figures it can be seen that the range of length of interview was from 18:22 minutes to 1:51:57, and the range of length of transcription was from 5 pages to 37 pages. The variability in length was due to the fact that the interviews were driven by each participant. The neurologist and the physiotherapist, and presumably as well, the nurse, were aware that the interview was taking longer than one hour. I had the feeling the participants felt that they had had adequate opportunity to share their narratives, which appeared to be supported by the fact that not one participant chose to add further reflections in writing when encouraged to do so. The audio recording was downloaded to the computer for the transcription, and then retained on a disc for storage in a locked file cabinet.

2. Analysing the empirical material – A document was produced with edited quotations from each healthcare professional in order to gain a fuller picture of the narrative of each healthcare professional. Another document was produced with each question followed by the responses from the six healthcare professionals, with the responses to questions sometimes coming in response to different questions (See Appendix F). Each question was analyzed directly below the responses to that question, and then the questions and responses were moved to become Appendix F, revealing the analysis. An Empirical Material Analysis Table was constructed with three columns –

quotations from the interview, code and theme - in order to chart the relationship among the empirical material, codes and themes of the inquiry (See Table 1 for a sample from this table). Artistic renderings based on the transcriptions of the healthcare professionals' metaphors were produced by artist Christina Gray (Figures 1 – 4). A representational diagram was made of the three overlapping primary themes (Figure 5). Each of these documents added a layer of analysis to the inquiry. The empirical material and the analysis documents were contained in two binders.

3. Synthesizing the analysis - The write-up began with a summary analysis of the findings from each interview questions, divided into descriptions of present work experiences of care and prescriptions of ideal work experiences of care. These findings were then outlined in terms of the metaphors offered by the healthcare professionals; observations on the interview responses; visual cues; and the three primary themes, including the representational diagram. The issues raised were then analyzed in light of the interviews, the literature review, and my personal reflections, whereby the interviews, the literature review, and personal reflections all informed one other within the three primary themes; the theoretical construct of care; and social, economic and cultural contexts. Hermeneutics “strives for understanding through reflection, analysis, and interpretation of text. In the process, meanings and underlying intentions of persons in particular situations are revealed” (Lashley, 1994, p 111).

4. Generating reflections – Reflections and ‘aha’ moments were recorded directly on the transcriptions with coloured felt pens. An example of a reflection included thinking about what was explicit and what was implicit in what was being said within a culture of caring. An example of an ‘aha’ moment was realizing that the physicians

appeared to take a broader look at their work experiences of care within the whole healthcare system, whereas the allied healthcare professionals focused more directly on their own specialty.

5. Authenticating the analysis - There was coherence among the healthcare professionals for the three overall primary themes that were found in the interviews. There was coherence with the combined findings of the literature review, the interviews, and the personal reflections. These coherences showed support for the authenticity and trustworthiness of the inquiry. Allowing the participants an opportunity to respond to the initial interview added further to this. In the write-up of this inquiry the transcriptions from the interviews are included, as well as artistic renderings of the metaphors offered by the healthcare professionals, and a representational diagram of the three overall primary themes. All of these allow the reader(s) to personally verify the findings of the inquiry.

Table 1 – Qualitative Empirical Material Analysis Table – A Sampling from this Inquiry

The unit of analysis was the work experience of care of healthcare professionals of people with Parkinson's.

Quotation from interview	Code	Theme
General Practitioner ... "...it's a tragic disease and it is a difficult disease to deal with... it's a very devastating disease and it's a frustrating disease to try to manage"	<ul style="list-style-type: none"> • Tragic & devastating disease • Difficult & frustrating to manage <p>* Medical model</p>	<i>Parkinson's is a difficult disorder for people with Parkinson's and for healthcare professionals</i>
Neurologist ... "What I would like to see in general, not just for Parkinson's, is some kind of alternate funding plan ... I would prefer to see a system where the funding is in place to allow multidisciplinary care." "It's not the amount of money that's being spent probably that's the problem. It's the way it's distributed. So it needs in my view a major restructuring, but I don't pretend to be an expert on that."	<ul style="list-style-type: none"> • Multidisciplinary funding • Reorganization of healthcare payment <p>* Medical model</p>	<i>Funding is needed for multidisciplinary care – through a reorganization of healthcare</i>
Gastroenterologist ... "... very difficult problems for these people ... only success is trying to improve quality of life as people move through progression of their disease" "The problems are complex and they are frustrating."	<ul style="list-style-type: none"> • Limited success • Progressive • Complex disorder • Frustrating <p>* Medical model</p>	<i>Parkinson's is a difficult disorder for people with Parkinson's and for healthcare professionals</i>
Nurse ... "There isn't a good understanding of the emotional components of the disease so that they're addressed." "There's a whole ripple effect of the disease that has no place to go. Nobody addresses it... So I think it's true neglect of the whole psychosocial aspect of a chronic disease." "The first front of the ideal is ... to have a multidisciplinary centre where people can get this 'whole person' care."	<ul style="list-style-type: none"> • Non-motor symptoms • Complete care for chronic disease • Multidisciplinary care <p>* Medical model employing whole person care</p>	<i>Multidisciplinary team is needed</i>

Table 1 – Qualitative Empirical Material Analysis Table – A Sampling from this Inquiry (Continued)

Quotation from interview	Code	Theme
Social Worker ... "...I mean all we can do is try to optimize function for as long as possible, but it is a progressive condition."	<ul style="list-style-type: none"> • Limited success • Progressive <p>* Medical model</p>	<i>Parkinson's is a difficult disorder for people with Parkinson's and for healthcare professionals</i>
Physiotherapist ... "[Ideal healthcare policy would be] for people living with Parkinson's, giving them optimum conditions so that they can remain at the peak of their physical performance, plus assistance with their non-motor component of their disease if it's present."	<ul style="list-style-type: none"> • Both motor and non-motor symptoms <p>* Medical model employing whole person care</p>	<i>Multidisciplinary team (for both motor and non-motor symptoms) is needed</i>

3.10 Ethical considerations

An outline of the inquiry including research design, methods, Letter of Initial Contact (See Appendix A) and Consent Form (See Appendix B) was submitted to the Behavioural Research Ethics Board for review. A Certificate of Approval (See Appendix G) was issued on August 12, 2009. To protect the privacy and confidentiality of the participants, the empirical material from the inquiry was stored in a locked filing cabinet and password protected computer accessible only by me. Participants were informed during the consent process that the results of their participation would appear in a written report that would be shared with them, and that would be accessible, in the form of this thesis, through the university library system, and possibly other future publication venues.

CHAPTER 4: ANALYSIS: UNDERSTANDING THROUGH INQUIRY

4.1 Introduction

Chapter IV: Analysis: Understanding Through Inquiry focuses on describing and understanding work experiences of care of healthcare professionals of people with Parkinson's. The following findings from the interviews are outlined: present and ideal work experiences of care of healthcare professionals of people with Parkinson's, including metaphors; observations on the interview responses; visual cues; and three primary themes. This is followed by a combined analysis of the interviews, the literature review and my personal reflections, in light of the three primary themes, the theoretical construct of care, and the social, economic and cultural contexts as defined by the healthcare professionals. The chapter ends with a description and a critique of a multidisciplinary model of care.

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4.2 Findings: Part One: descriptions of work experiences of care

In Part One of the inquiry the healthcare professionals described their work experiences of care of people with Parkinson's. The following section contains a summary analysis of the responses to the questions. See Appendix F for the full responses to the individual questions. In the quotations by the healthcare professionals, "..." indicates that words or phrases have been redacted.

With the exception of the general practitioner, the healthcare professionals enjoyed their roles in the care of people with Parkinson's, whether as a result of their enjoyment of the people with Parkinson's themselves, their satisfaction with their interactions, or their satisfaction with making a difference in another's life. Frustration on

the part of the general practitioner was evident in the statement: “I really don’t enjoy working with Parkinson’s patients because it’s a tragic disease and it is a difficult disease to deal with. It’s sad to watch people go downhill. It’s a very devastating disease and it’s a frustrating disease to try to manage.” These sentiments revealed a sense of powerlessness in the presence of Parkinson’s. It is interesting to note that the role of a general practitioner as dictated by the Ministry of Health is that of being the primary care physician which translates into being the central co-ordinator of care and referrals among the physicians and allied healthcare professionals. Parkinson’s being a multi-faceted, systemic (multiple organ), progressive disorder makes co-ordinating care particularly challenging. Perhaps this was a cause of frustration for the general practitioner? Elsewhere in the inquiry the general practitioner implied that the care of people with Parkinson’s involved only a general practitioner and a neurologist. Perhaps if the general practitioner included allied healthcare professionals in the care of people with Parkinson’s there would be less frustration?

The general practitioner and the neurologist referred respectively to the paraprofessionals (the care aids in the home and in the care facilities) and the healthcare professional team as the strengths in their workplace experiences of care, rather than describing their own personal strengths. By citing their strength as the other members in the healthcare team, the older model of care with physicians in charge was being refuted here by the physicians themselves in favour of the healthcare team. The three allied healthcare professionals outlined their strengths as what they offered personally within their work experiences of care, with the nurse citing her ability to make changes in the attitude of other healthcare professionals; the social worker providing experienced

supportive counselling; and the physiotherapist using good communication skills, motivation and humour (emphasized twice) with people with Parkinson's.

There was universal agreement among the six healthcare professionals that the care they delivered was acceptable care, given the constraints of a progressive health disorder, healthcare budget cuts and limited time. This sentiment was summed up by the gastroenterologist who said: "I think there is a success in trying to improve the quality of life (of people with Parkinson's) as they move through the progression of their disease."

In looking at what they disliked about their work experiences of care for people with Parkinson's, two healthcare professionals referred to the activity of caring for people with Parkinson's, and four healthcare professionals referred to the healthcare system. In the dislike referring to caring for people with Parkinson's, the general practitioner and the neurologist responded respectively: "It's a progressive tragic condition where you watch people deteriorate over a period of years," and "The truth is some people may not do well..." In the dislike referring to working within the healthcare system, the basic frustrations were a lack of communication and coordination among the healthcare professionals in disease management, having to fight the system to get the best care for a person with Parkinson's, and the limited system in terms of limited community resources and limited time.

In looking at dislikes, it was interesting to note that the neurologist referred to the extensive demands of people with Parkinson's when he said: "It can be quite exhausting and I think sometimes people with Parkinson's don't realize ... what a toll they take on the lives of those trying to care for them." In answer to a separate question the gastroenterologist also referred to this toll when he said: "It's a very draining

condition, it's a draining condition for the practitioners, it's draining for the family, it's draining for colleagues and friends and workmates."

All of the healthcare professionals thought there were limitations in the work experiences of care of people with Parkinson's. Their responses on this subject could be divided into two main areas: first the broader area of the challenges of an incurable, progressive disorder that has limited treatment options and no cure; and second, the functional challenges of limited or no access to multidisciplinary care, limited understanding of the emotional aspects of Parkinson's, lack of availability of both general practitioner and specialist care, limited office space, and lack of disease management practices in terms of co-ordination of healthcare professionals.

In describing limitations in the work experiences of care, the neurologist, the gastroenterologist and the nurse each referred to the importance of caring for more than just the motor aspects of Parkinson's. The neurologist did not see allied healthcare professionals (specifically a social worker, physiotherapist, speech therapist, etc.) as a luxury, rather that they were a necessary part of care. The gastroenterologist referred to the fluctuating symptoms of Parkinson's:

So some Parkinson's patients, their dominant symptoms may be related to their G.I. tract at some point, and others at another point in their illness it may be purely emotional or psychological, and then yet another point it may be neurological or related to their movement disorders and so there is such a shifting focus of their problems and needs that it is difficult to sometimes know what is the dominant symptom at any given point, and what's the dominant problem to address.

The nurse stated: "There isn't a good understanding of the emotional components of the disease so that they're addressed." Elsewhere in the interview the nurse stated: "So my

view and my interest in Parkinson's has always been to the whole picture, the whole person in Parkinson's, and also the impact on the family."

Limitations for the neurologist, the nurse and the physiotherapist all referred to the limitations of access to physicians for people with Parkinson's. In answer to another question, the neurologist said: "So suboptimal (care) is seeing the patient once every 18 months." In British Columbia it is the primary care physician, or general practitioner, who is responsible for the day-to-day care, with a 'standard' referral interval of one year for a Parkinson's specific neurologist. For concerns about care in the interim, including medication specific questions, it is possible for a person with Parkinson's to phone a Parkinson's specialist nurse at the Pacific Parkinson's Research Centre at U.B.C., but only if one is a patient at a centre. This centre, which due to its limited number of healthcare professionals and limited size, serves less than 1300 of the 11,000 people with Parkinson's in British Columbia. This leaves the majority of people with Parkinson's depending on their general practitioner for most of their care.

There was no consensus as to what constituted unacceptable, or as the neurologist redefined it, suboptimal care. Rather, it was variously viewed as including: not treating to the best of one's ability; unneeded suffering and unneeded interventions; access being denied to the specialists by the general practitioners; the healthcare professionals not being available, either on a particular day or with too great a time lag between visits; inadequate Parkinson's education for healthcare professionals; and people with Parkinson's being seen outside the complex of multidisciplinary care. In summary, in recognizing the limitations of their role when their role was less than fully existent, these responses showed that the healthcare professionals understood the value of their

role, including their expertise, information and support, as being an important part of the care of people with Parkinson's.

The general practitioner and the gastroenterologist viewed unacceptable care more from an ethical point of view when they said respectively: "Basically not treating to the best of one's ability," and "... unneeded suffering and unneeded investigations, unneeded interventions, and unnecessary suffering ...". In identifying unacceptable care, the neurologist, the nurse and the physiotherapist pointed to the more comprehensive view of the 'whole person' with their respective comments: "Somebody with an established disease seeing them ... outside the complex of multidisciplinary care...", "It's disrespectful to try to treat the Parkinson's patients as if they live in isolation ... I think it's true neglect of the whole psychosocial aspect of a chronic disease", and "Not getting to see a movement disorder specialist, being turned down by their G.P." In contrast the social worker downgraded the word 'unacceptable' as something more like a frustration, and cited not being available on the day when there was a patient who needed social work intervention.

Concerns about significant healthcare policies affecting work experiences of care of people with Parkinson's mainly centred around resources and the most effective use of those resources. The general practitioner stated that there was no healthcare policies that interfered with his particular work. The neurologist and the gastroenterologist thought the structure of the healthcare system needed improving, with suggestions made for an overhaul change in the organization of chronic disease management, and for greater financial reward for a central co-ordinating primary care physician, respectively. The neurologist thought it odd that funding was not provided for

allied healthcare professionals by either the university or the health regions. The nurse advocated for more resources in terms of more nurses and more education for the nurses. The social worker and the physiotherapist felt the arbitrariness of government funding, with its continual threat of withdrawal and seemingly arbitrary allocation respectively. The physiotherapist said: “I always have felt for a long time in healthcare, that they do have money for the things they want to do.” These views about healthcare policy are probably not unique to the care of people with Parkinson’s and could likely be used to describe treatment for other chronic health conditions as well.

Responses to the question of the significant social, economic and cultural conditions affecting work experiences of care varied. The general practitioner said: “I don’t really see any big problems” with these conditions affecting work experiences; there was “appropriate care” in a care facility, the \$600 cost of medication was covered, and only in certain cultures was there a delay in getting treatment. The neurologist stated that these conditions did not affect his work experience *per se*, rather it was more the limitations of the healthcare system that affected his work experiences. The gastroenterologist viewed the social condition of Parkinson’s as draining on the family, friends and colleagues as well as the physician; the economic condition as the healthcare payment system affecting work experiences, with physicians being rewarded economically proportionately more for simple problems; and a cultural condition where different cultures offered different levels of support to family members with Parkinson’s which affected the work experiences of healthcare professionals of people with Parkinson’s, including the challenges of multiple languages. The social worker pointed to the significant differences in the United States where healthcare delivery was so limited

for people without access to medical insurance or medical care, as opposed to the ‘panacea’ in Canada where everyone had access to healthcare. The physiotherapist spoke of the culture of patient focused care that existed in the United Kingdom forty years ago, concluding that socially now there was not enough focus on the quality of care nor on the quality of life of the elderly.

The varied responses to this question showed there was not a consistent theme as to how healthcare professionals viewed the social, economic and cultural conditions that affected their work experiences of care. Interestingly the social worker and the physiotherapist reflected on the value of another jurisdiction (the United States) and another time (forty years ago) in looking for significant social, economic and cultural conditions affecting present work experiences of care and came to opposite conclusions. The social worker stated that Canada was a panacea, and the physiotherapist stated that there was not enough focus on the quality of care, or the quality of life here in Canada now.

4.3 Part Two: prescriptions for ideal work experiences of care

In Part Two of the inquiry the healthcare professionals offered prescriptions for ideal work experiences of care of people with Parkinson’s. The following is a summary analysis of the responses to the questions. See Appendix F for full responses to individual questions.

Two of the participants described ideal care as already being present within the healthcare system. Ideal care for people with Parkinson’s was defined by the general practitioner as ideally a cure, but secondly where one made every effort to maintain

function of people with Parkinson's. The social worker described ideal care as providing the best effort possible within the context of what was presently available. The social worker did not believe that "anybody is ever perfect, any situation is ever perfect."

Ideal care was described by the other healthcare professionals as changes needing to be made to the healthcare system. The neurologist described ideal care as multidisciplinary care with a focus on ambulatory (outpatient) care with staff to monitor patients over time. The neurologist included in ideal care, the combination of research and clinical care together, where research was driven by the clinical care. Ideal care was described as multidisciplinary care by the gastroenterologist. It was a readily available combination of healthcare professionals co-ordinated on the different aspects of care. The ideal multidisciplinary care would be in a clinic setting involving multiple practitioners with ready access in co-ordinated fashion to communicate and coordinate the care of people with Parkinson's. The nurse described "the first front of ideal is ... to have a multidisciplinary centre where people can get this 'whole person' care." This would include access to information, education, and support both for the people with Parkinson's and their families, as well as updated information for the healthcare professionals in the hospital. The physiotherapist described ideal care as "absolutely no restraints" with every person with Parkinson's being seen by the physiotherapist, including ongoing treatment and monitoring of their physical condition, and assistance with their exercise programs and activities.

Whereas the general practitioner previously stated that all was well in the present system, when asked about ideal healthcare policy to support ideal care, a team approach was cited, with a healthcare team in place to assess function. Both the

neurologist and the gastroenterologist sought an alternate funding plan to allow multidisciplinary care, with the neurologist urging a policy where a physician was not economically disadvantaged for caring for someone with a chronic disease, and the gastroenterologist urging a policy toward rewarding the primary care physician in a central co-ordinating role in the management of complex care. However as the neurologist stated earlier there was a problem around healthcare policy and funding: “The hospital doesn’t see itself as having a role, the health region doesn’t seem to see itself as having a role in providing the care, they look to us to do that. So, if we want nurses, physios, social work, they want us (the physicians) to come up with the funds to support that. Yah, I find that a little bit odd.”

Ideal healthcare policy for the nurse addressed uniformly across the whole healthcare system, the ‘whole person’ with better accessibility to healthcare professionals and better education on how to manage Parkinson’s for healthcare professionals. The social worker was interested in funding in the community for financing, medication and equipment support, and subsidies for homemakers. The physiotherapist wanted optimum conditions so that people with Parkinson’s could remain at the peak of their physical performance, as well as assistance with the non-motor component of Parkinson’s if present. The physiotherapist’s ideal list included team support, easy access, no waiting lists, support for the caregiver, and respite care for both the person with Parkinson’s and the caregiver.

It would appear from these descriptions of healthcare policy for ideal care that the healthcare professionals had a consistent view of a multidisciplinary team as the comprehensive model of care and treatment for people with Parkinson’s. The

multidisciplinary team approach represented a departure from the traditional model of healthcare delivery in British Columbia where people with Parkinson's were seen by the primary care physician and perhaps the neurologist. The approach encompassed the complexity of the disorder and the benefits of allied healthcare professionals in the management of the disorder. Thus the healthcare professionals working within the healthcare system were recognizing that the model of healthcare delivery needed changing.

The healthcare professionals had various ideas for social, economic and cultural conditions for support of ideal care. The general practitioner did not see any outstanding issues related to social, economic and cultural conditions. The neurologist responded: "I think probably I've covered that." The gastroenterologist expressed that there had to be some support for the social consequences of the disorder at whatever level that might be, whether people were affected by Parkinson's at a young age with young families early on in their careers, or as older retirees. Culturally the gastroenterologist thought it was important to recognize the cultural *milieu* of people with Parkinson's and if the cultural *milieu* was not very supportive then there had to be some ability to try to gain support, whether through a psychologist, healthcare workers, care aids, or financial support. The nurse surmised that there would be differences in how different cultures would experience Parkinson's, and that there would be a need for education materials and translators in multiple languages. The social worker said: "Again I think, to me, so much of it is tied to money and the economy. ... Canada has a very paternalistic open arms philosophy about taking care of our citizens and so that's a great place to be sick, if you're going to be sick." The physiotherapist expressed that there needed to be enough

money to fund programs for healthcare professionals for more expertise in the management of the disorder, including educating general practitioners about their role in the management of Parkinson's and about the existence of the Movement Disorders Clinic at U.B.C. This was all in addition to having exercise programs and respite care for people with Parkinson's. The physiotherapist also believed that from a social point of view the government should be pressured into putting more funds into educational programs and better staffing in places like extended care and assisted living facilities.

Different conceptions of models for ideal care emerged from the inquiry. The general practitioner and the social worker both did not have an ideal model, with the social worker proclaiming: "I can't imagine what perfect would be." The neurologist cited the upcoming (June 2011) N.I.C.E. (National Institute for Health and Clinical Excellence in the United Kingdom) Parkinson's clinical guidelines, which he hoped would endorse multidisciplinary care as the model of care. The neurologist also cited the Booth Gardner Parkinson's Care Center in Seattle Washington as an ideal multidisciplinary model worth considering. The gastroenterologist cited this same centre as a model for centralizing diagnosis and care, as well as having short and long term respite care. The nurse cited the Nephrology Clinic at Vancouver General Hospital in Vancouver, B.C. as being both 'stellar' and patient focused. The physiotherapist cited the ParkNet scheme in the Netherlands for setting up physiotherapy centres with specialized training in Parkinson's, and the local Healthy Heart program for setting up cardiac assessment and rehabilitation programs in individual communities in British Columbia.

In summary, concepts for an ideal model of care put forth by the healthcare professionals included: patient focused care, centralizing diagnosis, multidisciplinary

care, short and long term respite care, an assessment and rehabilitation program, and paraprofessional centres throughout the province. There was no one ideal model but there were many models both within the Parkinson's experience and without. The number of different proposals advanced by the healthcare professionals supported the fact that a majority believed there were deficiencies in the present healthcare model.

As for what was preventing ideal care from happening in the workplace both the general practitioner and the social worker thought that all was well. This acceptance of current conditions was evidenced by their respective comments: "I don't think there's anything outstanding that is missing from my current experience in my current workplace," and "We *are* doing our, the best that we can do, we *are* providing ideal under the circumstances that we have."

In contrast, the neurologist opined that the present model was focused on delivery of acute care as opposed to chronic care, and stated that the B.C. Ministry of Health would agree with this. The neurologist suggested a major restructuring of the provincial health budget, saying that there was no more money to be spent on healthcare. The gastroenterologist cited the overwhelming workload for physician time and physician care in dealing with the complexity of Parkinson's, with much of that time spent in co-ordination and communication among healthcare professionals; the solution offered was an experienced healthcare co-ordinator to help people understand which healthcare professional dealt with which particular problem. Both the nurse and the physiotherapist saw a lack of resources preventing ideal care from happening in the workplace, with the nurse referring specifically to lack of staff resources, as preventing ideal care from happening in the workplace. The nurse stated: "Part of it is money, of course we all know

that. There is a huge financial issue for all these things.” This comment revealed that the nurse thought the lack of funding in the healthcare system was well recognized. The physiotherapist concluded by saying: “But we shouldn’t let that (the lack of resources) hold us back (from trying to arrange for more funding), because if there is a need there is a need.”

Responses to ways of overcoming the problems that were preventing ideal care from happening in the workplace continued earlier themes of each of the healthcare professionals. The general practitioner and the social worker saw no particular problems, with the general practitioner seeing the problems being associated with the disease itself, and the social worker seeing that the care needed was already being provided. The neurologist indicated a need for restructuring the healthcare system in terms of payment to healthcare professionals, and suggested an ‘envelope’ or salary payment. The gastroenterologist observed the need to mobilize and co-ordinate the healthcare professionals to address the various needs of people with Parkinson’s. The nurse and the physiotherapist again stated the need for more resources, with the nurse realizing that there would be neither more staff nor more money. The nurse challenged: “Let’s problem solve guys. We don’t have any more staff or money. Is there a way that we can, as a group, come up with another way we can accomplish this?” The nurse believed the government priorities needed to be placed in human places, with real acknowledgement and support for the healthcare professionals which would then make a difference for the care of people with Parkinson’s.

4.4 Findings: inquiry through metaphor

A metaphor takes an idea and links it to another idea for better understanding.

Following are metaphors provided by the healthcare professionals at the end of the interview.

“In closing I am wondering if you can imagine a metaphor for either your present workplace experiences of care for people with Parkinson’s, or a metaphor for your ideal workplace experiences of care for people with Parkinson’s.”

- General Practitioner ... “Can you give me an example of what you mean by a metaphor?” [*example of metaphor provided by interviewer*] “No. I don’t have a metaphor. I think the disease is a very difficult condition and it’s progressive, it’s tragic, and it’s a challenge to treat medically and from a nursing point of view.”
- Neurologist ... The metaphor for the present work experiences of care is a group of healthcare professionals peddling hard to keep the healthcare system going and upright. The healthcare system is not moving forward as fast as the people would like. The whole healthcare system is very fragile. Anything that happens to tip the balance could result in catastrophe, much like falling off a bicycle.

The metaphor for an ideal work experiences of care is a more relaxed, less fragile situation with the healthcare professionals peddling together to keep the healthcare system moving forward.

- Gastroenterologist ... The metaphor for the present work experiences of care is a chuck wagon, with the wagon being the person with Parkinson’s, being pulled along by their Parkinson’s. A driver is trying to drive the chuck wagon and “he has got eight horses to control with eight different sets of reins.” The horses represent the healthcare professionals. Each horse wants to go its own different way, and yet each horse is critically important to the movement of the chuck wagon. A wagon pulled by one horse is relatively easy to control, two horses become more difficult, and a wagon pulled by eight or ten horses becomes remarkably difficult to control, particularly as the horses become more powerful and more autonomous. If the horses are not coordinated and controlled it can be a hindrance as the horses go off in different directions. This would destroy the chuck wagon, the chuck wagon race and all the people who are involved in the race.

- Nurse ... The metaphor given for the present work experiences of care is a mule. This is a strong and capable mule that thinks it has an important job, but it is pulling a wagon with a heavier and heavier load, and being fed less and less, and even being given longer and longer work hours, and now it is struggling. It is wondering what happened because everything has changed. The mule is not able to remedy its own situation. It needs someone from the outside with a bigger vision who will say, "O.K., you're doing it the wrong way here. The mule needs to work half the number of hours, or you need to buy a second mule, or we need to give him extra carrots 'cuz that's really good for energy." Somebody outside the story needs to have a big vision, rather than the guy with the whip who hits the mule from behind and says, 'Well, we've got the secret, we'll just make the mule work harder or faster.'

The accompanying metaphor for ideal work experiences of care is a village as seen in a World Vision type advertisement on television. This is a village with lots of adversity and the children are struggling, although there is a lightness and hopefulness with a circle of people, who are joyfully working on the problem. There's enough support that although the situation is not fixed or easy, there is still a lightness about the story, people are hopeful, unlike the mule that's just dragging himself and can hardly keep going. The narrator in the background is saying, "We are going to help the individuals in this story, and by helping Johnnie in the one family, we are going to help Johnnie's whole family, and we are going to help the village because we are going to get a well here." So it's not only the individual people who are being supported, but now there is a well for the whole community. There is a community-ness to it, where no one individual is unimportant. It is not a vision where the problems have all disappeared, because that will never be, rather there is a willingness to collaborate and co-operate in the sense of community, and to do this by connecting with hope. The people in the village know that they are not alone.

- Social Worker ... The metaphor for the present work experiences of care is a person with Parkinson's as the conductor of an orchestra. The person is taking charge of the 'performance', and is very much in control of the piece and so, the Parkinson's. The members of the orchestra are all the rest of the people surrounding the person with Parkinson's, whether family, friends, doctor, nurse, social worker, or workplace employer. All of the other people who are part of this person's world play a different part in the performance. "How do you like that?" whispered the social worker to me after she relayed her metaphor. I acknowledged the positive tone of the metaphor and asked her if she would consider using this metaphor in her practice with people with Parkinson's in the future, and she was surprised by this but said she would consider it.

- Physiotherapist ... “You know I didn’t give that much thought. Can I think about it a bit more and get back to you?”

The metaphors of each healthcare professional worked to reflect and summarize what each had been describing earlier in the interviews. The neurologist, the gastroenterologist, and the nurse employed metaphors that demonstrated that the present healthcare system was not working, and that there were changes that needed to be made. The social worker employed a metaphor that demonstrated the present healthcare system was working, with people with Parkinson’s being in charge of both their own lives and the healthcare professionals. Included in this inquiry are drawings of the metaphors (See Figures 1 – 4) which are artistic renderings drawn by artist Christina Gray upon reading the *verbatim* transcriptions of each of the metaphors of the healthcare professionals.

The themes within the metaphors for the present work experiences of care incorporated several different types of movement namely, the precarious and unsteady movement of the healthcare professionals peddling to support the healthcare system (See Figure 1); the aggressive, and out of control, movement of the chuck wagon and horses (See Figure 2); and the sweaty, underappreciated, and sluggish movement of the mule (See Figure 3). These were all powerful images, with the first three metaphors acknowledging the precarious and somewhat chaotic nature of the present healthcare system. These metaphors were in contrast to the beautiful, harmonic movement of an orchestra led by a person with Parkinson’s (See Figure 4) which was given as the present work experiences of care by the social worker who considered the present experiences to be ideal and which were defined as including multidisciplinary care.

The themes within the metaphors for ideal work experiences of care incorporated movement as envisioned in the relaxed peddling of the bicycle by a group of

healthcare professionals (See Figure 1), the steady and co-ordinated movement of the chuck wagon now in control (See Figure 2 – this is the artist’s rendering; the gastroenterologist did not provide a metaphor for ideal work experiences of care), and a circle of joyful people in a village working together in lightness and harmony (See Figure 3). These metaphors revealed a healthcare system that was upright and running smoothly.

Each of the metaphors for both present and ideal work experiences of care emphasized the importance of communication and co-ordination, and all but the two bicycle metaphors included the role of a central organizing presence. There was a definite sense that in our society the person with Parkinson’s was not alone, as shown by the metaphors centered around a chuck wagon with eight horses, multiple people keeping a bicycle upright, a mule working within a system, a village of people with a co-ordinator, and an orchestra conductor with full orchestra. This sense of interdependence pointed to the interconnectedness of people with Parkinson’s within society. In conclusion, independent of the inquiry questions, each of the metaphors for both present and ideal work experiences of care underscored that care in Parkinson’s was part of a bigger picture, centered on movement and balance, communication and co-operation.

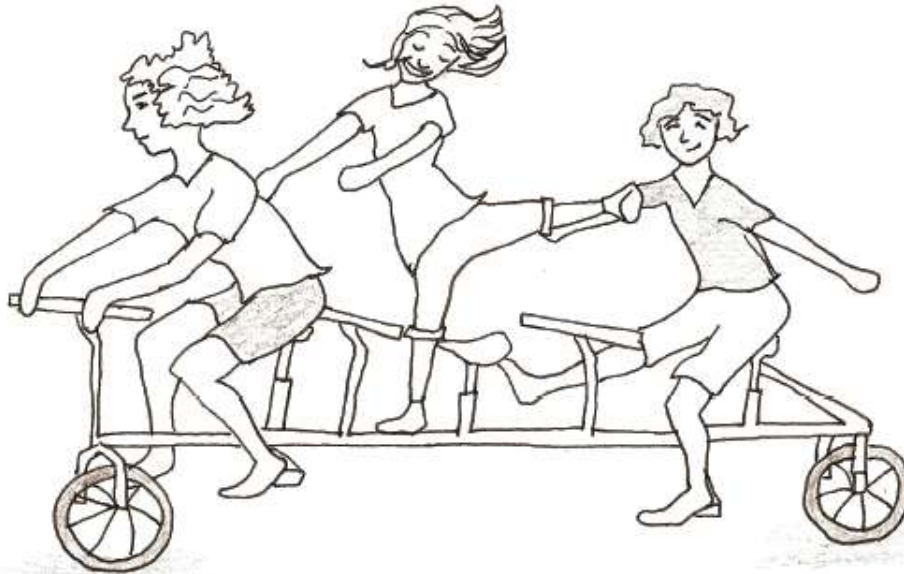
As for the general practitioner and the physiotherapist, neither produced metaphors for present or ideal work experiences of care. When asked for a metaphor, the general practitioner first said, “Can you give me an example of what you mean by a metaphor?” I responded with an example of a metaphor. The general practitioner responded: “No. I don’t have a metaphor. I think the disease is a very difficult condition and it’s progressive, it’s tragic, and it’s a challenge to treat medically and from a nursing point of view.” It should be noted that the general practitioner alone did not have

forewarning of the metaphor question as it was not included in the questions sent to the general practitioner prior to the interview. I had waffled about whether or not to include a request for a metaphor in the inquiry, had removed the request, but then had been encouraged when the first participant spontaneously provided a metaphor in answer to one of the interview questions. Although the general practitioner was able to theorize the medical model throughout the interview, the general practitioner was not interested or able to provide a metaphor. Perhaps the general practitioner was able to think concretely in terms of answering questions, but had difficulty thinking more abstractly? It should be remembered that at the start of the interview the participants were informed that they had the right to decline to discuss anything causing discomfort and/or to withdraw their participation at any time without consequence, and so the lack of providing a metaphor, or answering any question in the interview, was perfectly acceptable.

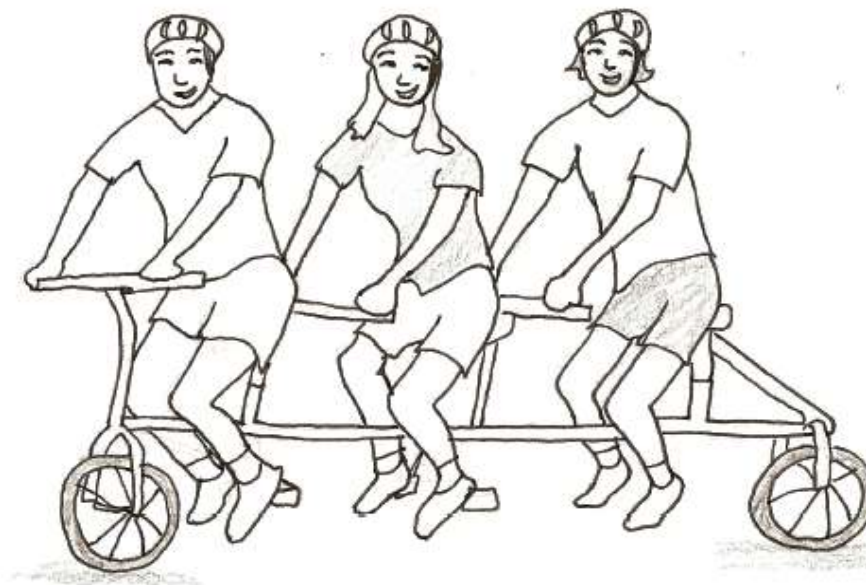
As for the physiotherapist the response to the metaphor question was: “You know I didn’t give that much thought. Can I think about it and get back to you?” So the physiotherapist showed prior knowledge of the metaphor question being included in the interview questions, but then indicated in this answer that providing a metaphor required more thought than answering the other questions of the interview.

Figure 1: Metaphor: Present & Ideal Work Experiences – Neurologist

“I regard the whole healthcare system, not just what we do, as people peddling hard to keep it going ... to keep the bicycle upright ... we’re not going forward as much as we would like ... very fragile, and anything that happens to tip the balance could result in a catastrophe ...”



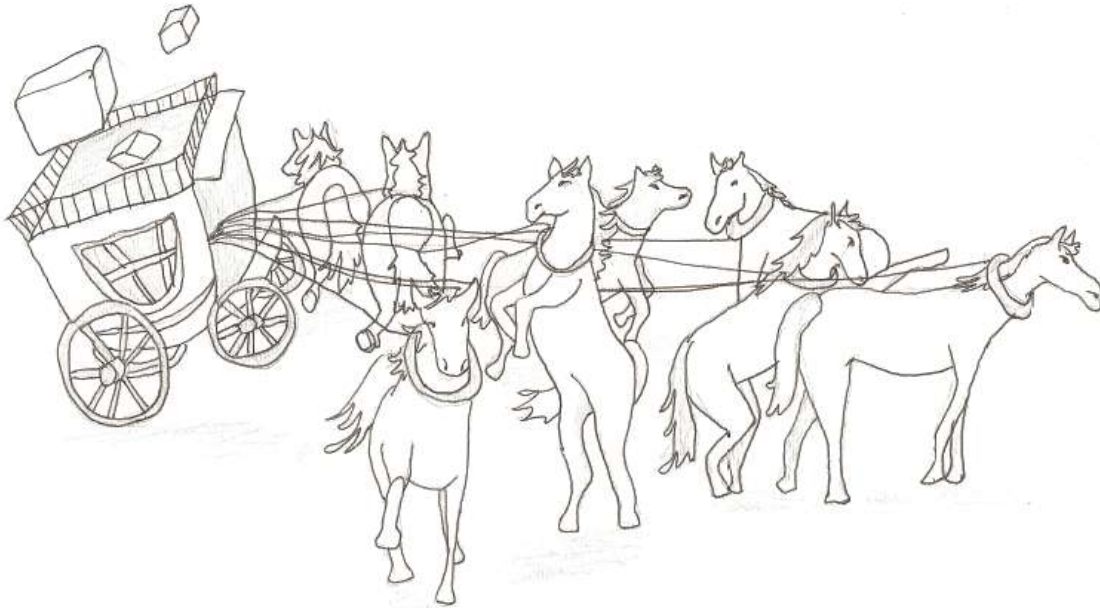
“ ... a more relaxed, less fragile of a situation...”

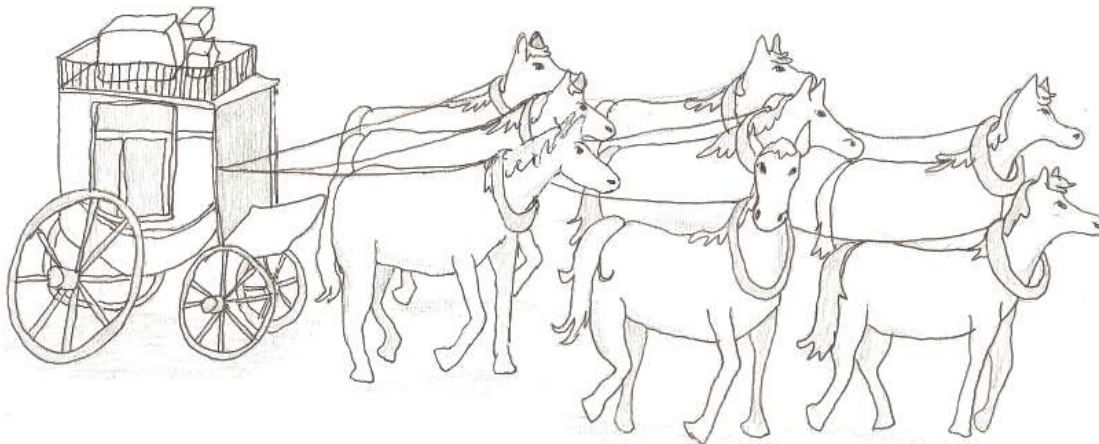


Credit: Christina Bernadette Gray

Figure 2: Metaphor: Present & Ideal Work Experiences – Gastroenterologist

“A chuck wagon ... each horse wants to go its own different way, and yet each horse is critically important to the movement of the chuck wagon, but ... if the horses aren't coordinated and controlled they go off in their own tangent and that can destroy the whole chuck wagon, the chuck wagon race and all the people that are involved with it. ... The wagon would be the patient, the sufferer of the illness.”

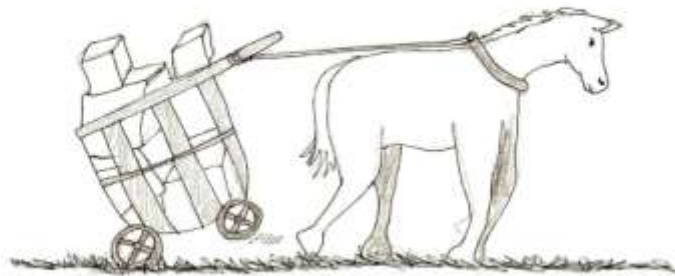




Credit: Christina Bernadette Gray

Figure 3: Metaphor: Present & Ideal Work Experiences – Nurse

“The image that appears in my head is the mule that’s pretty strong and capable, but at the same time somebody’s put a wagon behind him that they keep adding more stuff to ... they’re giving him less to eat ... Somebody outside the story needs to have a big vision, rather than the guy with the whip who’ll hit him from behind and say, ‘Well, we’ve got the secret, we’ll just make him work harder or faster.’”



“... a World Vision type of ad. So we’ve got a village where there’s lots of adversity, and the kids are struggling, and at the same time, we’ve got this lovely circle of people, that are joyfully working on the problem, and there’s enough support that although the situation’s not fixed or easy, there’s still a lightness about the story, people are hopeful ... But it isn’t a vision of mine where the problems have all disappeared, because that will never be, but there is a willingness to collaborate and co-operate in the sense of community that makes it ... more likely you are to find some solutions”



Credit: Christina Bernadette Gray

Figure 4 : Metaphor : Present Ideal Work Experiences – Social Worker

“ ... the patient is the conductor, and the patient is therefore taking charge, and is very much in control of the piece, and the disease, and that the members of the orchestra are all of the rest. They’re the family, the friends, the doctor, the nurse, the social worker, the work place employer, all of the other people who are part of this person’s world, and we all play a very different part in a performance, and reaching an optimal performance.”



Credit: Christina Bernadette Gray

4.5 Observations on the interview responses

In defining present work experiences of care a distinction appeared between the responses of the physicians and the responses of the allied healthcare professionals. The physicians looked at the broader picture of the healthcare system and their own inability to change the outcome of people with Parkinson's with the inevitable decline in health over the progression of the Parkinson's. This contrasted with the allied healthcare professionals' focus on their personal role or specialty within the healthcare system. Presumably the different *foci* would lead to different expectations of work experiences of care of the two groups.

The inquiry found that the healthcare professionals of people with Parkinson's believed there were areas which needed to be addressed in their work experiences of care. Simply put, the present healthcare system was not adequate for the care of people with Parkinson's. In analyzing the responses it appeared that healthcare professionals were outlining a move from a traditional care model of physician and patient to a comprehensive care model with a team of multidisciplinary healthcare professionals supporting people with Parkinson's. This shift from physician to multidisciplinary team would see allied healthcare professionals involved in more of the work that physicians were doing.

The healthcare professionals supported changes in healthcare policy toward a team approach and multidisciplinary care. The general practitioner stated:

Well I think the ideal healthcare policy is to have a team approach and for people to be aware of a system in place to assess function, and a system that is communicated through the healthcare team so that everybody on the healthcare team was aware of what could be adverse effects or what could be done to improve function...

The neurologist tied multidisciplinary care in with funding: “Well, I’m not a policy wonk. ... I would prefer to see a system where the funding is in place to allow multidisciplinary care.... But the basis, the beginning for it would have to be an alternate funding plan.” The gastroenterologist placed the multidisciplinary care within a clinic:

I think there has to be a policy that supports, that recognizes the complexity of this disease and recognizes the need for complex care, and so that there is a policy that allows for creation of such a network of support, presumably coordinated through some sort of central Parkinson’s facility or Parkinson’s clinic that would then use neurologists as a small part of that. At the moment the neurologist tends to be the main component of that clinic in my view but I think it needs to be beyond that.

The physiotherapist supported multidisciplinary care by defining ideal healthcare policy as: “So always the team support, easy access, no waiting lists and of course a lot of support for the caregiver.” In looking beyond healthcare policy, the benefits of multidisciplinary care were espoused by the social worker: “... they (people with Parkinson’s) are happy to be coming to a clinic ... where it’s multidisciplinary, and I think that for the most part they feel that their needs are being addressed.”

In discussing healthcare policy, the nurse noted the importance of the whole person supported within the healthcare system: “I think the ideal healthcare policy would be a policy that addresses uniformly across the whole healthcare system, the whole patient, talking a theme here, where that was the policy of the way the whole healthcare system worked.” It is interesting to note that “(n)urses are increasingly in positions to influence this process (of noticing the limitations of the biomedical model in favour of whole person care) as they are the largest group of health care practitioners to be embracing the wider philosophy and understanding of illness and health through the integration of whole-person care ...” (Benor & Benor, 1997, p. 3).

All the healthcare professionals, with the exception of the general practitioner, pointed to a need to address funding resources. There were suggestions made by the neurologist toward treating Parkinson's as a chronic condition and restructuring the payment system from 'fee for service' to an 'envelope' or salary payment. The gastroenterologist stated that the role of the general practitioner should be re-emphasized as primary care physician, with added financial incentive for the time required for the chronic care needs of people with Parkinson's. This concept was supported by a recent story in *The Vancouver Sun* newspaper story on the importance of the general practitioner. The article included the following quotation:

... by guaranteeing that health care services are fully and properly utilized, the health care system could realize significant savings while also improving the health of the population. ... (Health researcher Marcus) Hollander found that the more attached a patient was to a primary care practice, the less that patient's treatment cost the health care system ... largely the result of a decrease in hospital visits (The importance of family physicians, 2010).

The frustration of the ongoing lack of funding within healthcare was described by the physiotherapist as follows: "I've come from a background of providing the best possible healthcare from the point of view of efficiency. I mean we had to be efficient, but compassionate and caring, and more patient focused care, and so I would say that really shaped me and now I get frustrated by: 'Well, there isn't any money.'"

Both the neurologist and the nurse recognized that there was not likely to be more funding within the healthcare system. The neurologist stated: "It's got to be close to 50% of the provincial budget is being spent on healthcare, so they can't spend more money. It's not the amount of money that's being spent probably that's the problem, it's the way it's distributed. So it needs in my view a major restructuring, but I don't pretend

to be an expert on that.” The nurse offered forth a challenge to other healthcare professionals to find ways to problem solve without an increase in funding. The physiotherapist observed that the government did have money for the things that they wanted to do.

With the number of general practitioners in the province being around 6,000 and there being approximately 11,000 people with Parkinson’s in the province, it is interesting to note that most general practitioners on average only have a handful of people with Parkinson’s in their practice. A low volume of people with Parkinson’s is likely a similar story for the general neurologists practicing throughout the province. On this topic the Parkinson’s specific neurologist in this inquiry observed: “There’s northern B.C., there are large segments of the island that ... may have access to neurologists, the access is, even to a neurologist is not perfect and certainly to a subspecialized care is sort of, not there.” Low volume practices become a challenge in terms of both gaining and maintaining expertise in Parkinson’s. Another difficulty with geographical distances in the province is the lack of communication and coordination among healthcare professionals directly caring for people with Parkinson’s.

As for points of view the social worker had a difficult time imagining what an ideal work experience would be like, as shown by the comment: “You know to me when you talk about something that’s ideal you’re talking about a concept of something that’s perfect, and I’m not sure than anyone, anybody is ever perfect, any situation is ever perfect” and, “I can’t imagine what perfect would be ... I think also part of that is just who I am, which is that I am a very practical, realistic person.” This meant that imagining beyond the present healthcare situation was difficult for the social worker. Although

perhaps this was not necessary as the social worker named the healthcare in Canada as a panacea, particularly in comparison to the United States.

Although the inquiry was open-ended and although the healthcare professionals were not discouraged from talking around or beyond the questions, the interview was basically focused around 20 previously determined questions. It is worth surmising what it was that the healthcare professionals of people with Parkinson's did *not* say in their interviews. What was missing? What was not addressed? Was there communication in the silences?

In their responses the healthcare professionals did not speak about wellness or prevention, both topics of much conversation in *public pedagogy* (Luke, 1996). Media and popular culture function as mass 'informal' education, and wellness and prevention are presently hot topics in both media and popular culture:

Because public culture is woven into every crevice of everyday experience and cuts across traditional boundaries of class, ethnicity, age, and, certainly, nation and geography, the public texts of popular culture are probably a more powerful pedagogy than the generally decontextualized knowledge and skills taught in formal institutions of learning, disconnected as they are from what is referred to as "the real world" (Luke, 1996, p. 184).

As for public pedagogy, the focus of care being 'whole person care' is another example where the public has a keen interest. "Fortunately, the public is not indoctrinated in scientific methods and thinking as health caregivers are ... [and] this is bringing about a major return to whole-person care" (Benor & Benor, 1997, p.2). "The public is actually very much aware of the need for this (whole person) approach. And their biggest complaint is often about the absence of this kind of presence in the healthcare practitioners they're dealing with. So, we feel the public has some very useful things to say and questions to ask" (Flynn, 2010, McGill Reporter).

The healthcare professionals also did not mention the role of people with Parkinson's in their own care, as active participants rather than passive recipients. Perhaps the relative age of the healthcare professionals, and their corresponding medical training being greater than twenty years ago, affects their non-inclusion of topics of wellness, prevention and personal responsibility in care?

As for public pedagogy of Parkinson's it is interesting to note that public awareness and acceptance of Parkinson's has been increased over time through very recognizable public figures such as Muhammad Ali, Pope John Paul II, and Michael J. Fox. Public education of Parkinson's is increased through these public figures through media and popular culture which function as mass informal education.

As the majority of people with Parkinson's are elderly, and often affected by increasing speech challenges due to Parkinson's, they are often ineffective in advocating on their own behalf for better care. This was observed by the gastroenterologist in the statement: "... patients with Parkinson's by definition become very debilitated and are often not able to speak out, whereas an individual with diabetes, or kidney failure, or cancer can often be remarkably viable and remarkably verbal and able to speak out about their condition." Progressive speech challenges make it difficult for people with Parkinson's to be heard, including to their healthcare professionals. This is another reason why an inquiry such as this one encouraging communication about Parkinson's is important.

All six healthcare professionals declined the offer of adding further thoughts and reflections in writing when they signed off on the accuracy of their interview

transcriptions. I did not ask why they declined to add further thoughts. I surmised that they likely felt that they had fully expressed themselves in the interview already.

4.6 Findings: visual cues

Three of the interviews took place in a workplace office and three in a home office. The workplace office spaces were uniformly ‘no frills’ functional, each with a computer, metal file cabinet, arborite desk, and (unanswered) ringing telephone or personal digital assistant. The home offices included two sitting rooms, and one kitchen, complete with laptop computer and journal articles on the kitchen table. I had the feeling that each one of the healthcare professionals was keen about participating in the inquiry. Not one healthcare professional answered a ringing telephone or personal digital assistant during the interview, although there was ‘ringing’ during five interviews. There was a sense of busy-ness emanating from the hallways of the workplace offices. Muffled voices could be heard through the walls of three of the interviews, and in one interview, there was the constant ‘ping, ping’ of an elevator door opening and closing. In another interview an ‘outside’ physician bounded into the room without knocking, in order to obtain pharmaceutical samples from a file drawer. Perhaps the interruption could be explained by the fact that the interview was taking place in a ‘borrowed’ office of somebody who was known to be away at that time? The home office spaces were private, without interruption or noise other than the telephones ringing. There were offers of tea in two home office settings, one accepted, one declined. Regardless of the location of the interview in either workplace office or home office, the healthcare professionals wore comfortable office attire.

There was no information obtained from the visual cues that would augment the content of the interviews. Other than the ‘outside’ physician bounding into the one interview, I did not observe a healthcare professional interacting with either another healthcare professional or a person with Parkinson’s during the course of the interviews.

4.7 Findings: three overlapping primary themes

Three overlapping primary themes emerged from the interviews with the healthcare professionals. The first primary theme was that Parkinson’s is a difficult and complex disorder. Parkinson’s is multifaceted, meaning it can involve a complexity of health and living challenges. As the physiotherapist stated: “It’s probably one of the hardest (health) conditions.” The general practitioner and the social worker both stated that there were no particular problems in the healthcare of people with Parkinson’s, rather that the problems were associated with the complexity of the disorder itself.

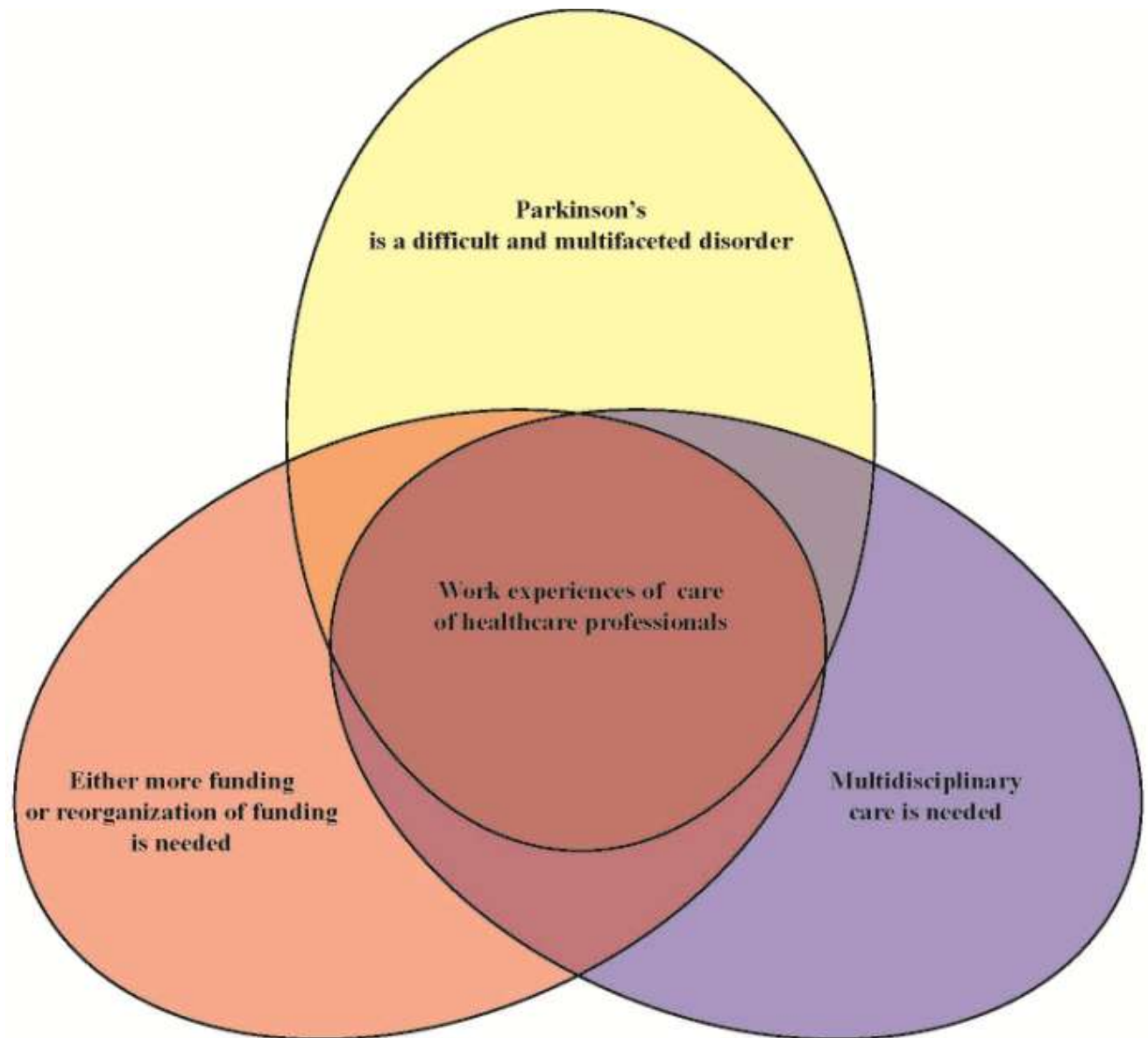
Directly related to the complexity of the disorder, the second primary theme to emerge was that a multidisciplinary team approach by healthcare professionals was needed for optimal quality of life for people with Parkinson’s. The essence of the work experiences of healthcare professionals of people with Parkinson’s was that within their individual area of specialty the healthcare professionals were able to provide good care, albeit with limited time, but that people with Parkinson’s required multidisciplinary care for optimal quality of life. In repeatedly recognizing this, the neurologist stated: “I hesitate to say multidisciplinary once again, but ... ”

The third primary theme to emerge from the interviews complemented the first two themes in that any changes to be made to the work experiences of care of healthcare

professionals of people with Parkinson's required funding. Other than the general practitioner, the healthcare professionals repeatedly referred to the need for more funding, or a different organization of funding, in order to improve work experiences of care.

Although the work experiences of care of the healthcare professionals were far more complex than can be illustrated in a simple diagram, Figure 5 offers a visual representation of the themes that emerged from the interviews. These three primary themes were not separate issues, rather they were overlapping issues of one big issue, namely the work experiences of care of healthcare professionals of people with Parkinson's. These work experiences were represented by the central space in the diagram. The interviews revealed that the healthcare professionals considered the disorder of Parkinson's to be complex and to require complex healthcare in the form of a multidisciplinary team which in turn required funding, or a reorganization of funding, in order to support it.

Figure 5: The Three Primary Themes of the Inquiry



Credit: Christina Bernadette Gray

4.8 Introduction to analysis of interviews, literature review and personal reflections

The issues raised in this inquiry are examined in light of the interviews, the literature review, and personal reflections. First will be a discussion of the three primary themes, followed by a discussion of the theoretical construct of care, followed by a discussion of the social, economic and cultural contexts as viewed by the healthcare professionals.

4.9 Analysis within three primary themes

The first theme of the inquiry was that Parkinson's is a difficult and multifaceted disorder. Words used in the interviews to describe Parkinson's included: 'incurable', 'progressive', 'tragic', 'difficult', 'sad', 'devastating', 'frustrating', and 'not always easy.' These words revealed the emotion and complexity of dealing with Parkinson's. A review of the literature supported the complexity of the disorder. Parkinson's is a multifaceted neurological disorder which people may live with for thirty years or longer (*Taking charge: a guide to living with Parkinson's*, 2008). There is no cure, with treatment focused on limiting symptoms, increasing function, and delaying progression (Chrischilles, Rubenstein, Voelker, Wallace & Rodnitzky, 2002). This first primary theme is of significance because the difficulties and complexities of Parkinson's have now been described and explored by the healthcare professionals themselves. The inquiry illustrated the challenges of Parkinson's for the healthcare professionals, as opposed to the challenges of Parkinson's for people with Parkinson's.

It would take little reflection on my part to agree with the descriptions of Parkinson's. In the interviews I was surprised each time a healthcare professional

discussed the difficulty of the disorder of Parkinson's, in addition to the difficulty in dealing with it professionally. I knew that my family had been challenged by Parkinson's but I was surprised to learn that the healthcare professionals were also challenged by Parkinson's. For me, the healthcare professionals' observation of the disorder of Parkinson's was an (unintentional) acknowledgement of my ongoing time and effort toward the care of people with Parkinson's around me.

The second theme to emerge from the inquiry was that due to the complexity of health needs of people with Parkinson's, a multidisciplinary team approach by healthcare professionals was needed. The healthcare professionals working within the healthcare system seemed to be recognizing that the model of healthcare delivery needed changing. The neurologist said: "I just think these things (social worker, physiotherapist, speech therapist, etc.) are a necessary part of the care. I don't see them as a luxury. I think without that ... you cannot possibly provide the optimal level of care." The gastroenterologist viewed ideal care as: "ready access in a coordinated fashion for these different specialist groups to be able to communicate together and coordinate the care of an individual patient." The nurse outlined a multidisciplinary centre as follows:

The first front of the ideal is ... to have a multidisciplinary centre where people can get this 'whole person' care. That they could come to this one place where they would be able to access information, and education, and support for themselves and their family, in a cohesive way where people talk to each other. ... So that would be the ideal in that place.

A multidisciplinary approach recognized the complexity of the disorder and the benefits of allied healthcare professionals in the management of the disorder. This represented a departure from the traditional model of healthcare delivery in British Columbia where the majority of people with Parkinson's are cared for by a primary care

physician and a neurologist, without benefit of allied healthcare professionals. It appeared from the interviews that the healthcare professionals had a view of a multidisciplinary team as the comprehensive model of care and treatment for people with Parkinson's, with the exception of the general practitioner who suggested the simpler idea of a team comprised of only a general practitioner and a neurologist.

In the literature review the different roles of the physicians and the allied healthcare professionals were outlined. The physician's role was to treat symptoms with medication and the allied healthcare professional's role was to minimize the impact of the disorder through improving participation in everyday activities (van der Marck *et al*, 2009). These different roles were attributed to the underlying working mechanisms of the brain; with the physician attempting to correct brain dysfunction through medication or surgery, and the allied healthcare professionals trying to engage alternate brain circuitries through different therapies. The literature review also revealed that practical clinical guidelines for allied healthcare professionals were already available in the Netherlands and will be available in the U.K. in 2011. In British Columbia a 2009 survey (Parkinson Society British Columbia Membership Survey, 2009) of 520 people with Parkinson's and their caregivers showed that between 10-20%, of people with Parkinson's were seeing allied healthcare professionals, specifically a physiotherapist, massage therapist, dietitian, speech and language therapist or occupational therapist. Clearly there was interest expressed by healthcare professionals in providing multidisciplinary care, and by people with Parkinson's in obtaining multidisciplinary care.

Although with my background interest and experience with Parkinson's I had seen a need for multidisciplinary care for optimal care for people with Parkinson's, I was

most surprised to learn that the healthcare professionals thought this was needed. I had assumed that healthcare professionals did not see a need for multidisciplinary care as there was scant reference to its availability or efficacy within the healthcare experiences of my family. In reflecting on this I now realize that healthcare professionals have to work within a healthcare system *as it is*, which should not be interpreted to mean that they necessarily agree with how it is. In fact this inquiry shows quite the opposite. In undertaking this inquiry it was after I completed the interviews that I added the section on multidisciplinary care to the literature review.

The third theme to emerge from the inquiry was that any change in the healthcare system required funding, or at the very least, a reorganization of present funding. Five of the six healthcare professionals felt that Parkinson's care required some change in funding, with the exception being the general practitioner.

The neurologist and the gastroenterologist offered suggestions for a reorganization of present funding. Both sought an alternate funding plan to allow multidisciplinary care. The neurologist urged a policy in which a physician was not economically disadvantaged for caring for someone with a chronic disease, and the gastroenterologist urged a policy toward greater reward for the primary care physician in a central co-ordinating role in the management of complex care. The neurologist saw a need for restructuring the healthcare system in terms of payment to healthcare professionals, and suggested an 'envelope' or salary payment. The neurologist observed that funding was not provided for allied healthcare professionals by either the university or the health regions and commented: "Yah, I find that a little bit odd."

Better utilization of healthcare professionals was suggested by the neurologist who understood the limitations of medical therapy and appreciated the counselling expertise of the social worker:

Literally the first day the social worker was here I realized that there's so much more there (counselling work to be done) and you're (the neurologist) not getting at it. Now there's a limit to what you can do, you can't be all things to all people but if there are huge problems there, then you should be trying to address them. And of course you won't if all you do is hand out more drugs. Not only is it incomplete care, but it won't work.

The expertise of the social worker was evident in response to the following question:

“What strengths do you see in your workplace experiences of care within the system? In other words in your personal involvement with people with Parkinson's what are you best able to do well?”

I think that what I personally are best able to do, is that I'm really bringing to my work with people, many years of experience in social work, in healthcare, in community, in all of those areas, that allow me to have a perspective that, of their situation, in a very wide open systemic looking at all of the things that are going on in their life, and all of the things that are affecting it, and help them to, well if not identify what their issues, help them to identify what the issues may be, but help them to come to some solutions, or help them to problem solve that kind of thing. Supportive counselling is probably the thing that I do the most and I think I do it well.

This example shows that better utilization of healthcare professionals could result in better care for people with Parkinson's *and* more efficient use of the expertise of healthcare professionals. Allied healthcare professionals are less costly with fewer years of training and lower salaries than physicians. “Primary care should shift from small doctors' offices to clinics where it is delivered by teams in which nurses and other qualified personnel do more of the work” (Kent, 2010, A19). However there is still debate about whether allied healthcare professionals or a solitary physician would reduce

costs, and also which would produce better outcomes with better promotion of good health (Nijkraake *et al*, 2007).

In recognizing the arbitrariness of funding in healthcare, the physiotherapist said: “I always have felt for a long time in healthcare that they do have money for the things they want to do.” Both the nurse and the physiotherapist saw a lack of resources, with the nurse referring specifically to a lack of staff resources, as preventing ideal care from happening in the workplace. Revealing that the lack of funding in the healthcare system was well recognized, the nurse remarked: “Part of it is money, of course we all know that.” The physiotherapist observed: “But we shouldn’t let that (the lack of resources) hold us back (from trying to arrange for more funding), because if there is a need there is a need.” The nurse rallied: “Let’s problem solve guys. We don’t have any more staff or money. Is there a way that we can, as a group, come up with another way we can accomplish this?” Unlike the surprises in the first two primary themes of the complexity of Parkinson’s and the need for multidisciplinary care, there were no surprises here in the primary theme of there being a need for further funding and/or a reorganization of healthcare around funding.

These three primary themes were not separate issues, rather it was evident from the interviews, the literature review and personal reflections, that they were one big issue. In describing the complexity of Parkinson’s, and the need and organization for multidisciplinary care, the healthcare professionals questioned the current funding approach of the healthcare system. This was a noteworthy finding of this inquiry.

4.10 Analysis within the theoretical construct of care

The theoretical construct of care served to help in understanding work experiences of care of healthcare professionals of people with Parkinson's. In this inquiry the definition of care was outlined to each healthcare professional at the start of the interview as the professional interaction encompassing both technical care and caring for a person in a caring relationship (Lashley *et al*, 1994).

The book *Being Called to Care* (Lashley *et al*, 1994) was about responding to the call to care in nursing, although the subject of being called to care could apply to any healthcare professional. The call to care included being authentic and acknowledging vulnerabilities, and living within or reforming the structure within which care and being develop. This call to care was evident in the interviews with the nurse, the social worker, and the physiotherapist. The nurse said: "So I've just, I've always been drawn to illness, and to the impact on the bigger family.... I've always been sort of interested in the ripple effect." The social worker said: "You know, my interest, certainly has always been a geriatric slant ... You know, what we think is for the most part geriatric, but it's not. It's what drew me. It would have been what drew me to it." The physiotherapist said: "I would say that culture of helping and caring from my early days would have shaped to a large extent why I became ... a physiotherapist." These three healthcare professionals were not asked directly about their reasons for becoming healthcare professionals, rather these responses came in response to other questions.

Two healthcare professionals shared examples of gaining new understanding of their work experiences of care during the interview process. "Engaging in reflective dialogue may enhance participants' self-awareness and understanding and may enable

participants to envision new possibilities for caring for the elderly” (Lashley *et al*, 1994, p. 100). Outlining the importance of education for healthcare professionals, the nurse came up with the practical idea of attaching Parkinson’s fact sheets to the medical charts of people with Parkinson’s when they were in the hospital. This was in response to a situation where the nurse observed nursing staff simply did not have adequate knowledge of Parkinson’s, nor did the staff appear to care about their lack of knowledge. These two concerns comprise the technical and caring components of the definition of care used for this inquiry. After one week of self-described worried contemplation about producing a metaphor for the interview the social worker was evidently excited to arrive at a metaphor for a person with Parkinson’s as an orchestra conductor, being in charge of his or her life, Parkinson’s, and the healthcare professionals. At the time of the interviews I sensed that gaining these new understandings of their work experiences of care was satisfying for both the nurse and the social worker.

Concern for the whole person was apparent in multiple observations made by the nurse. In her caring the nurse looked at the whole person and sought a policy that addressed uniformly across the healthcare system, the ‘whole person.’ “So my view and interest in Parkinson’s has always been to the whole picture, the whole person in Parkinson’s, and also the impact on the family.” This care for the whole person included better accessibility to healthcare professionals and better education on how to manage Parkinson’s. The nurse continued:

And very often people on the outside, healthcare professionals too, think they know what the person needs and they forget to ask. The person themselves has a whole different view of what they feel they need in the circumstance so that is a big coaching component for me, in *asking*, honouring people’s right to choose, what’s important as opposed to being told, which the healthcare professionals often do.

The difference between technical care and a caring relationship was seen by the nurse in the comment: “They (healthcare professionals) are trained to fix, they’re trained to fix the problem, as opposed to see the person. It’s a different, a different energy completely when you connect to somebody that way.” Unacceptable care as defined by the nurse was: “I think it’s disregard for the humanity, their humanity, which is like what I was saying, they’re just not seeing them as a whole person.” It would appear that the nurse understands that caring and being are the core to knowing and doing as discussed in the book *Being Called to Care*.

In her books, *Caring: A Feminine Approach to Ethics and Moral Education* and *Starting at Home: Caring and Social Policy*, Nel Noddings argued for a relationally based ‘ethics of care’ with caring as a foundation. Noddings’ theory of care supported relationships, interconnectedness and caring for others. A caring relationship between all six healthcare professionals and people with Parkinson’s was evidenced in the interviews when asked what they personally enjoyed the most in their work experiences of care. The neurologist remarked: “I enjoy the patient interaction. I don’t enjoy it 100%, but I enjoy it and I wouldn’t give it up.” The social worker remarked: “I really do enjoy almost everything about my job. You know I enjoy the people, of course you can have difficult patients, but for the most part the people who come here, want to be coming here.” The physiotherapist remarked: “I’ve always enjoyed the interaction with people and caring for them and getting them to be better, you know, to reach their optimum capacity.” The physiotherapist centered on feelings of care, and the importance of humour in relationship with people with Parkinson’s with the comment: “I think I care about people a lot, and how they’re functioning.... I didn’t say earlier, that I have a sense of humour, I

think that helps in treating Parkinson's." Even when the general practitioner stated he did not enjoy working with people with Parkinson's there was a sense of care expressed for people with Parkinson's.

Noddings referred to reciprocity and a relationship needing to work both ways. She stated that a caring relationship without reciprocity resulted in "disillusionment, fatigue, and eventual burnout" for people in any role such as family members, teachers, and healthcare professionals (Noddings, 2002, p 19). This sense of fatigue was shown by both the neurologist and the gastroenterologist in the comments: "The truth is some people may not do well, some people may place pretty extensive demands on one and it's kind of wearying. It can be quite exhausting and I think sometimes people with Parkinson's don't realize ... what a toll they take on the lives of those trying to care for them" and "It's a very draining condition; it's a draining condition for the practitioners, it's draining for the family, it's draining for colleagues and friends and workmates."

Noddings' theory of reciprocity and relationship in a caring relationship makes sense in a healthcare setting. However it is interesting to note that although reciprocity and relationship may work well in many relationships of care, when one of the people in a relationship is non-responsive due to poor health, reciprocity comes not from that person, but from the circle of support surrounding that person, such as family members, care home workers, healthcare professionals, and society in general. Without reciprocity from the circle of support surrounding that person, disillusionment and fatigue may result, just as Noddings suggests for person-to-person relationships.

4.11 Analysis within social, economic and cultural contexts

All experiences occur within, and are shaped by, particular social, economic and cultural contexts. The contexts inform the experiences, and the experiences inform about the contexts. “Generally speaking, there has been a tension between treating the accounts of the people being studied as sources of information about themselves and the world in which they live, and treating those accounts as social products whose analysis can tell us something about the socio-cultural processes that generated them” (Hammersley & Atkinson, 2007, p. 97). In this inquiry the healthcare professionals are asked, “*In your opinion what are the significant social, economic and cultural conditions affecting your work experiences of care as a healthcare professional of people with Parkinson’s?*” These contexts as seen by the healthcare professionals inform the work experiences of care, and the work experiences of care inform about the contexts.

In contrast to this, Parkinson’s was seen solely as a medical issue by the neurologist who stated that social, economic and cultural conditions did not affect work experiences of care *per se*, rather it was more the limitations of the healthcare system that affected these work experiences. But by viewing Parkinson’s solely as a medical issue, attention was averted from social, economic, and cultural contexts surrounding the issue. What did the other healthcare professionals have to say about these contexts?

The healthcare professionals offered various responses to the question of the social context of their work experiences of care. The general practitioner said: “I don’t really see any big problem,” and viewed people with Parkinson’s as being well cared for in public care homes if they were unable to afford healthcare in their homes. The gastroenterologist looked at the impact of social functioning on work and family, and

thought people with Parkinson's had a need for support whether they were young or old. The social worker referred to the United States with its very limited healthcare, and observed: "Canada has a very paternalistic open arms philosophy about taking care of our citizens and so that's a great place to be sick, if you're going to be sick, I think it is a great place to be sick." The physiotherapist pointed out that: "I think we do a pretty poor job at looking after the elderly. Socially I don't think there's enough focus on the quality of care, or the quality of life, I should say really, the quality of life of the elderly." The physiotherapist thought the government was responsible and should be pressured into funding more programs, extended care and assisted living.

Responses about the social context of work experiences of care reflected the values of the healthcare professionals. Interest was expressed in supporting people with Parkinson's with both quality of care and quality of life from young to old, at home and in the care home. This fits with a U.K. slogan for the healthcare of people with Parkinson's, 'Whole person, Whole system, For life' (Conference Report, 2005). The healthcare professionals recognized the role and responsibility of the Canadian government in caring for people with Parkinson's through the healthcare system and beyond.

Concerning economic contexts the general practitioner said that there were no economic issues since the \$600 annual medication cost was covered by the government. The gastroenterologist interpreted the question in terms of physician practice management efficiency for best patient care and said that, as the patients became more complex, the economic reward for the physician became proportionately less than for simple problems. The social worker spoke of being in the United States at an allied

healthcare conference; “Everything is about money, and the patients providing the money. It wasn’t even so much about the resources that are available.” The physiotherapist spoke of there being fewer constraints around economics in the old days:

Now when you talk about healthcare, you talk about money, whereas in those days you talked about healthcare as healthcare, and how best healthcare could work. There’s been kind of a big swing ... I’ve come from a background of providing the best possible healthcare from the point of view of well, efficiency, I mean we had to be efficient, but compassionate and caring, and more I think, patient focused care, and so I would say that really shaped me, and now I get frustrated by, ‘Well, there isn’t the money.’

For the physiotherapist, ideal economic conditions included funding for education for healthcare professionals and people with Parkinson’s.

These responses around the economic contexts of work experiences of care showed the healthcare professionals recognizing the dependency of healthcare on economics; the government provided the cost of medication, and reorganization for complex care that was deemed necessary for people with Parkinson’s would require a different payment structure. With the focus on economics, comparisons were made to another jurisdiction and another time. Firstly to the United States where, “Everything is about money, and the patients providing money,” and secondly to the good old days when healthcare was about healthcare, not money. As for the \$600 per year cost of medications estimated by the general practitioner, this was disputed in a recent study of the *monthly* costs of Parkinson’s medications before Pharmacare and/or insurance payments as being: \$0 (6%), \$1-\$100 (18.5%), \$100-\$200 (18.1%), \$200-\$300 (24.5%), \$300-\$400 (9.3%), \$400-\$500 (6.9%), \$500-\$600 (6.9%); and the monthly costs of medications after Pharmacare and/or insurance payments showed costs as being: \$0

(20.8%), \$1-\$100 (49.1%), \$100-\$200 (15.5%), and \$200-\$300 (8.4%) (Parkinson Society British Columbia Membership Survey, 2009).

In discussing cultural contexts of their work experiences of care the healthcare professionals focused on the differences in cultural beliefs surrounding healthcare of different cultural groups. The general practitioner observed certain cultures delayed getting treatment. The gastroenterologist spoke of there being many cultural groups in Canada and particularly Vancouver, noting that cultural differences posed challenges for healthcare professionals in terms of understanding how the families saw their own role in providing care. Language was cited as another concern. The gastroenterologist thought that ideally, support needed to be determined for groups that did not support their own people when they had chronic illness. The nurse thought cultural context was an interesting issue, noting a need to provide educational materials in different languages. The physiotherapist tied culture in with care with the statement: “I was thinking about the cultural contexts and I was thinking surely we have a culture of caring and helping people.”

Responses about cultural contexts revealed that the healthcare professionals recognized multiple cultures within society and the varying roles of the healthcare professionals in caring for people from multiple cultures. In discussing the cultural contexts of work experiences of care the healthcare professionals revealed a culture of inclusion and collective responsibility, demonstrating compassion for people with Parkinson’s and the multiple cultures they lived within.

As stated previously, *care* was defined in this inquiry as both technical care and caring for a person in a concerned way. Looking at the cultural context it became evident

that healthcare professionals cared about people with Parkinson's in a caring relationship, not just in a technical sense. The healthcare professionals recognized multiple cultures within Canada, including "a culture of caring and helping people."

This analysis of work experiences of care of healthcare professionals within the social, economic and cultural contexts revealed that there was much more to understanding the work experiences of care than a primary care physician and specialist dipping into a medicine chest.

4.12 Multidisciplinary care model – description

A review of the literature, the interview responses from the healthcare professionals, and personal reflections led to the construction of the following model for healthcare of people with Parkinson's. The purpose of such a model would be to maintain the highest level of health for people with Parkinson's in order that they remain active members of society for as long as possible, with the additional purpose of reducing healthcare expenses for the individual and for society.

This model should support people with Parkinson's from initial assessment of Parkinson's through to end-of-life, in other words, 'Whole person, Whole system, For life' (Conference Report, 2005). A multidisciplinary model should be centered on whole person care with its focus on both treatment and healing. "While the neurologist determines disease severity and optimizes medical treatment to reduce symptoms, allied health therapists aim to minimize the impact of the disease process and improve the patient's participation in everyday activities" (van der Marck *et al*, 2009, p. S210). Due to the complexity of Parkinson's, "[a] multidisciplinary team approach, combining

pharmacological and nonpharmacological therapies, thus seems necessary to obtain optimal therapeutic efficacy” (van der Marck *et al*, 2009 p. 221).

A multidisciplinary team could include any of the following professionals: general practitioner, Parkinson’s specific neurologist, neurosurgeon, psychiatrist, geriatrician, Parkinson’s specific nurse, social worker, physiotherapist, occupational therapist, dietitian, and pharmacist. Elements of teamwork should include: shared goal setting, effective communication and collaboration, and appropriate referrals among the team members (van der Marck *et al*, 2009).

The organization for care should include a central co-ordinator such as a general practitioner who would play a critical role in co-ordinating care among the healthcare professionals by working closely with the person with Parkinson’s as an important member of the team. Integrated care should be tailored toward the needs of each individual. There should be a description of services provided by each healthcare professional so that people with Parkinson’s could better understand these services. People with Parkinson’s should be invited to name their ‘top five’ concerns prior to each office visit, so that the healthcare professionals could be co-ordinated according to the needs of the person with Parkinson’s (van der Marck *et al*, 2009). The caregiver plays a vital role in the life of a person with Parkinson’s and should be included in having their role and needs as a caregiver addressed.

A simplified model should be based around acceptance of multidisciplinary care as an important basis for healthcare for people with Parkinson’s. This model should be centered on improved communication and co-ordination among healthcare professionals in their present individual offices and clinical settings. This communication and co-

ordinated network could be set up in both populated and remote areas of the province. The model in an urban setting would likely be different from a rural setting, with the greater availability of more specialized healthcare professionals.

The preceding is a model of delivery of healthcare services, but the ultimate multidisciplinary model would be a Parkinson's centre where the care could be conveniently located under one roof. Having one centre should lead to cohesion of services and a better possibility for an integrated approach. A Parkinson's centre should be comprised of a Parkinson's specific day health program which could incorporate a range of high quality integrated care tailored to each individual's specific needs. There should be a short-stay 24 hour care residence for short term treatment and respite care. A counselling/medication information hotline should be set up for use by people with Parkinson's and their caregivers, as well as healthcare professionals. The centre would attract people from throughout British Columbia and should become a resource for the promotion of wellness in Parkinson's for the province, and possibly beyond.

The care of people with Parkinson's could benefit from the experiences of care of chronic diseases such as HIV/AIDS. The Dr. Peter Centre in Vancouver which addresses the needs of the HIV/AIDS population and which is supported by the government, has both a day program and a residential program, something suggested by a healthcare professional in this inquiry for the care of people with Parkinson's. In discussing the separate B.C. Centre for Excellence in HIV/AIDS, Dr. Julio Montaner states, "This is not just about HIV. This is about a model for chronic care that should be the prototype that we're trying to implement ... We're not monitoring our outcomes (the effectiveness of doctors and treatments); so any company, anyone, can make a claim and

you're obliged to honour it because you have no data." (Renshaw, 2007, p. 30) Montaner provides the following operating principles for a medical operation:

- Aggressively monitoring health outcomes
- Establishing an open feedback loop between the centre and its patients to promote continuous improvement; and
- Using an arm's length group to test the integrity of the centre's data, the value of its treatments and their cost effectiveness (Renshaw, 2007, p. 30)

4.13 Multidisciplinary care model - critique

The interviews, the literature review and personal reflections all support multidisciplinary care for people with Parkinson's. Following is a critique of multidisciplinary care outlining both its advantages and disadvantages.

There are certainly advantages of multidisciplinary care for people with Parkinson's. From studies undertaken within the last ten years it appears that multidisciplinary care leads to an improved quality of life for people with Parkinson's (Nijkrake *et al*, 2007).

There are also advantages of multidisciplinary care in terms of healthcare organization. As symptoms of Parkinson's are variable among different people at different stages of the disorder, not all people require the same care, and a multidisciplinary approach could address this on an individual by individual basis. Collaboration and communication among various healthcare professionals could lead to less wasted inappropriate treatments, more considered selection of appropriate treatments, and better co-ordination between home, community and hospital.

Multidisciplinary care could be a cost-saving measure, with a shift from physician care to multidisciplinary care employing allied healthcare professionals to do

more of the work at lower cost. The increased use of allied healthcare professionals could result in more efficient use of the expertise of the healthcare professionals *and* better care for people with Parkinson's. The example cited in this inquiry was psychosocial issues under the specialized counselling care of a social worker, rather than the higher paid general practitioner or neurologist.

For outlying areas there could be travelling healthcare professionals offering services which do not require full time support in the community. There would be a need to determine the logistical and financial costs of travel expenses for people with Parkinson's versus healthcare professionals. In other words, would it be more efficient to have people with Parkinson's travelling for their healthcare, or have healthcare professionals travelling to the outlying areas?

A Parkinson's specific multidisciplinary care centre would provide a focus and a resource for excellence in Parkinson's care. Clinical care and research could be combined to support one another and raise the level of both. Better communication and co-ordination under one roof could lead to better care for people with Parkinson's.

Alternatively there are disadvantages of multidisciplinary care for people with Parkinson's. These are primarily logistical and financial concerns, both of which have likely prevented multidisciplinary care from being implemented in the past. The delivery of multidisciplinary care is threatened by low patient volumes of people with Parkinson's as well as insufficient expertise of healthcare professionals (van der Marck *et al*, 2009). This could be of particular concern for outlying areas.

The financial costs of multidisciplinary care could be considerable. Would there be savings in employing allied healthcare professionals in place of physicians, or would

multidisciplinary care be more expensive? Would a physiotherapist teaching about the prevention of falls and hips fractures result in lower overall healthcare costs due to prevention? Not every person with Parkinson's needs every service so there is a possibility of overuse of services, which could prove costly.

The cost of a Parkinson's specific multidisciplinary care centre would be extremely high, ultimately in the millions of dollars. The question remains as to whether allied healthcare professionals or a solitary physician reduces costs as well as produces better quality of life for people with Parkinson's (Nijkrake *et al*, 2007). The healthcare cost-effectiveness of multidisciplinary care has yet to be determined (van der Marck *et al*, 2009).

CHAPTER 5: DISCUSSION: SO WHERE DO WE GO FROM HERE?

5.1 Introduction

Chapter V: Discussion: So Where Do We Go From Here? begins with a summary that reflects new understanding of the work experiences of care of healthcare professionals of people with Parkinson's. This is followed by a discussion of the inquiry's significance, as well as implications and recommendations for further inquiry. The chapter ends with a conclusion.

5.2 Summary

The healthcare professionals of this inquiry included a general practitioner, a Parkinson's specific neurologist, a gastroenterologist, a nurse, a social worker and a physiotherapist. Describing present work experiences of care and prescribing ideal work experiences of care resulted in these six healthcare professionals considering better work experiences of care. As American educational philosopher, social activist and author Maxine Greene once stated: "It is only when we have in mind a better state of things that we are likely to pay heed to what is lacking in the now and act to surpass it somehow, to get it right" (Greene, 1984, p. 13, in Lashley, 1994, p. 58).

In discussing care of people with Parkinson's, three overlapping primary themes emerged from the interviews. These themes were subsequently verified by both the literature review and personal reflections. The themes were as follows. Firstly, Parkinson's is a difficult, complex and multifaceted disorder; secondly, due to the complexity of the disorder, a multidisciplinary team approach by healthcare professionals

is needed; and thirdly, more funding or a change in organization of funding, is needed in order to support this model of healthcare. In describing both the need and the system for multidisciplinary care, the healthcare professionals questioned the current funding approach for the healthcare system. This was a noteworthy finding of this inquiry.

The complexity of Parkinson's was apparent in the comments of the healthcare professionals in the inquiry. The general practitioner showed frustration in the statement: "I really don't enjoy working with Parkinson's patients because it's a tragic disease and it is a difficult disease to deal with. It's sad to watch people go downhill. It's a very devastating disease and it's a frustrating disease to try to manage." In looking at the complexity of Parkinson's the neurologist said: "So there are big psychosocial issues partly because of the behavioural and cognitive impact of the illness." Likewise the nurse referred to the complexity of the disorder, observing the breadth of care that was missing: "So I think it's true neglect of the whole psychosocial aspect of a chronic disease." In discussing the need for a healthcare policy that supported the complexity of Parkinson's, the gastroenterologist said: "The neurologist may be helpful for the diagnosis, they may be helpful for looking for other differential diagnoses, and they may be helpful for coordinating medications, but clearly patients move beyond, their problems move beyond the medications and they move beyond the need, the mandate of the neurologist."

With the exception of the general practitioner, the healthcare professionals observed that people with Parkinson's required multidisciplinary care for optimal quality of life. But even the general practitioner showed an interest in a team approach with the statement: "Well I think the ideal healthcare policy is to have a team approach and for people to be aware of, to have a system in place to assess function, and a system that is

communicated through the healthcare team ...” In repeatedly recognizing the need for multidisciplinary care, the neurologist said: “I hesitate to say multidisciplinary care once again, but ...” and “I think without that (social worker, physiotherapist, speech therapist, etc.) ... you cannot possibly provide the optimal level of care.” The gastroenterologist opined: “I think ideal care would be a readily available combination of healthcare practitioners to co-ordinate and consult on the different aspects of care to try to reduce the fragmentation of care.” The nurse outlined ideal care as: “... a multidisciplinary centre where people can get this ‘whole person’ care. That they could come to this one place where they would be able to access information, and education, and support for themselves and their family, in a cohesive way where people talk to each other ...” The social worker, with consideration toward a multidisciplinary setting, stated: “We *are* doing our, the best that we can do, we *are* providing ideal under the circumstances that we have.” The physiotherapist sighted several needs: “For people living with Parkinson’s, giving them optimum conditions so that they can remain at the peak of their physical performance, plus assistance with the non-motor component of their disease if it’s present. So always the team support, easy access, no waiting lists, and of course a lot of support for the caregiver.” In citing multidisciplinary care as the ideal for people with Parkinson’s the healthcare professionals showed recognition of the complexity of Parkinson’s as a multifaceted disorder.

A summary critique of multidisciplinary care revealed an advantage of multidisciplinary care being an improved quality of life for people with Parkinson’s. Other advantages included: co-ordination of services; more considered selection of appropriate treatments; and better communication and collaboration among healthcare

professionals as well as among home, community and hospital. The disadvantages of multidisciplinary care included: the difficulties of logistics for implementing multidisciplinary care; and the question of unknown financial costs which could be considerable, particularly if there was a dedicated Parkinson's care centre.

In this inquiry, other than the general practitioner, the healthcare professionals saw a need for more funds for the healthcare of people with Parkinson's. The neurologist, the gastroenterologist, and the nurse each spoke about the need to rearrange the present funding situation, rather than just obtaining more funding, whereas the social worker and the physiotherapist cited more specific funding needs within the healthcare system. The neurologist saw the present system that was focused on acute care rather than chronic care and said: "It's not the amount of money that's being spent probably that's the problem, it's the way it's distributed. So it needs in my view a major restructuring, but I don't pretend to be an expert on that." In the present system healthcare professionals are getting paid more for seeing more patients, rather than for spending more time with patients. In other words, volume is rewarded over quality. The neurologist offered an 'envelope' or salary system as a solution. The gastroenterologist stated:

... I think encouragement on an individual level for primary care physicians to become involved and to encourage them and reward them to become involved in these complex cases is very important because I think the more complex care becomes and the more different facets of care that are being co-ordinated, the more difficult it is to keep everything under control.

The social worker realized the constant threat of the lack of funds and stated: "Well I think the significant healthcare policies are really around funding and healthcare. ... as the funding remains threatened at all times, I think that that's what affects my work and what I can do for people. There's no surprise there I think." Looking more precisely than

restructuring the funding of the healthcare system, the social worker cited the need for funds for medication support, equipment support, and homemaker subsidies; and the physiotherapist cited the need for funds for educational programs for healthcare professionals, exercise programs, and respite programs. Reminiscing about the good old days in healthcare, the physiotherapist remembered back to when talk around healthcare was about healthcare and how it worked best, not about money.

In summary, the six healthcare professionals of this inquiry, in recognizing a need for multidisciplinary care for people with Parkinson's, at the same time questioned the current funding approach for the healthcare system. The challenge, as the neurologist stated, was in being able to offer proof, including controlled studies with outcomes research, to the government to show that multidisciplinary care was indeed the most effective, best quality care delivered in the most efficient way possible for people with Parkinson's.

There were both strengths and limitations in this inquiry. The strengths of the inquiry included the maximum variation of the participants with the healthcare professionals coming from six different healthcare professions, and the timeliness of the inquiry with both increasing numbers of people with Parkinson's and the present organizational and financial challenges of the healthcare system. The limitations of the inquiry included the lack of breadth and depth of the empirical material with only a single interview of only six participants all located within one geographical area.

5.3 Overall significance

Healthcare professionals are at the frontline intersection of the nation's healthcare system and the healthcare of people with Parkinson's. With increasing numbers of people with Parkinson's, and finite healthcare dollars, this inquiry is of particular significance. In discussing work experiences of care, healthcare professionals from six different professions revealed concerns. The three primary themes of the inquiry are of significance as the difficulties and complexities of Parkinson's have now been described and explored from the point of view of the healthcare professionals themselves. The need for changes to work experiences of care of these healthcare professionals was supported by both the literature review and personal reflections, in addition to the interviews.

The healthcare professionals of this inquiry discussed the need for education for healthcare professionals, calling for education on both expertise and management of Parkinson's, as well as education on the existence of different services that are available. The nurse and the physiotherapist stated respectively: "There needs to be better education across the whole range of healthcare of how to manage Parkinson's patients" and "... (W)e would need enough money to fund programs in terms of courses for healthcare professionals to have more expertise in the management (of Parkinson's), educating G.P.s ... or physios and O.T.s ..." The physiotherapist also cited a need to educate general practitioners about the existence of the Movement Disorders Clinic at U.B.C.

In describing ideal care for people with Parkinson's the nurse describes: "The first front of ideal is ... to have a multidisciplinary centre where people can get this 'whole person' care" and "So my view and interest in Parkinson's has always been to the

whole picture, the whole person in Parkinson's, and also the impact on the family.” Education could include discussion of this ‘whole person’ approach where achieving health depends on collaboration between the physician treating symptoms with medication or surgery, and the allied healthcare professional providing support for “some kind of change, action, insight, or redirection on the part of this person” (Barbour, 1995, p. 33) with a focus on minimizing impact of the disorder by improving participation in everyday activities. Education for healthcare professionals could include the different roles of the physician and the allied healthcare professional, and how these roles related to the underlying mechanisms of the brain, as revealed in the literature (van der Marck *et al*, 2009). Allied healthcare professionals could include any of the following: nurse, physiotherapist, occupational therapist, speech and language therapist, exercise specialist, dietitian, and pharmacist. Education for healthcare professionals could also include wellness, prevention, and self-care, topics of much interest in public pedagogy these days.

This inquiry also opened educational avenues for involving healthcare administrators and healthcare service providers, as well as people with Parkinson's. Education for healthcare administrators could include changes in healthcare policy to best support the multidisciplinary care needs of people with Parkinson's. Education for healthcare service providers in the community could include an outline of the range of services that are available to support people with Parkinson's. Education for people with Parkinson's could include a better understanding of both general care and multidisciplinary care in Parkinson's and methods for best navigating the healthcare system. Education could also include the benefits of self-care and self-management.

With a striking concordance in views among the healthcare professionals toward multidisciplinary care, this inquiry revealed that multidisciplinary care could be the educational focus toward better management of Parkinson's. Healthcare professionals, healthcare administrators, healthcare service providers, as well as people with Parkinson's, could be educated about the better outcomes for people with Parkinson's when under multidisciplinary care, as well as the differing costs of multidisciplinary care. Ultimately education should be about the best support possible for people with Parkinson's with a goal of optimal quality of life.

The inquiry showed support for healthcare policy and continued study into multidisciplinary care in terms of health and wellness benefits for people with Parkinson's and cost benefits to the healthcare system. Healthcare policies that minimize the impact of the progression of Parkinson's while maximizing quality of life should help to ensure optimal use of limited resources. Healthcare professionals, by being involved in this inquiry, have helped to support possibilities for change in their work experiences of care for people with Parkinson's, future healthcare policy and future study. In discussing multidisciplinary care, healthcare professionals have come up with a solution that could possibly improve their work experiences of care, improve quality of life for people with Parkinson's, and at the same time reduce costs to the healthcare system.

5.4 Implications for a specific next step

Specifically within British Columbia there are implications for a possible next step toward a collective understanding about Parkinson's among healthcare professionals and people with Parkinson's. Throughout 2009 there were six *Regional Conversations on Parkinson's* being held around the province between Parkinson Society British Columbia

and people with Parkinson's, with the purpose of a greater understanding around Parkinson's healthcare. This was followed up with a 36 question survey which 520 people with Parkinson's and their caregivers completed. With the information gathered from the conversations and the survey, as well as the six healthcare professionals of this inquiry, it would be interesting if there could be a collaborative partnership involving healthcare professionals and people with Parkinson's to develop a better understanding of the present healthcare system and a shared vision for the future. This would be a case of combining the knowledge and experience of healthcare professionals with the knowledge and experience of people with Parkinson's. There is a need to work collaboratively, grounded in a shared commitment to support the best possible Parkinson's healthcare.

A collaborative partnership centered on exchanging experiences and idealizing the future, could act as a springboard for change in work experiences of care of healthcare professionals of people with Parkinson's, ultimately affecting both the healthcare professionals and people with Parkinson's. More broadly, a collaborative partnership could have implications for approaching government to support changes in healthcare policy; and approaching private agencies for funding for changes in the healthcare of people with Parkinson's, as well as for further study.

5.5 Recommendations for further study

Future inquiry involving greater numbers of healthcare professionals in British Columbia would develop a more complete understanding of the work experiences of healthcare professionals of people with Parkinson's. Longer and more detailed empirical

material would add depth to the analysis. Other provinces and territories of Canada could be studied for comparison and collaboration of experiences.

The models for healthcare as suggested by the healthcare professionals of this inquiry provide important information and could be investigated further, with a view to how they could support healthcare of people with Parkinson's. These include the Booth Gardner Parkinson's Care Center in Seattle, the Nephrology Unit at V.G.H, the Healthy Heart Cardiac Program throughout British Columbia, and the ParkNet physiotherapy scheme in the Netherlands.

This inquiry pointed repeatedly toward multidisciplinary care being needed in the care of people with Parkinson's. It is important to acquire and develop more knowledge on multidisciplinary care. The important question that needs to be studied further is whether multidisciplinary care and/or a multidisciplinary centre would make a difference in the quality of life of people with Parkinson's, and whether it would be cost effective. In the Netherlands there is presently a large cluster controlled trial, the IMPACT study, to evaluate the effectiveness and costs of integrated, multidisciplinary care in Parkinson's as compared to monodisciplinary care (van derMarck, 2009). The multidisciplinary care question could be put forth to the Michael J. Fox Foundation for further study. The purpose of the Michael J. Fox Foundation is for research toward better diagnosis and treatment of Parkinson's as well as toward finding a cure.

The N.I.C.E. (The National Institute for Health and Clinical Excellence, in the United Kingdom) Guidelines on Parkinson's would also be of interest in the study of multidisciplinary care. These Parkinson's guidelines are expected in June 2011. A draft copy of the review includes guidelines for treatment beyond pharmacological and

surgical treatments, including recommendation for Parkinson's specific nursing, physiotherapy and occupational therapy, speech and language therapy, and palliative care. Important further study would include a cost and benefit analysis of these recommendations.

The first-ever epidemiological study on the prevalence and impact of neurological diseases in Canada, as announced by the federal government in 2009, will be a first step toward a better understanding of neurological diseases and their impact on people with Parkinson's, their families, the healthcare system and Canadian society in general. This information will be important toward future healthcare planning and policies. There is also a need for data on the economic and social costs of Parkinson's to British Columbia and to Canada.

Recipients of findings from any further study would be healthcare professionals of people with Parkinson's and other chronic disorders; people with Parkinson's; caregivers; federal and provincial health agencies; health organizations, both Parkinson's and other; Parkinson Society British Columbia; Parkinson Society Canada; and the Neurological Health Charities of Canada.

5.6 Conclusion

Narratives of people with Parkinson's exist in the literature as well as in the public domain. A literature search did not reveal narratives of work experiences of care of healthcare professionals of people with Parkinson's. It would appear that the voices, perspectives and narratives of these healthcare professionals have not been previously recorded. This inquiry then serves as an introduction to narratives of healthcare

professionals, providing an opening for conversation among healthcare professionals, possibly starting with the three primary themes found in the inquiry. With narratives of both people with Parkinson's and healthcare professionals now in existence, people with Parkinson's and healthcare professionals could converse together and produce a collective narrative.

This inquiry has contributed in two ways toward a better understanding of work experiences of care of healthcare professionals of people with Parkinson's. The inquiry has included descriptive writing with descriptive details of these work experiences, and it also has also included theoretical writing in support of theories of care.

Descriptive details of acceptable, unacceptable and ideal care of people with Parkinson's were identified according to six healthcare professionals. Acceptable work experiences of care included: trying to come to some improvement or resolution of Parkinson's problems, optimizing function for as long as possible, and improving quality of life throughout progression of Parkinson's. Unacceptable work experiences of care were variously viewed as: not treating to the best of one's ability; seeing a person with Parkinson's once every 18 months; seeing a person with Parkinson's outside the complex of multidisciplinary care; unneeded suffering and unneeded investigations; healthcare professionals not being educated adequately; treating people with Parkinson's as if they lived in isolation, and not caring for the circle in which they live; not getting to see a Movement Disorder specialist; and being turned down by a general practitioner. Ideal work experiences of care were identified as multidisciplinary care by five of the six healthcare professionals, with empirical material, a literature review and personal reflections to support this view. In composite, ideal care was described by the healthcare

professionals as including: patient focused care, centralizing diagnosis, multidisciplinary care, short and long term respite care, an assessment and rehabilitation program, and paraprofessional centres throughout the province.

The theoretical construct of care served to help in understanding work experiences of care of healthcare professionals of people with Parkinson's. Educator and philosopher Nel Noddings' care theory supported relationships, interconnectedness and caring for others, including reciprocity in relationship. This caring and reciprocity was evidenced in this inquiry in the caring relationships that the healthcare professionals had with people with Parkinson's. A second theory of care outlined in the inquiry was a theory of being called to care based on authenticity, vulnerability and the structure within which caring and being occur (Lashley *et al*, 1994). In this inquiry the six healthcare professionals showed a willingness to being open to authenticity and vulnerability in their discussions of the many challenges of caring for people with Parkinson's.

This inquiry set out to better understand work experiences of care of healthcare professionals of people with Parkinson's. The inquiry could be labelled *action research* as a result of better understanding of experiences leading to recommendations for change (Bogdan & Biklen, 2003). Recommendations for change would be based on the following accomplishments: the inquiry has provided a new understanding of work experiences of care which has helped to make an argument for multidisciplinary care; the inquiry has helped to identify areas in the healthcare system which need to be challenged; the inquiry could work as a catalyst toward starting conversations around Parkinson's healthcare, and getting people involved in better practices; and the inquiry has helped to develop

confidence, with the empirical material supporting multidisciplinary care, which could then lead to strategic planning and the development of an action plan.

In conclusion, this inquiry has led to a better understanding around work experiences of care of healthcare professionals of people with Parkinson's. The inquiry has demonstrated that there is much to be learned from healthcare professionals. In discussing present and ideal work experiences of care the healthcare professionals have defined a model of healthcare that could possibly address their present work experiences of care, improve the quality of life for people with Parkinson's, and question the current funding approach for the healthcare system.

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APPENDICES

Appendix A – Letter of Initial Contact



THE UNIVERSITY OF BRITISH COLUMBIA
Department of Educational Studies

**Descriptions and Prescriptions
Healthcare Professionals Consider Care for People with Parkinson's:
Letter of Initial Contact**

Dear Potential Participant,

October 7th, 2009

I am sending this letter of initial contact to you as you are a healthcare professional of people with Parkinson's. I am a graduate student at U.B.C. and in fulfillment of my Master of Arts degree in the Educational Studies department I am undertaking a thesis study titled ***Descriptions and Prescriptions: Healthcare Professionals Consider Care for People with Parkinson's***. The purpose of this study is to explore, through description, the work experiences of healthcare professionals of people with Parkinson's. The central question of this study will be how healthcare professionals of people with Parkinson's define acceptable, unacceptable and ideal care for people with Parkinson's.

Participants will be interviewed by me in an individually conducted interview of no longer than one hour. The interview will employ an open-ended, semi-structured format, taking the form of a conversation organized around the primary study question. A transcription of the individual interview will be sent to each participant to check for accuracy of recording, with the opportunity to clarify and expand original descriptions and prescriptions in writing, if desired.

I would like to invite you to be part of this study. As a healthcare professional of people with Parkinson's you have a unique perspective on what is happening in healthcare today. Your contributions to this study could lead to improved care for people with Parkinson's in British Columbia. Participation in this study is completely voluntary, with the results of the study being anonymous and confidential.

If you have any questions or concerns about the study, please contact Principal Investigator Dr. Leslie Roman, Associate Professor, Department of Educational Studies at U.B.C. at 604 822 9186.

If you are willing to participate in this study, kindly contact Jane Gray, Graduate Student and Co-Investigator.

Thank you most kindly in advance for considering this invitation.

Sincerely,

Jane Gray
Graduate Student
Educational Studies

Appendix B – Consent Form



THE UNIVERSITY OF BRITISH COLUMBIA Department of Educational Studies

Descriptions and Prescriptions: Healthcare Professionals Consider Care for People with Parkinson's Consent Form

October 7th, 2009

Principal Investigator: Dr. Leslie Roman, Associate Professor, Department of Educational Studies, University of British Columbia 604 822 9186.

Co-Investigator: Jane Gray, Graduate Student, Department of Educational Studies, University of British Columbia. This research is being undertaken in order to fulfill the thesis requirement of a Master of Arts degree.

Purpose:

You are being invited to take part in this study because you are a healthcare professional of people with Parkinson's. The purpose of this study is to explore, through description, the work experiences of care of healthcare professionals of people with Parkinson's. The central question of this study will be to identify what care means to healthcare professionals and how they define acceptable, unacceptable and ideal professional care of people with Parkinson's.

Study Procedures:

Participants will be interviewed by Jane Gray in an individually conducted interview of no longer than one hour. The interview will employ an open-ended, semi-structured format, taking the form of a conversation organized around the primary study question. The interview will be tape-recorded and transcribed by Jane Gray. A transcription of the individual interview will be sent to each participant to check for accuracy of recording, with the opportunity to clarify and expand original descriptions and prescriptions in writing, if desired.

Potential Risks:

In order to eliminate potential risks, Jane Gray will conduct the interview in the privacy of each participant's office; offer an explanation of the research procedures and answer any questions prior to the interview; review the interview questions with the participant prior to the interview; and inform the participant that he/she has the right to stop the interview, decline to discuss anything causing discomfort, and/or withdraw his/her participation from the study at any time without consequence.

Potential Benefits:

Given the descriptive and prescriptive nature of the study, participation will provide participants with an opportunity to voice their opinions and reflect on their workplace experiences of care for people with Parkinson's. The knowledge generated from this study could lead to improved care and services for people with Parkinson's in British Columbia.

Confidentiality:

To protect participant anonymity, each participant will each choose a pseudonym at the start of the interview that will be used throughout the study. Confidentiality of the audio tapes will be maintained through use of this pseudonym. Neither participants, nor place of work, will be identified at any time during the study. To protect the privacy and confidentiality of participants, all data will be stored in a locked filing cabinet and password protected computer accessible only by Jane Gray. Participants will be informed during the consent process that the results of their participation will appear in a written report that will be shared with them if desired, and that will be accessible (in the form of Jane Gray's thesis) through the university library system, and possibly other future publication venues.

Contact for Information About the Study:

If you have any questions or desire further information with respect to this study, please contact Principal Investigator Dr. Leslie Roman at 604 822 9186.

Consent:

Your participation in this study is entirely voluntary and you may refuse to participate, or withdraw from the study, at any time.

Your signature below indicates that you:

- have received a copy of this Consent Form for your own records
- have given your consent to participate in this study.

Participant Signature

Date

Printed Name of Participant

Your signature below indicates that you are interested in the results of the study and would like a copy of the final report mailed or emailed to you.

Participant Signature

Date

2:2

Appendix C – Interview Guiding Questions

Descriptions and Prescriptions: Healthcare Professionals Consider Care for People with Parkinson's Interview Guiding Questions

October 7th, 2009

The purpose of this study is to discover how healthcare professionals of people with Parkinson's define and understand acceptable, unacceptable and ideal professional care. For purposes of this study, 'care' is defined as the professional interaction between healthcare professionals and people with Parkinson's, excluding other aspects of professional experiences such as benefits, professional development, etc. This interaction has two components: physical or therapeutic care (technical care); and care as in caring for a person in a concerned way (in a caring relationship).

Part One: Description of workplace experiences

1. What is your background or connection or interest in being a healthcare professional caring for people with Parkinson's? Also, I would be interested to know if you have any family members, friends or otherwise with Parkinson's if you are willing to share this with me.
2. What are your typical dealings with people with Parkinson's? In other words, describe your role in the care of people with Parkinson's.
3. What do you personally enjoy the most in your work experiences of care as a healthcare professional working with people with Parkinson's?
4. What strengths do you see in your workplace experiences of care? In other words, in your personal involvement with care for people with Parkinson's what are you *best able* to do well, what services do you feel you provide well?
5. What would you say constitutes acceptable care for people with Parkinson's?
6. What do you dislike about your work experiences of care?
7. What limitations of care do you see in your workplace experiences of care?
8. What would you say constitutes unacceptable care for people with Parkinson's?
9. Do you think your descriptions and reflections are representative (as opposed to unique) of your specialty as a healthcare professional of people with Parkinson's?
10. In your opinion what are the significant healthcare policies affecting your work experiences of care as a healthcare professional of people with Parkinson's?
11. In your opinion what are the significant social, economic and cultural conditions affecting your work experiences of care as a healthcare professional of people with Parkinson's?

Part Two: Prescriptions for ideal care in workplace experiences

1. In the context of your work with people with Parkinson's what *one* thing would you most want to change in order to improve your care of people with Parkinson's?
2. In the context of your work with people with Parkinson's how would you define ideal care? Blue sky, optimal, money no object ...
3. What would be ideal in terms of healthcare policy in order to support your conception of ideal care for people with Parkinson's?
4. What would be ideal in terms of broader social, economic and cultural conditions in order to support your conception of ideal care for people with Parkinson's?
5. Are you aware of an ideal model of care for healthcare delivery for people with Parkinson's elsewhere in the world? Describe.
6. What is preventing ideal care from happening in your workplace?
7. Are there ways of overcoming the problems that are preventing ideal care from happening in your workplace, as in are there ways of bringing ideal care about in your workplace?
8. In closing I am wondering if you can imagine a metaphor for either your present workplace experiences of care for people with Parkinson's, or a metaphor for your ideal workplace experiences of care for people with Parkinson's.
9. Is there anything further that you would like to add, either about something that has been discussed, or something else?

Appendix D – Interview Protocol and Practicalities and Guiding Questions Form

Descriptions and Prescriptions: Healthcare Professionals Consider Care for People with Parkinson's Interview Protocol and Practicalities

Purpose of This Study: To discover how healthcare professionals of people with Parkinson's define and understand acceptable, unacceptable and ideal professional care of people with Parkinson's. For purposes of this study, 'care' is defined as the professional interaction between healthcare professionals and people with Parkinson's, excluding other aspects of professional experiences such as benefits, professional development, etc. This interaction has two components: physical or therapeutic care (technical care); and care as in caring for a person in a concerned way (in a caring relationship).

Central Questions:

- 1) What are the present workplace experiences of care of healthcare professionals of people with Parkinson's? (exploration of key issues/needs; *descriptions* and *reflections* of your experiences and your role in the care of people with Parkinson's)
- 2) What do healthcare professionals of people with Parkinson's think ideal care of Parkinson's looks like? (pie in the sky, money no object, optimal) "It is only when we have in mind a better state of things that we are likely to pay heed to what is lacking in the now and act to surpass it somehow, to get it right." Maxine Greene (1984, p. 13). *Towards wide-awakeness: Humanities in the lives of professionals*. In *Literature and medicine: A claim for a discipline*. Proceedings of the Northeastern Ohio Universities College of Medicine's Literature and Medicine Conference.

Would you like to review the questions prior to the interview?

Protocols:

Discuss anonymity and confidentiality of the study; discuss consent form and obtain signature(s) for consent form; study results will appear in a written report that will be shared by mail or email, if desired (2nd signature), and that will be accessible (in the form of Jane Gray's thesis) through the university library system, and possibly other future publication venues; describe mailing transcription and opportunity for corrections/additional reflections by writing; determine pseudonym; explain my note-taking; state length of interview, roughly two halves - Part I and Part II, one hour = four minutes per question; inform participant that he/she has the right to stop the interview, decline to discuss anything causing discomfort, and/or withdraw his/her participation from the study at any time without consequence; enquire if there are any concerns/questions ...

Date and Time of Interview:

Location:

Interviewee (pseudonym):

Professional Position of Interviewee:

Length of Interview:

Part One: Description of present workplace experiences

1. What is your background or connection or interest in being a healthcare professional caring for people with Parkinson's? Also, I would be interested in learning if you know of any people *outside* of your workplace, such as family members, friends or colleagues with Parkinson's, if you are willing to share this with me.

2. Please describe your work experiences of care of people with Parkinson's. In other words, what is your typical day dealing with people with Parkinson's? ... What is your relationship with other healthcare professionals of people with Parkinson's?

3. What do you personally enjoy the most in your work experiences of care as a healthcare professional working with people with Parkinson's?

4. What strengths do you see in your workplace experiences of care within the system? In other words, in your personal involvement with people with Parkinson's what are you *best able* to do well?

5. Within your role are you able to provide what you would consider to be acceptable care for people with Parkinson's?
6. What do you dislike about your work experiences of care for people with Parkinson's? What is the most difficult part of your job?
7. What limitations of care do you see in your workplace experiences of care for people with Parkinson's?
8. What would you say constitutes unacceptable care for people with Parkinson's?
9. Do you think your descriptions and reflections are representative (as opposed to unique) of your specialty as a healthcare professional of people with Parkinson's?
10. In your opinion what are the significant healthcare policies affecting your work experiences of care as a healthcare professional of people with Parkinson's?
11. All experiences occur within, and are shaped by, particular social, economic and cultural contexts. In your opinion what are the significant social, economic and cultural conditions affecting your work experiences of care as a healthcare professional of people with Parkinson's?

Part Two: Prescriptions for ideal care in workplace experiences

1. In the context of your work with people with Parkinson's what *one* thing would you most want to change in order to improve your care of people with Parkinson's?
2. Thinking Big ... In the context of your work with people with Parkinson's how would you define ideal care? Pie in the sky, money no object, optimal ... [*Pie in the sky* is a phrase that means a fanciful notion or ludicrous concept. It was apparently coined by Joe Hill in his song "The Preacher and the Slave" in reference to Christian evangelists' promise of paradise in Heaven after death. "Pie in the sky" was later popularized by televangelist Reverend Ike who preached that you should forget about "pie in the sky by and by" and to look instead within yourself for divine power. ... Wikipedia November 2009]
3. What would be the ideal healthcare policy in order to support your conception of ideal care for people with Parkinson's?
4. What would be ideal social, economic and cultural conditions in order to support your conception of ideal care for people with Parkinson's?
5. Are you aware of an ideal model of care for healthcare delivery for people with Parkinson's elsewhere in the world? Describe.
6. What is preventing ideal care from happening in your workplace?

7. Are there ways of overcoming the problems that are preventing ideal care from happening in your workplace, as in, are there ways of bringing ideal care about in your workplace?
8. In closing I am wondering if you can imagine a metaphor for either your present workplace experiences of care for people with Parkinson's, or a metaphor for your ideal workplace experiences of care for people with Parkinson's.
9. Is there anything further that you would like to add, either about something that has been discussed, or something else?

Example ... focusing on communication and coordination in the care of a person with Parkinson's ... chuck wagon with eight horses, driver controlling eight sets of reins, each horse wants to go its own different way, and yet each horse is critically important to the movement of the chuck wagon; if the horses are not coordinated they would go off in their own directions and destroy the whole chuck wagon, the race, the horses, and all the people who are involved in it. The wagon is the person with Parkinson's being pulled along by their disease. Agree/disagree?

Thank participant for your participation; reassure anonymity and confidentiality of study; describe mailing transcription and opportunity for further additions by writing; offer results of study to be mailed or emailed; ask for concerns ...

Appendix E – Transcription Authority and Further Reflections



THE UNIVERSITY OF BRITISH COLUMBIA
Department of Educational Studies

Descriptions and Prescriptions: Healthcare Professionals Consider Care for People with Parkinson's Transcription Authority and Further Reflections

Whomever
Whomever's Address
December 7th, 2009

Dear Whomever,

Thank you once again for being involved in the study ***Descriptions and Prescriptions: Healthcare Professionals Consider Care for People with Parkinson's***. As a healthcare professional you have a unique perspective on what is happening in healthcare for people with Parkinson's and your input has been of great value and much appreciated.

Enclosed please find the transcription of your interview. As per the instructions given prior to the interview I am sending the transcription to you in order that you may read it for accuracy of transcription. As well, I would encourage you to add any further thoughts or reflections to your responses, if you so desire.

If you find the transcription to be accurate, kindly sign below. If you are interested in adding any further thoughts or reflections please include them on a separate sheet of paper. If you have any concerns or questions please do not hesitate to call me. Enclosed is a stamped envelope for your return(s).

Your signature below indicates that you find the transcription of your interview to be accurate:

Participant Signature

Date

Printed Name of Participant

Kindest regards,

Jane Gray
Graduate Student, Educational Studies

Appendix F – Findings: “Descriptions and Prescriptions”

The findings from the inquiry follow in the form of questions and edited responses. This allows for a first-hand narrative ‘picture’ of each individual healthcare professional in his or her own words, as well as allows the best understanding of each individual healthcare professional’s work experiences of care. Points of particular interest to me have been *italicized* in the edited responses. Three periods represents where a word, phrase, or sentence has been edited for brevity. Although the interviews were transcribed *verbatim*, the transcriptions in this appendix do not include discourse markers such as “Um”, “Umhmm” and “You know.”

Findings: Part One: Descriptions of work experiences of care

“What do you personally enjoy the most in your work experiences of care as a healthcare professional of people with Parkinson’s?”

- General Practitioner ... “I really don’t enjoy working with Parkinson’s patients because it’s a tragic disease and it is a difficult disease to deal with. It’s sad to watch people go downhill. *It’s a very devastating disease and it’s a frustrating disease to try to manage.*”
- Neurologist ... “Well, that’s an interesting question. ... One of the things is that my job does have a lot of variety in it. ... That can be a negative in terms of feeling spread in many different directions and spread thin but it is also stimulating. *I enjoy the patient interaction.* I don’t enjoy it 100%, but I enjoy it and I wouldn’t give it up. *I enjoy having the link between the patient care and the research* where the two are relatively closely intertwined. And it can be a plus or a minus depending on the situation but ... the plus side of dealing with Parkinson’s and other chronic diseases is that you get to know your patients. So in some cases it’s a very friendly and close relationship. It’s not ever going to be with all individuals, but ...”
- Gastroenterologist ... “*Trying to solve what are very difficult problems for these people.* They tend to be troubled by their disease and the many different aspects of

their disease and my involvement is a small part of their condition, but it's satisfying to be able to help them deal with those particular issues of their disease."

- Nurse ... "I think ... (what I enjoy the most is that) *one small thing makes a very significant difference.*"
- Social Worker ... "... *I really do enjoy almost everything about my job.* You know I enjoy the people, of course you can have difficult patients, but for the most part the people who come here, want to be coming here. ... I'm working with some really talented people, so for me who's only been working in Parkinson's for two and a half years I had quite a lot of learning to do and I'm learning from some pretty bright and accomplished people, so that's been great. I enjoy the autonomy that I have in that I can set my day up, the way *I* feel it needs to be set up. I can prioritize the way I need to do, and I have that respect among the people that I work with.... So I personally enjoy almost all of it."
- Physiotherapist ... "*I've always enjoyed the interaction with people and caring for them and getting them to be better, you know, to reach their optimum capacity.*"

"What strengths do you see in your workplace experiences of care within the system? In other words, in your personal involvement with people with Parkinson's what are you best able to do well?"

- General Practitioner ... "... *strengths are that of the professional healthcare providers (the paraprofessionals) particularly the care staff and the relatives.*"
- Neurologist ... "... *we have an expert team here ... We have the link to the research which I think is a great strength. ... the team is very committed to what it does ...*"
- Gastroenterologist ... "... *broadening experience, and then using the experience gained from one patient to be able to help deal with subsequent patients.*"
- Nurse ... "... *in the healthcare setting ... they've become more receptive, ... they've actually grown to recognize that it's an area that they do need some information in (as a result of my encouragement for them to change their attitude).*"
- Social Worker ... "I think that what *I* personally are (sic) best able to do, is that I'm really bringing to my work with people, many years of experience in social work, in healthcare, in community, in all of those areas, that allow me to have a perspective

that, of their situation, in a very wide open systemic looking at all of the things that are going on in their life, and all of the things that are affecting it, and help them to, well if not identify what their issues, help them to identify what the issues may be, but help them to come to some solutions, or help them to problem solve that kind of thing. *Supportive counselling is probably the thing that I do the most and I think I do it well.*”

- Physiotherapist ... *“I think I’m a good communicator with patients. I think I can motivate the patients well. I think I care about people a lot, and how they’re functioning.... I didn’t say earlier, that I have a sense of humour, I think that helps in treating Parkinson’s.”*

“Within your role are you able to provide what you would consider to be acceptable care for people with Parkinson’s?”

- General Practitioner ... *“It really depends how you define acceptable care. It’s a degenerative condition, and people ... gradually deteriorate no matter what treatment they have. It would be nice if we had a cure for the condition or if there was something we could do to, I mean all we can do is try to optimize function for as long as possible, but it is a progressive condition. So I think I can provide care as well as most primary care physicians with the aid of a consultant neurologist. So I think my care is standard and I suppose means that it is acceptable.”*
- Neurologist ... *“Acceptable yes. More than acceptable, but we’ll talk about the limitations.”*
- Gastroenterologist ... *“...acceptable care would be to try to come to some improvement or resolution of their gastrointestinal problems, whether it be their difficulty swallowing or their difficulty with constipation, and to help them to manage the different problems ... Acceptable care is often not very acceptable because the outcome is so poor. ... And I think it is inevitable that there is a progression of their disease and the symptoms that go with their disease, so I think there is a success in trying to improve the quality of life as they move through the progression of their disease.”*
- Nurse ... *“Within my role I can because I’m independent. So even with the mess in the hospital I’m able to do, because I’m a nurse.”*

- Social Worker ... “*Absolutely*. And you know I have no hesitations in feeling that I think the care that I provide is acceptable because at some level *I feel with all of the healthcare budget cuts* and things like that, that if patients can receive anything, they’re fortunate at this point, so, yah, it’s absolutely acceptable care.”
- Physiotherapist ... “*Yes*. Except that I don’t have enough time to see all the people who require physiotherapy ... *The time is probably the biggest limiting thing*.”

“*What do you dislike about your work experiences of care for people with Parkinson’s? What is the most difficult part of your job?*”

- General Practitioner ... “*It’s a progressive tragic condition where you watch people slowly deteriorate over a period of years*.”
- Neurologist ... “One is the frustrations of the limitations ... The other is that it’s not always easy looking after people with Parkinson’s even with unlimited resources. The truth is some people may not do well, some people may place pretty extensive demands on one and it’s kind of wearying. *It can be quite exhausting and I think sometimes people with Parkinson’s don’t realize ... what a toll they take on the lives of those trying to care for them*.”
- Gastroenterologist ... “*I dislike the complexity of their problems, and I dislike the necessity of having to coordinate with so many different healthcare providers*, so that it becomes very difficult to coordinate the various aspects of care for these individuals that have got emotional problems, neurologic problems, nutritional problems, gastrointestinal problems, dementia problems, and so many different problems, and each of them has different care needs and often the care is fragmented, or the communication between various care providers is fragmented or poor, making it very difficult to fully understand where my part of the problem management lies.”
- Nurse ... “I just think it’s the frustration of it because to me I think it’s challenging enough to have to manage a person with Parkinson’s, and I don’t think that *having to fight the system to get good care*, to get someone to come and see them when they’re frozen, to get someone to put a blanket on them, to take them to the bathroom. It escalates the frustrations of family members. It puts a lot of extra strain in an already difficult circumstance. And even as a healthcare professional, I, you want to be able to have the person have a good experience, and I felt humiliated when I walked in thinking, what the nurses in my profession are doing to this woman (the nurse’s aunt who has Parkinson’s and who was in hospital), lying there like that, I mean, it’s

embarrassing to be a nurse when you see that that's what they thought was acceptable."

- Social Worker ... "So, the most difficult part I think would be *where I identify a need, would really be around the limited community resources*. So you know you see somebody who is struggling who could use so much more assistance and that the system isn't there, that the community resources, the supports that they need to keep them in the community are limited. And that's really frustrating ... *That would be my most difficult job, is recognizing that there's somebody out there that's struggling, and there isn't anything more that I or the system can provide.*"
- Physiotherapist ... "*Lack of time, and lack of time to follow-up* ... And not being available to see everyone."

"What limitations of care do you see in your workplace experiences of care for people with Parkinson's?"

- General Practitioner ... "I think that the nursing staff do their best, the care staff do their best but the limitations are that this is a disease that we cannot treat well ... *the limitations are really are that it is an incurable, progressive condition.*"
- Neurologist ... ".... The biggest generic one is that ... apart from the fact that we don't have a cure, and there's even a limit as to what we can do with symptomatic treatment, my view is very firmly that *the care required is multidisciplinary* and that management of chronic disease requires a completely different model from the management of acute disease ... I think our healthcare system does an appalling job for the management of chronic care ... *I just think these things (social worker, physiotherapist, speech therapist, etc.) are a necessary part of the care, I don't see them as a luxury*. I think without that ... you cannot possibly provide the optimal level of care. Umm. ... *clinic space itself is woefully*, I mean it's dangerous. It's actually appalling. I don't think it would pass an inspection. ... even if you do get into our clinic the waitlist is now, I mean for me, the lag between follow-up visits, the *average lag is around 14 months.*"
- Gastroenterologist ... I think the big limitation gets back to the *complexity of the problems* that these people have, have such complex needs that the difficulty is placing them in the environment that addresses their own particular dominant symptoms. So some Parkinson's patients, their dominant symptoms may be related to their G.I. tract at some point, and others at another point in their illness it may be

purely emotional or psychological, and then yet another point it may be neurological or related to their movement disorders and so there is such a shifting focus of their problems and needs that it is difficult to sometimes know what is the dominant symptom at any given point, and what's the dominant problem to address ... and that gets back to *that coordination*, it needs a very strong central focus or central caregiver whether it's a family physician or a family member who can grasp the different parts of the puzzle and co-ordinate them.

- Nurse ... "*Accessibility of the people (the healthcare professionals)*. It's very hard to reach them, even by phone, they don't return calls, they're in the O.R., they're just very busy. ... You can't find anybody, to go and see the G.P. or something. There's no kind of sounding board place. ... But the guys, the other neurologists don't address that at all. We all know that stress in Parkinson's causes the disease to deteriorate; they don't acknowledge that that's their other limitation. *There isn't a good understanding of the emotional components of the disease so that they're addressed.*"
- Social Worker ... "I guess really the only limitation that I see right now would be our *physical environment is limited in (size)* ... It's a frustration but it doesn't prevent me from doing my work."
- Physiotherapist ... "This is not my problem, but I know *that people wait a long time for appointments.*"

"*What would you say constitutes unacceptable care for people with Parkinson's?*"

- General Practitioner ... "Basically *not treating to the best of one's ability.*"
- Neurologist ... "... unacceptable is a pretty strong term, it wouldn't have been the term I would have chosen ... more realistically what I think you're getting at is suboptimal ... So *suboptimal is seeing the patient once every 18 months ... for somebody with an established disease seeing them ... outside the complex of multidisciplinary care...*"
- Gastroenterologist ... "I think unacceptable care would be related to *unneeded suffering and unneeded investigations, unneeded interventions, and unnecessary suffering* of the persons with their different symptoms."

- Nurse ... “(The healthcare professionals) not being educated adequately on the disease. ... *It’s disrespectful to try to treat the Parkinson’s patients as if they live in isolation*, and to not care for the circle that they live in, to not offer support to the caregiver, to the children, to whoever might be being impacted, because there’s a lot of employers, people lose jobs, there’s a whole ripple effect of the disease that has no place to go. Nobody addresses it. ... *So I think it’s true neglect of the whole psychosocial aspect of a chronic disease.*”
- Social Worker ... “I’m not sure I would really call it unacceptable, but it’s more a frustration, you know, it would be a frustration if there was a patient here who needed social work intervention and it’s a day that I’m not here.”
- Physiotherapist ... “*Not getting to see a movement disorder specialist, being turned down by their G.P.*”

“*What are the significant healthcare policies affecting your work experiences of care as a healthcare professional of people with Parkinson’s?*”

- General Practitioner ... “*I really don’t see any policy that ... interferes with my particular work as a healthcare professional ... I don’t think there is anything that could be particularly be done better from a physician’s point of view other than those points I’ve previously discussed.*”
- Neurologist ... “... *I think the structure of the healthcare system as I’ve already indicated is not well set up for chronic disease management*, and here we’ve got this unusual, I regard it as a somewhat bizarre situation where we’re seen as, in some ways we are perceived as private practitioners where we’re, in doing what we do as a business, well of course we get paid for it, but the hospital doesn’t see itself as having a role, the health region doesn’t seem to see itself as having a role in providing the care, they look to us to do that, so, if we want nurses, physios, social work, they want us to come up with the funds to support that. Yah, I find that a little bit odd.”
- Gastroenterologist ... *I think one of the biggest problems is the reduction in the interest and role of the primary care physician so that primary care physicians in the past would have a very central pivotal role in the management of these complex patients and then would communicate and co-ordinate with various specialists to offer optimal care ... encouragement on an individual level for primary care physicians to become involved and to encourage them and reward them to become involved in these complex cases is very important because I think the more complex*

care becomes and the more different facets of care that are being co-ordinated, the more difficult it is to keep everything under control. ... So I think a policy towards allowing some central co-ordination would be very important. Traditionally that co-ordination's been by the family physician, but *it could well be by some Parkinson's advocacy or a nurse practitioner experienced in the problems*, it wouldn't have to be a family physician, but it needs to be somebody who takes on a very central role in co-ordinating various aspects of the Parkinson's care, not just the neurology part of it, not just the nutritional part of it, but the whole facet and range of problems.

- Nurse ... "The policy, the biggest one, the part of it I'm sure, is the financial resources, is the one in terms of numbers of people. ... *the nurses should be, there should be more of them, and they should be trained adequately.* ... And in terms of her time, it would make the care and everything just, it (adequate training) would have a huge ripple effect, and the nurses would learn, they'd know more about Parkinson's, and if the more nurses know, the more that they'll know out in the communities and in their families, and *the more the wisdom of the disease would be propagated.*"
- Social Worker ... "Well I think *the significant healthcare policies are really around funding and healthcare.* ... as the funding remains threatened at all times, I think that that's what affects my work and what I can do for people. There's no surprise there I think."
- Physiotherapist ... "*Well always the budgetary constraints, right? I always have felt for a long time in healthcare, that they do have money for the things they want to do.*"

"All experiences occur within, and are shaped by, particular social, economic and cultural contexts. In your opinion what are the significant social, economic and cultural conditions affecting your work experiences of care as a healthcare professional of people with Parkinson's?"

- General Practitioner ... "I don't really see any big problem. If people can afford it they can get healthcare in their homes, if they can't afford it and they ... have a severe case they're going to *end up in a facility and get appropriate care there.* There are *only certain cultures* where there is a delay in getting treatment. However *I don't think there are economic issues* as far as the cost of medication is concerned because it is usually covered, about \$600 a year."

- Neurologist ... “Well, I don’t think they affect my experience per se, *it’s more the limitations of the healthcare system.*”
- Gastroenterologist ... “Well, from an economic standpoint, the more complex the care, the more time consuming ... So as these patients become more complex you’re being rewarded economically proportionately less than for simple problems. *So there needs to be a recognition of the complexity of the care for the financial reward to the physician and practitioners ...* And then from a social standpoint these are patients that have chronic illnesses that are very debilitating over a long period of time and so *it has an impact on their social functioning*, it has an impact on their family functioning, it has a huge impact on their ability to work and interact with their family members, and so it’s a very draining condition, it’s a draining condition for the practitioners, it’s draining for the family, it’s draining for colleagues and friends and workmates. From a cultural standpoint, *in a multicultural country like Canada, and particularly in Vancouver, the impact of chronic illnesses on different cultures is taken in many different ways* and so the support from family members in some cultures is much more useful than the support in other cultural groups. And so it can be very difficult for a physician to fully under... , particularly a physician from without some of these, from without cultural areas, may not be experienced with say an Asian culture, an Indian culture, will not entirely understand what, what role families sees in caring for a family member. Language barriers can be a big problem helping family members and patients to understand the problems and be able to communicate these problems can be often very difficult in the context of language barriers, recognizing that most medical care, particularly in a specialist setting, is given in English in Vancouver, and many of these patients come from ethnic backgrounds where they do not have English as their language of communication.
- Nurse ... Ah, my own experiences? I love being a nurse, so I’ve seen my life, every since I was four, if you asked what I was going to be when I grow up, I would tell you that I wanted to be a nurse that looked after children. So I’ve just, I’ve always been drawn to illness, and *to the impact on the bigger family.... I’ve always been sort of interested in the ripple effect ...*
- Social Worker ... So significant social, economic and cultural conditions, you know again I think *I would look at the global economy*, when we look at the economics that affect, it’s just, you look globally, and it does trickle down and it affects us all. ... It (a conference in the United States) was fantastic also because a lot of the people came from the United States and so you really got to see and hear how different their service delivery is, as a result of funding. ... *I mean we are in a panacea* compared to some things that they need to deal with. But also it’s just all around there being

patients out there that can't, don't have the free medical insurance to come to a clinic. ... I still think we're in a *very* privileged place to be able to access whatever is available. Anybody can access whatever is available. ... *I think culturally within where I work? That, that medical, nonmedical balance is really valuable.*

- Physiotherapist ... I was thinking about the cultural contexts and *I was thinking surely we have a culture of caring and helping people.* ... I basically came from a culture (the U.K.) where I would say it was a compassionate, a compassion for people who needed help. And in my early days we weren't so, I didn't feel constrained, maybe I was less aware in those days but *there was less constraint around the economics.* Now when you talk about healthcare, you talk about money, *whereas in those days you talked about healthcare as healthcare,* and how best healthcare could work. ... The social? I don't know how I would describe the social. ... *I think we do a pretty poor job at looking after the elderly. Socially I don't think there's enough focus on the quality of care, or the quality of life, I should say really, the quality of life of the elderly."*

Findings: Part Two: Prescriptions for ideal workplace experiences

"In the context of your work with people with Parkinson's how would you define ideal care?"

- General Practitioner ... "Well ideal care would be where *ideally where there is a cure,* but *secondly where one makes every effort to maintain function,* and this involves monitoring of medication on a regular basis."
- Neurologist ... "*Again, multidisciplinary.* But I would focus on the ambulatory rather than inpatient. Inpatient you do occasionally need, it may provide some benefits. ... I would focus on building better ambulatory facilities where you could have, if you had somebody who's doing *really* badly, in an ideal world, money no object? Have staff who could monitor, you have somebody who's doing terribly; you bring them in to a day hospital ... What you really want is people to observe them over several days. ... It also involves *combining clinical care with research* ... I recognize that it's good for the research. I actually think that it's good for clinical, not that purely clinically oriented centres can't provide excellent clinical care, they clearly can, but I actually think it is good for clinical care in the long run if you have curious people who are obsessed with trying to find something better, and whose research is driven by the clinical problems they see."

- Gastroenterologist ... “I think ideal care would be *a readily available combination of healthcare practitioners to co-ordinate and consult on the different aspects of care to try to reduce the fragmentation of care*. There needs to be a clinic setting where the clinic involves experts and practitioners that are experienced in the various problems that Parkinson’s patients suffer with, whether they be nutritional, gastrointestinal, neurologic, psychologic, mobility, pain, and there *needs to be ready access in a coordinated fashion* for these different specialist groups to be able *to communicate together and coordinate the care of an individual patient*.”
- Nurse ... “*The first front of the ideal is ... to have a multidisciplinary centre where people can get this ‘whole person’ care*. That they could come to this one place where they would be able to access information, and education, and support for themselves and their family, in a cohesive way where people talk to each other. ... So that would be the ideal in that place, and also in the hospital circumstance I think that the *education level of nurses and the care people on Parkinson’s needs to go up* because Parkinson’s patients are on every ward of the hospital. And I think the other ideal I think that the arrogance of the current supposedly specialists in Parkinson’s are so ivory tower living that they don’t *communicate well with G.P.s*, they don’t *see the whole family or the whole vision of these patients*, and have this very egotistical attitude, and the whole energy ..., the whole high performance ... is not inviting, it’s not warm, it’s not compassionate, it’s arrogant.”
- Social Worker ... “So ideal care and how would I define it? To me when you talk about something that’s ideal you’re talking about a concept of something that’s perfect, and I’m not sure that any one, anybody is ever perfect, any situation is ever perfect. Which is a good thing, absolutely, I don’t see that as a negative at all, but I guess when I think about you know the term ‘ideal care’ that’s what I’m thinking of is that we can’t strive to have something that isn’t, that can’t exist. So to me, as I thought about it, *to me ideal care is really us, me providing the best effort that I can*, in the context that I work.”
- Physiotherapist ... “*Absolutely no restraints. Every person with Parkinson’s would see a physiotherapist, free of charge, and that there could be ongoing treatment and monitoring of their physical condition, and assistance with doing their exercise program or their activities*. ... But having ongoing assistance with their exercise program and their activities. So there’s somebody there to motivate them, give them feedback and assist them with their activities of daily living, be (it) dressing, undressing, or help at the gym, or help them at home if they don’t want to go to the gym, in public.”

“What would be the ideal healthcare policy in order to support your conception of ideal care for people with Parkinson’s?”

- General Practitioner ... “Well *I think the ideal healthcare policy is to have a team approach* and for people to be aware of, to have a system in place to assess function, and a system that is communicated through the healthcare team so that, everybody on the healthcare team was aware of what could be adverse effects or what could done to improve function, so that if somebody was for example getting ‘on again off again’ phenomenas, there could be a method to first of all identify that and it to be communicated accordingly, so that medication adjustments could be considered.”
- Neurologist ... “Well I’m not a policy wonk. What I would like to see in general, not just for Parkinson’s, *is some kind of an alternate funding plan* ... So there’s several challenges with it, but the other thing is that these funding plans don’t actually take into consideration all the other disciplines. ... *I would prefer to see a system where the funding is in place to allow multidisciplinary care*, where funding is in place so that you are not economically disadvantaged by seeing people with chronic disease, and where you have, provide resources to permit, for instance, the management of people outside your catchment area. ... one of the problems is that ... the current models are almost in conflict. That you’ve got a university model that is based on academic activities, and you’ve got a health region model that’s based on delivery of care and each model does not value the activities that take place under the other model. ... It’s partly about the way they’re paid, but it is more than that. It’s really about trying to fulfill multiple duties and obligations, but until the two sides come together and recognize that each one benefits from growth in the other, I don’t see an end to it. But the basis, the beginning for it would have to be an alternate funding plan.”
- Gastroenterologist ... “I think one of the biggest problems is the reduction in the interest and role of the primary care physician so that primary care physicians in the past would have a very central pivotal role in the management of these complex patients and then would communicate and co-ordinate with various specialists to offer optimal care. ... I am not sure about policies on a governmental level, but *I think encouragement on an individual level for primary care physicians to become involved and to encourage them and reward them to become involved in these complex cases* is very important because I think the more complex care becomes and the more different facets of care that are being co-ordinated, the more difficult it is to keep everything under control. *So I think a policy towards allowing some central co-ordination would be very important.*”

- Nurse ... “A couple of things. *I think the ideal healthcare policy would be a policy that addresses uniformly across the whole healthcare system, the whole patient, talking a theme here, where they, that was the policy of the way the whole healthcare system worked.* Where we can treat a disease, we can treat a person. That would be the first thing. And I think in terms of specific disease, *I think that better accessibility for healthcare professionals, certainly on Parkinson’s itself.* I think that the disease is not well understood. ... *there needs to be a better sort of education across the whole range of healthcare of how to manage Parkinson’s patients.*”
- Social Worker ... “Well, again, ideally, there were be more resources, which again is back to funding. There would be more resources in medical availability of, so that patients would be able to get in when they feel that they need to get in, but even that I’m not sure is necessarily the best thing either. *In the community, financially, medication support, equipment support, and subsidies for homemakers* and all of that kind of stuff. Those are some of the policies that I would love to see changed in order, and that would certainly support what I do in providing better care.”
- Physiotherapist ... “*For people living with Parkinson’s, giving them optimum conditions so that they can remain at the peak of their physical performance, plus assistance with their non-motor, the non-motor component of their disease if it’s present.* So always *the team support, easy access, no waiting lists, and of course a lot of support for the caregiver.* In terms of respite care, *accessible respite care,* or people who are experienced with Parkinson’s being able to provide kind of very short term, like two hours, so somebody can go out ...”

“*What would be ideal social, economic and cultural conditions in order to support your conception of ideal care for people with Parkinson’s?*”

- General Practitioner ... “In my experience I don’t see any outstanding issues related to social, economic or cultural conditions. Other people you interview may give you a different answer to that.”
- Neurologist ... “I think probably I’ve covered that.”
- Gastroenterologist ... “... *there’s clearly a huge social impact of the disease,* and it can be at any stage of life. ... *So there has to be some support for the social consequences of the disease* at whatever level that might be, and again it’s such a broad age range of individuals with Parkinson’s, that that may be ... And then

culturally there's, that in some cultures a chronic illness is not well regarded, and there's not a lot of support in some cultures for people with chronic illnesses. Now other cultures are very much willing to take on ill members of the family and care for them and help them, either financially, emotionally, socially there can be some support, whereas some cultures don't offer that support and therefore those *individuals without the support are going to have to turn to outside agencies to get the support*. So one has to recognize the cultural milieu that an individual's in and if the cultural milieu is not very supportive then there has to be some ability to try to *gain support for that individual*, whether it be through psychologist, healthcare workers, care aids, financial support."

- Nurse ... "That's a whole another interesting issue, culturally. I don't know what the cultural thoughts are on Parkinson's disease. *I bet there's a huge diversity in how different cultures and stuff would actually experience Parkinson's* ... Even with *written information that you give out, you'd have to be able to produce it in enough languages that it would cover the bulk of the people*. And in a perfect world we'd have, the Parkinson's Society would have *translators*, that people could, that new Parkinson's, that if they needed some understanding, if they had questions they could actually access this person, and this person could answer some of the basic questions and then go to an appointment with them that would help them too."
- Social Worker ... "Well I have not really identified what my concept of ideal care is. Again I think, to me, *so much of it is tied to money and the economy*. And I think again *Canada has a very paternalistic open arms philosophy about taking care of our citizens* and so that's a great place to be sick, if you're going to be sick, I think it is a great place to be sick. So I'm not sure kind of from that perspective that we're in a good place, but it's the constraints that are brought upon us as a result of funds to pay for things."
- Physiotherapist ... "The economic one is easy because we would need enough money to fund programs in terms of courses for healthcare professionals to have more expertise in the management, educating G.P.s, especially about the Movement Disorders Clinic, and the role they have to play in the management of Parkinson's, *so having money to fund all those programs from whether it's educating G.P.s or physios and O.T.s to having programs available*, like exercise programs or respite care, all those different things. From the *social point of view I think taking on more responsibility and pressuring the government to put funds into this*. I mean there probably *needs to be more action and forcing the policy makers' hands* into putting money into those kinds of programs and better staffing in places like extended care facilities. More, more facilities like assisted living which I think are wonderful."

“Are you aware of an ideal model of care for healthcare delivery for people with Parkinson’s elsewhere in the world?”

- General Practitioner ... “No. I am not aware of an ideal model.”
- Neurologist ... “Well so across Canada there is, you’re probably aware there is currently a motion to get (Parkinson’s) *Clinical Guidelines*, clinical practice guidelines together, it’s been pretty difficult, this is again unpaid work ... One of the things that I, I want to see come out of it is *the multidisciplinary care* because personally I’m not that interested in getting a consensus on whether medication A is better than medication B or not. But around the world, the example that everybody here brings up is *Evergreen or whatever it’s called*, in, in Washington [*The Booth Gardner*.] ... I think patients are happy there because they’re treated pretty nicely by the sounds of it, from the reports I’ve heard. So like a positive uplifting experience, and probably isn’t a positive uplifting experience for people to come here. They see lots of staff. They’ve got all the time in the world for them. ... that’s another mod... and I know they have some multidisciplinary there so I think that’s probably an example of a place that works pretty well but I’m not aware, fully aware of its strengths and limitations. Otherwise, no I don’t really know. I’m aware that in many centres, other countries, that people either pay out of pocket or they get cranked through very busy clinics. Some of the major clinics in England I think if you’re going through the NHS you’re in and out in a few minutes.”
- Gastroenterologist ... “... I think there is a concept of trying to centralize diagnosis, centralize care, whether it be from initial care after diagnosis to end-of-life care after, a long term diagnosis but I am aware that *there is a model for trying to offer support both for diagnostic testing in one, under one roof, and then care, either respite care for short periods of time, or long term care for longer term support to try to help the people and their families through the illness in all its different stages*. I have heard that there is one in *Seattle* that is under, that’s been underway for a while and has certainly been talked of as a model but I am not very familiar with the details of it.”
- Nurse ... “Not for Parkinson’s. I did mention to you, and I haven’t got a lot of information on it, but I did hear just from a patient who’s been involved.
- *Nephrology Clinic at V.G.H. is stellar*. This clinic sounds like *the focus is the patient*. If they’re offering you a nurse, they’re giving you patient information evenings and stuff. They’re focusing on the patient.”

- Social Worker ... “No I am not aware of an ideal model ... , I can’t imagine what perfect would be, because I don’t know. I think I’ve been working in the field too long. ... I think also part of that is just who I am, which is that I am a very practical, realistic person and so I am just always very grounded, and say, “Well, hold on, I want this, what is going to prevent it from happening, or what’s going to enable it for happening?” And just looking at the whole picture, so that’s probably just a personal.”
- Physiotherapist ... “*The ParkNet*, regarding physiotherapy I think the ParkNet scheme in Holland is good. The *cardiac rehab programs* I think would be a good model for us to follow, in terms of setting up the program, assessing ... But again it’s not going to meet everybody’s needs because, you know, what happens to the people in the remote areas of B.C. and there are a lot of them? But it could meet some people’s ... He (Bas Bloem of ParkNet) kind of divided the Netherlands up into different sections, and so he kind of chose one area I guess close to his centre, and, and he was working very clo... they (the physiotherapists) had the opportunity to go for training and then in return they were an accredited Parkinson’s place, and so if he had patients he would refer them to those clinics where he knew there were people with expertise. Then he took another, he kind of did it section by section in Holland. And in his words, it spread out like an oil stain over. I don’t know if that is a good analogy, an oil stain in these green times.”

“*What is preventing ideal care from happening in your workplace?*”

- General Practitioner ... “There is no cure for Parkinson’s and *I don’t think in my opinion there’s anything outstanding* that is missing from my, the current experience, my current experience in my current workplace.”
- Neurologist ... “Well I think *it’s the model that is really focused on delivery of acute care*. Ministry of Health does not disagree with this. They know perfectly well that the system is not well set up for chronic care, and they worry about it. You know, it’s got to be close to 50% of the provincial budget is being spent on healthcare, so they can’t spend more money. *It’s not the amount of money that’s being spent probably that’s the problem. It’s the way it’s distributed*. So it needs in my view a major restructuring, but I don’t pretend to be an expert on that.”
- Gastroenterologist ... “I think a big limitation is just *the overwhelming workload that many physicians have for patients of all types*, not just Parkinson’s patients but there’s such a demand for physician time and physician care that it becomes very

difficult to offer the amount of care and time that many of these complex patients require. And so the difficulty is time and these are not easy patients or easy families to deal with. The problems are complex and they're frustrating. There's a requirement for communication with various other groups, other practitioners, and it can be very difficult to try to coordinate that communication, particularly if it's not under one roof, so coordination with a clinic under one roof or clinic with shared files, shared experiences would be much more effective, but at the moment it's completely fragmented ... I think often the patients are waiting for help in the wrong arena, so they're not getting their help guided for them, so they need again some sort of an experienced coordinator that can let them understand which healthcare provider deals with which particular problem and how they need to access that problem, so traditionally they thought of the neurologist as being the main healthcare provider, but I would venture to say that the neurologist is probably not the one to see for many of the complications of Parkinson's and that the neurologist is not at all interested or skilled in that part of their care."

- Nurse ... *"Part of it is money, of course we all know that. There is a huge financial issue for all these things, and that plays out not just in money but it also plays out in staff resources ... they may want to give better care, but they're not able to."*
- Social Worker ... *"You know what? I'm not sure that I can really... We are doing our, the best that we can do, we are providing ideal under the circumstances that we have."*
- Physiotherapist ... *"Resources. ... We need more resources. ... Personally I think Vancouver Coastal Health should be paying my salary, so it's all very tentative at this stage. ... But you know it's tough times, because some people are losing jobs at Vancouver Coastal with cutbacks. It is not a great, auspicious time. But we shouldn't let that hold us back, because if there is a need there is a need."*

"Are there ways of overcoming the problems that are preventing ideal care from happening in your workplace, as in, are there ways of bringing ideal care about in your workplace?"

- General Practitioner ... *"I don't think there are any particular problems in my workplace that need to be overcome. I think the problems are associated with the disease itself."*

- Neurologist ... “*I think restructuring of how the health system is set up in terms of payment.* That’s complex and I again, I do not pretend to be an expert in it, but I think there is a problem with the way physicians are funded. I understand if you work harder you want to get paid more money. I get that, and there is such a thing as seniority I get that, but I would like people to not really be thinking that much about that side of it, so that, you know, paid more for seeing more patients, potentially paid more for spending less time with patients, the frequency of visits has an impact, you bill a consult, in B.C. you can bill a consult every six months, if you see somebody earlier it’s not a consult, although you may be seeing more complex patients, and *none* of this covers the other disciplines, so I would like to see it set up so that there’s a payment system that, you know, is *basically an envelope payment* (i.e. payment by salary).”
- Gastroenterologist ... “Well I think *if there was a will and an interest* by individuals who are predominantly caring for Parkinson’s disease, if *they could mobilize* that will and interest and coordinate the other parts of the puzzle and take charge of it they could then accumulate a group of practitioners and care providers around them that would be able to offer various aspects of the care so I think they need to identify the various care needs within a Parkinson’s population ... and then have practitioners available that can work on short notice and effectively with Parkinson’s patients and their family members to address those various needs.”
- Nurse ... “I think the financial piece is one of those momentous things. *Government priorities need to be placed in the human places* rather than looking at the impact, the human impact of their decisions as opposed to some of the other ones because I certainly wonder sometimes, when they cut out fifty nurses in a place, what are they ... , how do they ... , do they really appreciate the experience and the safety and the health of the ripple effect of that? I think there’s also big room in there for *human appreciation of all of the healthcare workers* that are involved in working with patients at all levels. I think that it’s just, the more, even if you’re asking people to do more, things are cut back. Real acknowledgement and support. ... It makes a difference to patients. As we all get busier and the budgets get smaller. Even within that I think you can still help people to care and notice when they don’t, acknowledge those that do, and give them a voice for where their frustrations are. *Let’s problem solve guys. We don’t have any more staff or money. Is there a way that we can, as a group, come up with another way we can accomplish this?*”
- Social Worker ... “I mean I think I kind of addressed that in that *we are providing the best care that we can provide*, which I feel good about saying, I mean I really do, I

really do believe that, and what we have are frustrations, but I don't see it not providing the care to the people who come to us."

- Physiotherapist ... *"We need more resources.* Currently we have a very tentative exploratory project going on to look at another way of getting money for me. Personally I think Vancouver Coastal Health (rather than a grant from the United States as previously, or a grant from the clinic) should be paying my salary, so it's all very tentative at this stage."

Inquiry Through Metaphor

"In closing I am wondering if you can imagine a metaphor for either your present workplace experiences of care for people with Parkinson's, or a metaphor for your ideal workplace experiences of care for people with Parkinson's."

- General Practitioner ... "No. I don't have a metaphor. I think the disease is a very difficult condition and it's progressive, it's tragic, and it's a challenge to treat medically and from a nursing point of view."
- Neurologist ... The metaphor for the present healthcare system. "I would probably describe it as semi-controlled ... I regard the whole healthcare system, not just what we do, as people peddling hard to keep it going ... forward, well, to keep the bicycle upright ... we're not going forward as much as we would like. The problem is I regard the whole healthcare system, not just what we do here, as being very fragile, and anything that happens to tip the balance could result in catastrophe because people are working very hard to keep it going. Most of the people who are involved in healthcare, despite all the weaknesses, are actually pretty committed to caring for patients and will go to great lengths to provide that care, but they're working so hard at it that there's not a lot of room for forgiveness."

The metaphor for an ideal healthcare system. "[A] more relaxed, less fragile of a situation, I suppose would be nice in some ways."

- Gastroenterologist ... The metaphor for the present healthcare system. "The analogy comes to mind of somebody who is trying to drive a chuck wagon and they've got eight horses that they have to control with eight different sets of reins, and each horse wants to go its own different way, and yet each horse is critically important to the movement of the chuck wagon, but ... if the horses aren't co-ordinated and controlled they go off in their own tangent and that can destroy the whole chuck wagon, the chuck wagon race and all the people that are involved with it. ... The wagon would be the patient, the sufferer of the illness. And so there's the wagon, the chuck wagon

in that analogy would be the patient with Parkinson's disease being pulled along by their disease, and hopefully helped by all the different horses that are pulling them, but in some cases if the horses aren't co-ordinated right then it can be a hindrance and the horses can go off in the wrong way."

- Nurse ... The metaphor for the present healthcare system. "The image that appears in my head is the mule that's pretty strong and capable, but at the same time somebody's put a wagon behind him that they keep adding more stuff to the wagon, but they are actually feeding the guy less, they're giving him less to eat, and so he's getting weaker as they are adding more to his load. They're not feeding the mule. Instead of feeding him more and giving him extra rest because he's pulling a heavier load, they're actually scrimping on him too. He has to work two extra hours a day instead of getting more rest because his load is bigger, and they're gonna cut back and feed him less hay, 'cuz he's kinda expensive. At the same time they're adding more rocks to the back of his wagon, so he's just getting slower and slower, and his interest in the job, he used to love being a mule pulling a load and thought he had an important job, but now he's struggling and it's not fun any more because the load is too heavy and he's hungry at the same time and he wishes, in fact he liked what he used to have, and he is wondering what happened, because it kinda all changed, but he can't fix it himself, he's not, the mule by himself is not able to remedy his problem, he needs somebody on the outside, to have a bigger vision, who'll look at his whole plight, and say, "O.K. guys, you're doing it the wrong way here, he needs to work half the number of hours, or you need to get, you need to buy a second mule, or we need to give him extra carrots 'cuz that's really good for energy, or something." Somebody outside the story needs to have a big vision, rather than the guy with the whip who'll hit him from behind and say, 'Well, we've got the secret, we'll just make him work harder or faster.'"

The metaphor for the ideal healthcare system. "The imaginary one, um, I love this stuff because it appears without me looking. So the image that appears without losing my conscious brain, is one of those lovely images that you see on t.v. of children playing in, they show like a World Vision type of ad. So we've got a village where there's lots of adversity, and the kids are struggling, and at the same time, we've got this lovely, sort of, circle of people, that are joyfully working on the problem, and there's enough support that although the situation's not fixed or easy, there's still a lightness about the story, people are hopeful, unlike the mule that's just dragging his ass and can hardly, doesn't even wanna keep going, these people have connected to the, it's like when you see those little kids in those ads, and they've got a ball and they're playing skip or they're skipping around, in Ring Around the Rosie, or something, so even though their story isn't perfect, there's a lightness and a hopefulness about their story, and there's the World Vision kinda guy in the

background who's, it's an outside person that's kinda, "We're gonna help the individuals in this story, and by helping Johnnie in the one family, we're gonna help Johnnie's whole family, and we're gonna help the village because we're gonna get a well here." So that not only the people that are being sponsored by World Vision, now we're gonna have a well for the whole community, so there's a community-ness to it, where no one individual is unimportant. So, you know, the one little kid that doesn't have a sponsor, well, the community will just rally and make sure he gets a schoolbook too, or he gets some fresh water, or something, and so. But it isn't a vision of mine where the problems have all disappeared, because that will never be, but there is a willingness to collaborate and co-operate in the sense of community that makes it, you know the more heads you have the more likely you are to find some solutions, and if you can keep people connected to hope ..."

- Social Worker ... The metaphor for the present ideal healthcare system. "So you know. And I actually, I kind of looked at the one as the example, and I didn't like it, I didn't like his example at all. I didn't like the Parkinson's being, being pulled along by their disease, to me that was just, oh, I found it very negative, and you know, and I also thought that that's very, um, percept ..., individually based and perceptive, because not every person feels that they're being pulled along by their disease, other people feel that they're very much more in command and in control of their disease and their perception and so. And so that's how I kind of got to mine, which is more of like an orchestra. [*An orchestra.*] And that the patient is the conductor, and the patient is therefore taking charge, and is very much in control of the piece, and the disease, and that the members of the orchestra are all of the rest. You know, they're the family, the friends, the doctor, the nurse, the social worker, the work place employer, you know, all of the other people who are part of this person's world, and *we* all play a very different part in, in you know, in a performance, and reaching an optimal performance. (whispers ...) How do you like that?"
- Physiotherapist ... "You know I didn't give that much thought. Can I think about it a bit more and get back to you?"

Appendix G - U.B.C. Research Ethics Board Certificate of Approval



The University of British Columbia
Office of Research Services
Behavioural Research Ethics Board
Suite 102, 6190 Agronomy Road, Vancouver, B.C. V6T 1Z3

CERTIFICATE OF APPROVAL - MINIMAL RISK

PRINCIPAL INVESTIGATOR: Leslie G. Roman	INSTITUTION / DEPARTMENT: UBC/Education/Educational Studies	UBC BREB NUMBER: H09-01163																					
INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:																							
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CO-INVESTIGATOR(S): Stephen Petrino Jane B. Gray Hendel K Wright																							
SPONSORING AGENCIES: NA																							
PROJECT TITLE: Healthcare Professionals Consider Care for People with Parkinson's: Descriptions and Prescriptions																							
CERTIFICATE EXPIRY DATE: August 12, 2010																							
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The application for ethical review and the document(s) listed above have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.																							
<p>Approval is issued on behalf of the Behavioural Research Ethics Board and signed electronically by one of the following:</p> <p>Dr. M. Judith Lynam, Chair Dr. Ken Craig, Chair Dr. Jim Rupert, Associate Chair Dr. Laurie Ford, Associate Chair</p>																							