A RETROSPECTIVE COHORT STUDY ON THE PRIMARY CARE SERVICE DELIVERY TO MEN AND WOMEN DIAGNOSED WITH PARKINSON’S DISEASE AND DEPRESSION USING THE CANADIAN PRIMARY CARE SENTINEL SURVEILLANCE NETWORK

by

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Abstract

**PURPOSE** Parkinson’s disease is a complex neurodegenerative disease with depression as a common comorbidity known to negatively affect quality of life. Yet, limited evidence exists on how the two chronic conditions are treated simultaneously in Canadian primary care. This study aimed to describe the demographic and health characteristics of men and women with Parkinson’s disease and examine the differences in the number and type of medications for depression between men and women with Parkinson’s disease and depression.

**METHODS** This retrospective cohort study analyzed available electronic medical records of patients with Parkinson’s disease who had at least one encounter with a primary care provider between September 30, 2012 and 2014 from the Canadian Primary Care Sentinel Surveillance Network (CPCSSN). In addition to descriptive statistics, Poisson and logistic regression were conducted to examine gender differences in depression treatments. An advisory group comprised of five primary care providers provided additional interpretation of the results.

**RESULTS** A total of 1,815 patients (54.9% male) with Parkinson’s disease were found to be older, living in urban areas, overweight, non-smokers, and had an average of 15.5 encounters with a primary care provider over a two-year period. About 83.6% had at least one comorbidity with hypertension (64.1%) and depression (38.1%) as the most common. Of those who also had depression, 86.2% had at least one medication prescribed for depression; no significant difference was found in the number of medications prescribed by gender. The most frequently prescribed antidepressants were selective serotonin reuptake inhibitors (52.2%).

**CONCLUSIONS** This study is unique in its reporting of antidepressant medication management for those with concurrent diagnoses of Parkinson’s disease and depression in primary care. It is the first pan-Canadian study to examine clinical electronic medical record
data. The comorbidity of depression in those with Parkinson’s disease needs to be routinely assessed in primary care. Findings highlight the possible need for better decision-support tools consistent with Canadian guidelines to appropriately manage comorbid depression. While more population-level research is warranted, this study provided theoretical and practical knowledge for health care providers to holistically care and positively influence the quality of life of people with Parkinson’s disease.
Preface

This master thesis is original, unpublished, and conducted by the principal investigator, Kimberly Rose Pineda Singian. Drs. Sabrina Wong, Victoria. Bungay, and Morgan Price served as the supervisory thesis committee and provided substantive content guidance as well as feedback throughout the stages of this thesis, including the multiple edits of all five chapters. All of the work presented were conducted in the School of Nursing at the University of British Columbia (Point Grey campus) and were approved by the University of British Columbia’s Research Ethics Board [certificate #H14-2553].

Chapters 1 and 2. I was responsible for writing the introduction and literature review.

Chapter 3. I was responsible for writing the methods. Figure 1 was based on the works of Ferrans et al. (2005). I created Table 1 based on the power analysis output from G*Power (Version 3.1.9.2). Request for data were approved by the research team of the Canadian Primary Care Sentinel Surveillance System (project #2014SRSC25). I managed data using Microsoft Office Excel 2007, conducted statistical analyses using R Studio (Version 3.1.2), and consulted a UBC statistician, Rick White.

Chapter 4 and 5. I was responsible for writing the results and discussion. The supervisory thesis committee and advisory group consisting of five primary care providers verified the results and my interpretations on Tables 2, 3, 4, and 5. I summarized the advisory group’s feedback on the interpretations of the results on Table 6.

Appendix A was used with permission from the works of CPCSSN (2012).

Appendix B was used with permission from Table 1 in Wong et al. (2014b) and revised according to the feedback of the supervisory thesis committee and advisory group.

I wrote Appendices C, D, and E and they were edited according to Dr. Wong’s feedback.
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Chapter One: Background

Chapter One provides an overview of Parkinson’s disease by defining the disease with its cardinal motor and non-motor symptoms as well as describing the epidemiological status of Parkinson’s disease worldwide and specifically in Canada. This chapter also describes the gaps in the literature and provides background evidence of the predominant focus on research in managing Parkinson’s disease symptoms.

1.1. Significance

Parkinson’s disease is a progressive, neurological movement disorder characterized by the degeneration of dopamine-producing cells in substantia nigra in the brain (Lix et al., 2010). Dr. James Parkinson, a British physician, first recognized and described Parkinson’s disease in 1817 as shaking palsy or paralysis agitans (Hermanns, Deal, & Haas, 2012). Parkinson’s disease has no known cure and although young onset occurs, the typical age onset is 50 to 75 years old (Moore & Seeney, 2007; Muangpaisan, Mathews, Hori, & Seidel, 2011). There are a myriad of etiological theories surrounding the reduction of dopamine in Parkinson’s disease extending from acceleration of normal aging, stress, hereditary, infections, and environmental factors including pesticide exposures (Huang et al., 2003). The reduction of dopamine results in the manifestation of motor and non-motor symptoms in Parkinson’s disease. The cardinal motor symptoms of Parkinson’s disease include rest tremor, rigidity, bradykinesia, and postural instability (Alves, Forsaa, Pedersen, Gjerstad, & Larsen, 2008) while the non-motor symptoms include depression, anxiety, cognitive decline, pain, fatigue, insomnia, and autonomic dysfunction such as constipation and urinary urgency (Shearer, Green, Counsell, & Zajicek, 2012).
Numerous studies report on the epidemiological status of Parkinson’s disease throughout the world but the reported estimates of prevalence and incidence rates still require careful considerations (Muangpaisan et al., 2011; Twelves, Perkins, & Counsell, 2003). To date, it has been estimated that Parkinson’s disease is the second most common neurodegenerative disorder worldwide after Alzheimer’s disease (Lix et al., 2010). Parkinson’s disease has a wide prevalence rate ranging from 57 to 230 per 100 000 and an incidence rate of 1.5 to 26 per 100 000 (Muangpaisan et al.; Twelves et al.). The epidemiological estimates have been reported to increase steadily with age as well as to differ between gender, whereby men compared to women have a 1.46 greater incidence ratio of Parkinson’s disease (Taylor, Cook, & Counsell, 2007; Muangpaisan et al.). In Canada, the few studies that estimated the prevalence and incidence of Parkinson’s disease are often reflective of administrative data from a specific Canadian province leading to substantial geographical variation in rates (Jones, Wayne Martin, Wieler, King-Jesso, & Voaklander, 2012; Lai, Schulzer, Marion, Teschke, & Tsui, 2003; Lix et al.). It has been reported by the Parkinson Society Canada (2014) that there are about 100 000 people living with Parkinson’s disease while the 2010/2011 Canadian Community Health Survey estimated a 0.2% prevalence in the general household populations (Wong, Gilmour, & Ramage-Morin, 2014a).

The diagnosis of the disease relies primarily on reports by individuals and clinical criteria assessed by health care professionals often working in primary care settings (Huang et al., 2003; Swartztrauber & Graf, 2007). The two widely accepted diagnostic tools are the Unified Parkinson’s Disease Rating Scale and the Hoehn and Yahr Staging Scale (Alves et al., 2008). A common limitation to these two 5-stage scale diagnostics tools is that they generally capture motor symptoms better than non-motor symptoms (Alves et al.). A misdiagnosis of Parkinson’s disease by health care professionals is common since the clinical manifestations may be subtle
and can differ between men and women at the onset of the disease, making it a challenge to
differentiate from other neurological disorders with similar symptoms (Haaxma et al., 2007;
Thompson, Stone, Ochs, & Litvan, 2013).

There is a growing knowledge that depression as a non-motor symptom and comorbidity
is prevalent even prior to the diagnosis of Parkinson’s disease (Parkinson Society Canada, 2012;
Shearer et al., 2012). Current evidence show that depression occurs up to 40-50% of cases in
people with Parkinson’s disease and yet, the simultaneous occurrence of depression continues to
be undetected and undermanaged leading to the exacerbation of motor symptoms and negative
impact on quality of life (Hermanns et al., 2012; Parkinson Society Canada, 2012; Jones, Pohar,
& Patten, 2009). Given the prevalent depression diagnosis and utilization of primary care among
women in the general population, the existing studies on depression treatment, not linked with
Parkinson’s disease, generally suggest that women compared to men are likely to have higher
rates of treatment (Hinton, Zweifach, Oishi, Tang, & Unützer, 2006; Unützer et al., 2003; Wong
et al., 2014b). However, the examination of gender differences in depression treatments
associated with Parkinson’s disease remain poorly understood. More evidence is warranted to
investigate the treatments for comorbid depression within the complexity of Parkinson’s disease.

1.2. Problem Statement

Parkinson’s disease is a progressive neurological disease that consists of motor and non-
motor symptoms (Lix et al., 2010). Importantly, the available diagnostic tools are better in
detecting motor symptoms than non-motor symptoms (Alves et al., 2008). The treatment of
Parkinson’s disease has primarily focused on pharmacologic therapy, particularly dopaminergic
replacement therapy, to address the motor symptoms of the disease (Abudi et al, 1997; Singer,
2012). Despite the high reported frequency of depression as the most common non-motor
symptom and comorbidity of Parkinson’s disease, there is limited understanding and rigorous evidence on how the two commonly occurring chronic conditions, Parkinson’s disease and depression, are to be treated simultaneously by health care professionals.

Many people with Parkinson’s disease are diagnosed and managed through primary care (Swarztrauber & Graf, 2007). It is crucial that primary care providers consider the differences between men and women diagnosed with Parkinson’s disease to enhance effective treatment (Haaxma et al., 2007; Martinez-Martin et al., 2012; Taylor et al., 2007). In the current literature, there is paucity on describing the demographics and comorbidities of people with Parkinson’s disease in primary care settings. There is a need to develop more knowledge on the characteristics of men and women with Parkinson’s disease within primary care and to determine whether there are differences in treatments for comorbid depression in order to provide holistic care that can positively influence the quality of life of people living with Parkinson’s disease.

1.3. Statement of Purpose

The purpose of this retrospective cohort study was to describe the demographic and health characteristics of men and women diagnosed with Parkinson’s disease as well as to examine the differences in the number and type of pharmacologic treatments for depression between men and women with concurrent diagnoses of Parkinson’s disease and depression. A secondary analysis was conducted on the available data between September 30, 2012 and 2014 from the Canadian Primary Care Sentinel Surveillance Network (CPCSSN) and an advisory group comprised of five primary care providers assisted on the interpretations of study results.

1.4. Research Questions

Drawing on the data available from CPCSSN, this study focused on two main questions:
R1) What are the demographic and health characteristics of men and women with a diagnosis of Parkinson's disease?

R2) What are the differences in the number and type of pharmacologic treatments for depression between men and women with concurrent diagnoses of Parkinson’s disease and depression?

1.5. Hypotheses

Drawing on the data available from CPCSSN, the hypotheses for the two main research questions include:

R1) H0: There is no difference in the demographic and health characteristics of men and women with a diagnosis of Parkinson’s disease.

R2) H1: There is a difference in the number and type of pharmacologic treatments for depression between men and women with concurrent diagnoses of Parkinson’s disease and depression. It is hypothesized that there is a higher number of pharmacologic treatments for depression in women compared to men with concurrent diagnoses of Parkinson’s disease and depression. Existing studies on depression treatments in general have shown that women are likely to have higher number of prescribed medications for treating depression compared to men given the prevalence of depression diagnosis and utilization of primary care appear to be higher in women (Hinton, Zweifach, Oishi, Tang, & Unützer, 2006; Unützer et al., 2003; Wong et al., 2014b).
Chapter Two: Literature Review

Chapter Two reports the current motor and non-motor symptom management for people with Parkinson’s disease. Further, the existing literature on depression treatments as a chronic condition occurring frequently with Parkinson’s disease is synthesized. There is a description on the Canadian Guidelines for Parkinson’s Disease (Parkinson Society Canada, 2012) to highlight the recommendations for managing motor and non-motor symptoms and to discuss the corresponding gaps in knowledge relative to the nursing scope of practice in primary care.

2.1. Motor Symptom Management

The cardinal motor symptoms of Parkinson’s disease include rest tremor, rigidity, bradykinesia, and postural instability (Alves et al., 2008). Tremor at rest is the most common motor symptom at onset and it is typically asymmetric in pattern, most prominent in the distal part of an extremity, lost during sleep, reduced in action, and worsened by anxiety or excitement (Alves et al.). Rigidity, characterized by increased resistance to passive movements, and bradykinesia, referring to slowness in movements, are less common than rest tremor but remain frequently present at onset of the disease (Alves et al.). In contrast, postural instability is usually not an initial motor symptom but often appears as the disease slowly progresses leading to unsteadiness or freezing of gait (Alves et al.).

Differences in the manifestations of motor symptoms appear to exist between men and women with Parkinson’s disease (Haaxma et al., 2007; Taylor et al., 2007). Haaxma et al. (2007) reported that women compared to men present more often with tremor and bradykinesia while men are more likely to experience rigidity. In addition, the age of onset of motor symptoms are later in women than in men by approximately 2.1 years. The underpinnings of the differences remain unclear but some studies suggest that the hormonal status, particularly the
higher levels and activity of estrogens in women, might have a potential neuroprotective role that delays the development of Parkinson’s disease symptoms in women (Haaxma et al.; Taylor et al.). The precise nature of estrogen in Parkinson’s disease requires more investigation since there are limited larger-scale prospective studies examining the estrogen’s actions in the brain of people with Parkinson’s disease.

The dominance of biomedical research, specifically on pharmacological management, has offered guidance primarily for motor symptoms associated with Parkinson’s disease (Abudi et al., 1997; Singer, 2012). The goal of therapy in Parkinson’s disease is to help individuals retain functional independence for as long as possible and dopaminergic replacement therapy, such as carbidopa-levodopa (Sinemet®), is a legitimate choice and mainstay for motor symptom management (Singer). Moreover, there are pharmacologic alternatives in the early stage of Parkinson’s disease to postpone levodopa-induced dyskinesias and the “wearing off” effect, a condition when symptoms reemerge before the next scheduled dose (Singer). Pharmacologic alternatives include dopamine agonists, monoamine oxidase B inhibitors, and amantadine.

The use of surgical treatment, such as deep brain stimulation, is typically for people with advanced Parkinson’s disease when they no longer respond to medication and/or not able to tolerate the medication side effects (Hermanns et al., 2012, Singer, 2012). A recent systematic review, reflective of clinical studies from different countries between 2000 and 2009, showed that women (37.0%) compared to men (63.0%) with Parkinson’s disease were less likely to receive Parkinson’s disease-related surgical procedures (Hariz et al., 2011). The uneven distribution between gender groups was unclear but Hariz et al. suggested potential influencing factors such as the criteria for selection and patterns of referrals for surgery as well as the respective attitude of men and women toward surgery.
2.2. Non-Motor Symptom Management

There are a myriad of non-motor symptoms in Parkinson’s disease including depression, anxiety, cognitive decline, pain, fatigue, insomnia, and autonomic dysfunction such as constipation and urinary urgency (Shearer et al., 2012). Similar to the motor symptoms of Parkinson’s disease, the differences in non-motor symptoms between men and women may be present but remain poorly understood in the literature. Martinez-Martin et al. (2012) were unable to find statistically significant gender differences in their study’s sample; however, they suggested that certain non-motor symptoms appear to be more common and severe in women such as fatigue, feelings of nervousness and sadness, constipation, and pain.

2.2.1. Depression in Parkinson’s Disease. Depression is the most common non-motor symptom and comorbidity in people with Parkinson’s disease with an approximate prevalence of 40-50% (Hermans et al., 2012; Parkinson Society Canada, 2012; Shearer et al., 2012). Results from a recent epidemiological study across Canada reported that the age-adjusted prevalence ratio of depression has been shown to be twice as likely in people with Parkinson’s disease (Wong et al., 2014b). However, evidence on the gender differences in prevalence of comorbid depression is less clear in Parkinson’s disease (Martinez-Martin et al., 2012; van der Hoek et al., 2011). Further, there is a gap in the literature that specifically identifies differences in depression treatments between men and women with Parkinson’s disease. The existing studies on depression treatments, not linked with Parkinson’s disease, generally showed that women are likely to have higher rates of treatment compared to men (Hinton et al., 2006; Unützer et al., 2003). Potential reasons for this gender difference might be that women in general have higher utilization of primary care, more expressive in their depressive symptoms, and more likely to be detected and diagnosed with depression (Unützer et al.; Wong et al., 2014b).
Depression associated with Parkinson’s disease has been reported as “a feeling of guilt, lack of self-esteem, sadness, and remorse” and can even precede the development of Parkinson’s disease (Chaudhuri & Schapira, 2009, p. 238). Yet, a recent study found conflicting evidence suggesting that the feelings of guilt and suicidal thoughts are uncommon in people with concurrent diagnoses of Parkinson’s disease and depression (Costa, Rosso, Maultasch, Nicaretta, & Vincent, 2012). The inconsistent evidence often makes the diagnosis and treatment of comorbid depression difficult and has been further complicated due to the overlapping motor symptoms of Parkinson’s disease including slowed movement, loss of facial expression, and loss of concentration (Costa et al.).

2.2.2. Pharmacologic Treatment for Depression. The role of dopaminergic replacement therapy for depression in Parkinson’s disease warrants additional investigation. Chaudhuri and Schapira (2009) reported that managing non-motor symptoms with dopaminergic therapy continues to be a challenge due to under-reporting of symptoms by patients and under-recognition by primary care providers using diagnostic tools that are better in detecting motor symptoms. From a biological standpoint, depression might be a direct result of dopamine reduction but there is insufficient evidence to suggest the sole use of dopaminergic therapy for depression associated with Parkinson’s disease (Hermanns et al., 2012).

The additional treatment of antidepressants for people with Parkinson’s disease is quite variable in the literature. Recent systematic reviews and meta-analysis examined the use of antidepressants compared to a placebo and/or another antidepressant in people with Parkinson’s disease and depression (Liu et al., 2013; Rocha, Murad, Stumpf, Hara, & Fuzikawa, 2013; Troeung, Egan, & Gasson, 2013). Rocha et al. (2013) suggested that antidepressants, including selective serotonin reuptake inhibitors, serotonin norepinephrine reuptake inhibitors, and
tricyclic antidepressants, are only potentially efficacious for depression in Parkinson’s disease. In comparison, Lui et al. (2013) suggested that after using tricyclics and placebo as the standard of comparison for efficacy and acceptability, tricyclics might be the best choice when starting depression treatment in Parkinson’s disease. Tricyclics showed a better acceptability profile followed by serotonin norepinephrine reuptake inhibitors and dopamine agonists, and finally, selective serotonin reuptake inhibitors. Troeung et al.’s (2013) meta-analysis showed that tricyclics are more effective than serotonin norepinephrine reuptake inhibitors, but suggested the pooled effect of antidepressants in general was non-significant for treating comorbid depression. The common limitations in these recent studies that do not permit routine use of tricyclics related to the small sample sizes in each trial and the limited number of trials in the meta-analysis.

2.2.3. Non-Pharmacologic Treatment for Depression. Depression in Parkinson’s disease also has important psychological and social components. Depressive mood in people with Parkinson’s disease might relate to the diagnostic reaction, impact of social support levels, and/or the use of maladaptive coping strategies (Moore & Seeney, 2007). Although depressive mood can develop at the different progressive stages of Parkinson’s disease, Phillips (2006) found that the period surrounding diagnosis is clearly confusing and recommended for opportunities to be created to inform newly diagnosed people about disease progression and the available alternative treatments. These opportunities can be structured classes, support group referrals and/or individual nursing consultations (Phillips).

People with Parkinson’s disease who hold unrealistic expectations regarding long-term outcome and effectiveness of treatment might be at a greater risk for later depression (Hurt, Weinman, Lee, & Brown, 2012). Helping people to adjust to realistic life goals and utilize coping strategies that maintain self-worth and social contacts can reduce the risk of depressive
mood (Hurt et al.). Results from a recent systematic review on psychosocial interventions suggested that cognitive behavioral therapy compared to psychodrama, education, behavioral therapy, and multidisciplinary rehabilitation decreased depressive symptoms more in patients with Parkinson’s disease (Yang, Sajatovic, & Walter, 2012). Despite the promising psychosocial interventions for acute management of depression using cognitive behavioral therapy, longer-term effects after treatment continue to vary and thus, additional longitudinal studies are needed to examine psychosocial interventions for depression in Parkinson’s disease (Yang et al.).

2.3. Canadian Guidelines for Parkinson’s Disease

The first Canadian Guidelines for Parkinson’s Disease, published in July 2012 by Parkinson Society Canada and endorsed by Canadian Neurological Sciences Federation, aimed to enhance the care for all Canadians with Parkinson’s disease. The guideline is based on three previously published guidelines from other countries and involves expert consensus and good practice points when there was a lack of high-quality evidence. The three previously published guidelines include the American Academy of Neurology (AAN), the European Federation of Neurological Societies (EFNS), and the National Institute for Health and Clinical Excellence (NICE). The guideline offers practical clinical recommendations while accounting for patient informed decisions and is relevant for the health care system in Canada (Parkinson Society Canada, 2012). An expert consensus and good practice points refer to the input of a team of multidisciplinary professionals including movement disorder specialists, functional surgery specialists, family physicians, registered nurses, methodologists, physiotherapists, the Parkinson Society Canada as well as individuals with Parkinson’s disease.

The Canadian Guidelines for Parkinson’s Disease (Parkinson Society Canada, 2012) encompassed four main sections including communication, diagnosis and progression, treatment
for motor and non-motor features of Parkinson’s disease. Each section provides clinical recommendations that specifies the evaluated three published guidelines and ranks the evidence with a simplified grading scheme: A – established as effective, ineffective, or harmful; B – probably effective, ineffective, or harmful; C – possibly effective, ineffective, or harmful; D – expert opinion or formal consensus; U – data inadequate or conflicting; and GPP – good practice point (Parkinson Society Canada). The specific section on non-motor features of Parkinson’s disease and their treatments highlights depression as a prevalent neuropsychiatric problem that has a tremendous impact on the quality of life of people with Parkinson’s disease and their caregivers. In line with the current literature on depression diagnosis and treatment in people with Parkinson’s disease, the guideline suggests four specific clinical recommendations:

1. Clinicians should have a low threshold [or reference point] for diagnosing depression in Parkinson’s disease. NICE Level D (GPP);

2. Clinicians should be aware of difficulties in diagnosing mild depression in people with Parkinson’s disease because the clinical features of depression overlap with the motor features of Parkinson’s disease. NICE Level D (GPP);

3. The management of depression in people with Parkinson’s disease should be tailored to the individual, in particular, to their co-existing therapy. NICE Level D (GPP);


It is important to highlight that these clinical recommendations range from Level C to D, indicating only possible effectiveness, expert opinions, and/or good practice points from a multidisciplinary team when high-quality evidence is missing. The lack of established and effective recommendations from higher-level studies, such as meta-analysis, systematic reviews,
and randomized control trials, emphasize the current literature gaps on managing depression as a comorbid condition in people with Parkinson’s disease.

2.4. Parkinson’s Disease and Primary Care

In 1978, the Alma-Ata Declaration served as a major milestone in the twentieth century by identifying primary health care as the key to attaining health of all the people of the world (World Health Organization). Primary health care is multifaceted and has a system-wide focus from the provision of essential care to individuals as well as to changing social and economic policies (Smith, 2005). In Canada, primary care settings, such as family physicians offices and nurse practitioners clinics, often serve as the point of first contact for individuals and families in the community. It is arguable that these types of primary care providers are well positioned to promote effective management of Parkinson’s disease and its comorbidities.

Current literature suggest a combination of knowledge and practice gaps exist among family physicians and nurse practitioners regarding accurate diagnosis and management of the motor and non-motor symptoms of Parkinson’s disease (Swarztrauber & Graf, 2007; Thompson, et al., 2013). In 2007, Swartztrauber and Graf surveyed 370 physicians and allied health care providers to determine compliance with established guidelines for Parkinson’s disease management. The results suggested a gap between the established guidelines and actual practice; neurologists had a compliance rate of 73.0% while primary care and other types of providers had compliance rates of 48.3% and 45.6%, respectively. Results of a more recent study also suggested that primary care providers have significantly low baseline knowledge of accurate diagnosis and management of Parkinson’s disease (Thompson et al.).

2.4.1. Nurses’ Roles and Scope of Practice. Nurses working in primary care settings have pivotal roles within their scope of practice to provide effective management of Parkinson’s disease.
The regulatory bodies for nurses across Canada, including, but not limited to, the College of Registered Nurses of British Columbia (CRNBC, 2012), the College and Association of Registered Nurses in Alberta (CARNA, 2013) and the College of Nurses in Ontario (CNO, 2013), set out similar Professional Standards that represent the levels of performance that registered nurses and nurse practitioners are required to achieve whether their areas of practice are clinical, education, administration and/or research. The Professional Standards of the regulatory bodies require nurses to have the responsibility and accountability to provide safe, ethical care for their patients as well as the need to provide knowledge-based practice that appropriately focuses and meets patients’ needs.

It is within the nurses’ scope of practice to carry out the *Canadian Guidelines on Parkinson’s Disease* (Parkinson Society Canada, 2012). Nurses are educated and authorized to perform direct and ongoing patient assessments that promote screening and detection of Parkinson’s disease and its comorbidities including depression. Assessments of patient status include observation, communication, physical assessment and a review of pertinent clinical data such as comorbidities (CRNBC, 2014). In collaboration with physicians, these assessments are critical to achieve clinical recommendations pertaining to comorbid depression in the Canadian guidelines, whereby clinicians should have a low threshold for diagnosing depression and the awareness that clinical features of depression often overlap with the motor symptoms of Parkinson’s disease (Parkinson Society Canada, 2012). Nurses are also able to seek and utilize findings from meta-analysis, systematic reviews, and randomized control trials to disseminate and advocate for changes in policies in an ongoing basis (CARNA, 2013; CRNBC, 2014).

A patient-centered approach, particularly concerning communication, can facilitate the quality of care in managing depression associated with Parkinson’s disease (Parkinson Society
Canada, 2012). Consistent with the Canadian guidelines that encourage compassionate and clear communication, it is a Professional Standard of nurses to communicate a plan of care that evaluates patients’ response and advocates for necessary referrals to specialized care (CARRNA, 2013; CNO, 2013; CRNBC, 2012). Nurses have significant roles in administering, monitoring, and documenting medications and their side effects to promote patient adherence and informed choices (CRNBC, 2014). The nursing role on patient medications aligns directly with the Canadian guidelines in which Amitriptyline, a tricyclic antidepressant, may be administered as the treatment of choice for depression in Parkinson’s disease (Parkinson Society Canada, 2012).

In summary, the current literature provides knowledge on the cardinal motor symptoms and non-motor symptoms of Parkinson’s disease. Dopaminergic replacement therapy is a legitimate choice for motor symptom management of Parkinson’s disease and evidence show that depression is the most prevalent comorbidity in Parkinson’s disease. However, gaps in the literature warrant further research. The underlying gender differences in the manifestation and treatment of motor and non-motor symptoms of Parkinson’s disease remain poorly understood and lack rigorous evidence. Although many people with Parkinson’s disease are managed in primary care, evidence suggest that primary care providers have knowledge and practice gaps on accurate diagnosis and management of Parkinson’s disease and its comorbidities. Limited understanding exists on the differences in depression treatments between men and women with Parkinson's disease in primary care. There is a current need to examine the characteristics of people with Parkinson’s disease in Canadian primary care settings. Using available data from CPCSSN, this study addressed these literature gaps by examining the demographic and health characteristics of men and women with Parkinson’s disease as well as the pharmacologic treatments for depression between men and women with Parkinson’s disease and depression.
Chapter Three: Methods

Chapter Three describes the theoretical framework, methodology, and procedures used in the study including sampling, data collection, ethical considerations, data analysis, and validity of measures. This study was a retrospective cohort study that used available data as recorded in CPCSSN. A secondary analysis was conducted to look for differences between men and women with Parkinson’s disease and an advisory group was recruited to discuss and triangulate the interpretation of the results. The study’s theoretical framework was the Health-Related Quality of Life Model by Ferrans, Zerwic, Wilbur, and Larson (2005).

3.1. Theoretical Framework: Health-Related Quality of Life Model

The concept of quality of life has been widely evaluated in the last 30 years. In a systematic review of 100 articles on Health-Related Quality of Life (HRQoL), Bakas et al. (2012) found that the two most frequently used HRQoL tools are the Wilson and Cleary (1995) and Ferrans and colleagues (2005) HRQoL models. The published articles in Bakas et al.’s systematic review were from 21 different countries, such as United States, Canada, United Kingdom, Netherlands, and Australia, and pertained to HRQoL models that guided wide spectrum of studies including literature reviews, instrument development studies, descriptive or correlational studies, intervention studies, or clinical practice.

Ferrans et al.’s (2005) HRQoL model is a revision of Wilson and Cleary’s (1995) model. Both models conceptualize HRQoL as the “subjective well-being related to how happy or satisfied someone is with life as a whole” (Wilson & Cleary, 1995, p. 62). There is integration on the biological and psychological aspects of patient health outcomes that link individual and environmental characteristics through a taxonomy of five major domains: biological function, symptoms, function status, general health perceptions, and overall quality of life. However,
Ferrans et al.’s revised model provides clearer definitions and implies reciprocal relationships between individual and environmental characteristics. Ferrans et al. retained the five domains in the original model but provided a simplified depiction of the model by removing non-medical factors and labels on the arrows restricting relationships (Figure 1).

Figure 1. Ferrans et al.’s (2005) Health-Related Quality of Life (HRQoL) Model

According to Ferrans et al.’s (2005) HRQoL model, individual characteristics include demographic, developmental, psychological, and biological factors while environmental characteristics include social and physical factors. The first domain, biological function, focuses on the function of cells, organs, and organ systems and can be indicated by laboratory tests, physical assessments such as body mass index, and medical diagnoses including comorbidities. The second domain, symptoms, refers to an individual’s subjective experience relative to physical, emotional, and psychological status such as mood or pain. The third domain, functional status, is an individual’s ability to perform tasks either reported by the individual or assessed by others. The fourth domain, general health perceptions, refers to the individual’s
global perception of health status. Finally, the overall quality of life domain is the individual’s overall life satisfaction influenced by the other domains and the individual and environment characteristics.

Bakas et al. (2012) argued that Ferrans et al.’s (2005) model seems to provide the greatest potential to guide research and practice on HRQoL. For the purpose of this study, Ferrans et al.’s (2005) HRQoL model served as the theoretical framework to provide background and guide the entire research process. The assumed reciprocal influences of individual and environmental characteristics on the five major domains were important because they supported the selection of key variables and identified potential links between the variables within the complexity of patients with Parkinson’s disease in Canadian primary care settings.

3.2. Research Design

3.2.1. Methodology: Retrospective Cohort. A retrospective cohort design was used in this study because it allowed an existing dependent variable within a defined group of people to be examined with one or more previously occurring independent variables (Polit & Beck, 2012). The available electronic medical records of patients with Parkinson’s disease from CPCSSN were analyzed to answer the two main research questions. The use of secondary analysis allowed already collected data to be reanalyzed by another investigator to answer new research questions (Polit & Beck). The results were presented to an advisory group comprised of primary care providers to discuss and seek feedback on the demographic and health characteristics of men and women with Parkinson’s disease as well as the pharmacologic treatments for depression between men and women with concurrent diagnoses of Parkinson’s disease and depression. There was also discussion on the implications of the study results in relation to primary care and the role of nurses in caring for patients with Parkinson’s disease.
3.2.2. Canadian Primary Care Sentinel Surveillance Network. The Canadian Primary Care Sentinel Surveillance Network (CPCSSN), originally funded by the Public Health Agency of Canada, is the first pan-Canadian multi-disease electronic medical record surveillance system. There are 11 practice based research networks across Canada that anonymously collects health information from the offices of approximately 700 participating primary care providers including family physicians and nurse practitioners, referred to as sentinels (CPCSSN, 2014). All 11 networks have received ethical approval from their institutions and Health Canada, and the sentinels, though mostly urban-located, represent a very similar geographic distribution to the 2010 National Physician Survey (Williamson et al., 2013). At the time of this study, there were over 600 000 patients in CPCSSN, which were systematically older, but reasonably similar to the age distribution of the 2011 Canadian Census (Williamson et al., 2013). Further, the patients of the participating sentinels can decline consent and correspondingly, there is an exclusion of collecting their de-identified electronic medical records.

3.2.2.1. Data Quality. De-identified data (Appendix A) are extracted from electronic medical records on a quarterly basis from participating sentinels in CPCSSN. The types of data include: eight chronic conditions (hypertension, osteoarthritis, diabetes, chronic obstructive pulmonary disease, depression, dementia, epilepsy, and Parkinson’s disease), demographics, encounters, encounter diagnoses, billings, laboratory results, medications, allergies, physical signs, medical procedures, referrals, risk factors, vaccines, and disease cases and indications (CPCSSN, 2012). Data are put into a network repository where it is further cleaned and validated using case-finding algorithms to enhance data quality (CPCSSN, 2014).

The quality in the diagnoses of the eight chronic health conditions has been validated. Williamson et al. (2014) developed and validated the eight CPCSSN case definitions and case-
finding algorithms used to identify the eight chronic health conditions. The construction of the case definitions for the chronic conditions used a combination of diagnostic code descriptions (ICD-9 codes), free text searches within the problem list, billing and encounter diagnoses, laboratory results, and medication history (Williamson et al., 2014; Wong et al., 2014b). Also, the case definitions undergone several revisions guided by published evidence as well as general and specialist physicians prior to validation and implementation using case finding algorithms. The CPCSSN diagnostic algorithms showed excellent and acceptable results; the sensitivity ranged from 77.8% to 98.8% while the specificity was greater than 93.5% for all chronic conditions (Williamson et al., 2014). The positive predictive values showed a range from 72.1% to 92.9% and the negative predictive ranged from 86.0% to 99.9% for all chronic conditions.

Parkinson’s disease has 98.8% sensitivity, 99.0% specificity, 82.0% positive predictive values, and 99.9% negative predictive value (Williamson et al., 2014). The case definition used for Parkinson’s disease included paralysis agitans and parkinsonism while tremor, Wolf-Parkinson-White syndrome, and “suspected” or “possible” variants of the inclusions were excluded. The validation results for comorbid depression are 81.1% sensitivity, 94.8% specificity, 79.6% positive predictive values and 95.2% negative predictive values (Williamson et al., 2014). The case definition for depression included episodic mood disorders, depressive disorder, bipolar, manic affective disorder, manic episodes, mild depression (not simply clinical depression) while the exclusions were anxiety disorders, alcohol or drug-induced mental disorders, schizophrenic disorders, delusional disorders, nonorganic psychoses, pervasive developmental disorders, or other intellectual disabilities (Williamson et al., 2014).

3.2.3. Sample Size and Power Calculation. All electronic medical records of patients with a recorded diagnosis of Parkinson’s disease and had an encounter with a participating
primary care provider in CPCSSN between September 30, 2012 and 2014 were eligible in this study. The use of a two-year period is the recommended number of years of data to define the practice populations in primary care (Menec, Black, Roos, Bogdanovic, & Reid, 2000). An a priori power analysis was calculated to determine the sample size needed to detect gender differences in the number and type of pharmacologic treatments for comorbid depression. By convention, a Cohen’s medium effect size of 0.5, alpha of 0.05, and a power of 0.80 were used for the power calculation (Polit & Beck, 2012).

Based on consultation with a statistician (R. White, personal communication, September 18, 2014) and the G*Power results (Table 1), a 1-tail t-test for difference of two independent means requires 51 patients per group and a z-test for difference of two independent proportions requires 49 patients per group. All 11 practice based research networks in CPCSSN were included to acquire sufficient sample size and statistical power.

<table>
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<tr>
<th>Statistical Test</th>
<th>t tests</th>
<th>z tests</th>
</tr>
</thead>
<tbody>
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<td>Proportions: Difference between two independent proportions</td>
</tr>
<tr>
<td>A priori: Compute required sample size</td>
<td>A priori: Compute required sample size</td>
<td></td>
</tr>
<tr>
<td>Tail(s) = One</td>
<td>Tail(s) = One</td>
<td></td>
</tr>
<tr>
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<td>Proportion p2 = 0.375</td>
<td></td>
</tr>
<tr>
<td>α err prob = 0.05</td>
<td>Proportion p1 = 0.625</td>
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</tr>
<tr>
<td>Power (1-β err prob) = 0.80</td>
<td>α err prob = 0.05</td>
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<tr>
<td>Allocation ratio N2/N1 = 1</td>
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</tr>
<tr>
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<td>Critical z = -1.6448536</td>
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<td>Sample size group 2 = 49</td>
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<td></td>
</tr>
<tr>
<td>Total sample size = 102</td>
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</tr>
<tr>
<td>Actual power = 0.8058986</td>
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</tbody>
</table>

### 3.2.4. Data Collection Procedures

One of the co-directors of the British Columbia CPCSSN node is Dr. Sabrina Wong, a Professor at the University of British Columbia (UBC).
School of Nursing and Centre for Health Services and Policy Research. With Dr Wong’s supervision, a request to gain access to CPCSSN database was obtained. Further, a Letter of Intent, a Data Request Form, and a Data Sharing Agreement were submitted electronically and approved by the CPCSSN Research Committee. There was also a partnership with the two directors of the Alberta CPCSSN nodes: Dr. Neil Drummond from the Southern Alberta Primary Care Research Network (SAPCReN) and Dr. Donna Manca from the Northern Alberta Primary Care Research Network (NAPCReN). Dr. Wong provided direction to the CPCSSN Information & Technology manager and British Columbia CPCSSN data manager to extract available data on patients with Parkinson’s disease. Data extraction and collection were completed within a six-month period and structured forms using Microsoft Excel spreadsheet software were developed. A reflective journal and an audit trail were kept to assess objectivity and consistency of methods.

3.2.4.1. **Key Variables and Rationale.** Using Ferrans et al.’s (2005) HRQoL theoretical model and the available data in CPCSSN, a list of key variables was selected to answer the two main research questions, which examined the demographic and health characteristics of men and women with Parkinson’s disease as well as the pharmacologic treatments for depression between men and women with Parkinson’s disease and depression.

The key variables for demographic characteristics included gender, current age, age at diagnosis, duration of Parkinson’s disease, number of encounters with a primary care provider in a one-year and two-year period, and residence type. Such demographic data pertained to Ferrans et al.’s (2005) HRQoL model by informing the individual and environmental characteristics and the potential influences in the domains of biological function and functional status. Gender is a basic individual characteristic shown to be an influencing factor in determining differences between men and women related to the epidemiology, etiology, and pathology of many complex
diseases, including neurodegenerative diseases such as Parkinson’s disease (Haaxma et al., 2007; Taylor et al., 2007). The number of encounters with a primary care provider indicates the utilization of primary care services in a one-year and two-year period; social environmental characteristics, including interactions with healthcare providers, can affect continuity of treatments and health outcomes of individuals (Ferrans et al., 2005). Residence type, whether living in urban or rural, indicates a physical environmental factor that can affect health outcomes either positively or negatively due to the differences in exposures or access to care (Ferrans et al.). Current age, age at diagnosis, and duration of Parkinson’s disease are basic but significant characteristics that describe the neurodegenerative nature of Parkinson’s disease and influence the epidemiological status since its prevalence and incidence appear to increase with age and has a typical age onset of 50 to 75 years old (Moore & Seeney, 2007; Muangpaisan et al., 2011).

The key variables for health characteristics included body mass index (BMI), smoking status, and the number and type of comorbidities. Body mass index and smoking status are risk factors for many chronic diseases; being underweight or obese is known to have negative effects on the body while cigarette smoking contains hazardous toxins (Chang, Ho, Wong, Gentleman, & Ng, 2014; Pilhatsch et al., 2013). These health characteristics variables pertained to individual characteristics and their potential effects on the domains of biological function and functional status in Ferrans et al.’s (2005) HRQoL model. Individual characteristics can influence the biological vulnerability and resilience to health complications as well as the ability to perform tasks on a day-to-day basis (Ferrans et al.). The concurrent chronic conditions described the complexity of patients with Parkinson’s disease. There was an emphasis on collecting data on comorbid depression with age of diagnosis and duration given that depression is one of the most
common comorbidity in Parkinson’s disease and may even predate the diagnosis of Parkinson’s
disease (Hermanns et al., 2012; Parkinson Society Canada, 2012; Shearer et al., 2012).

The key variables for the pharmacologic treatments for depression included the number
and type of medications prescribed to men and women with concurrent diagnoses of Parkinson’s
disease and depression in a two-year period. The differences in number and type of medications
for comorbid depression can inform and affect the biological function, functional status, and
symptoms domains in Ferrans et al.’s (2005) HRQoL model. The type of medications were
categorized using Wong et al.’s (2014b) list of commonly used medications for the treatment of
depression with additional input from the supervisory thesis committee and advisory group
(Appendix B). The classification of medications included selective serotonin reuptake inhibitors,
tricyclics and tetracyclics, serotonin norephinephrine reuptake inhibitors, serotonin antagonist
and reuptake inhibitors, atypical antipsychotics, monoamine oxidase inhibitors, and bipolar
medications. Benzodiazepines and related hypnosedatives were also added with the rationale
that they can be prescribed for treating symptoms in depression, including insomnia and agitation
Anatomical Therapeutic Chemical index and RxFiles’ benzodiazepine comparison chart (Jensen,
2015) were utilized to create the list of common benzodiazepines and related hypnosedatives.

3.2.5. Ethical Considerations. Every stage of this research study encompassed ethical
considerations to uphold the underlying value of respect for human dignity, a basis for the core
principles in the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans
(2010). There were ethical approvals from the UBC Behavioral Research Ethics Board and
CPCSSN prior to extracting data on patients with Parkinson’s disease. There were also written
agreements with the Alberta CPCSSN node to ensure confidentiality of extracted data.
Polit and Beck (2012) stated that an informed consent “means the participants have adequate information about the research, comprehend that information and have the ability to consent to or decline participation voluntarily” (p. 157). Verbal and written consents were obtained from the recruited advisory group comprised of primary care providers to ensure they fully read and understood the study intentions. The consent form (Appendix C) was comprehensive and explicitly stated that primary care providers were in a voluntary position as required by UBC Behavioral Research Ethics Board (2012). The completed consent forms were kept in Dr. Wong’s office in a locked file cabinet in a secured building at UBC.

The use of secondary data was also assessed for ethical concerns which included the lack of direct informed consent from individuals on the specific use of data as well as the unknown vulnerable populations that might be at risk. Though the electronic medical records of patients with Parkinson’s disease in CPCSSN were already de-identified, the data were handled with utmost protection of confidentiality. There was a master list of data on patients with Parkinson’s disease in a hard copy and a computer file, which the co-investigator locked with a key in a secured office and protected by a password and encrypted, respectively. The primary investigator, co-investigator, and British Columbia CPCSSN data manager had access to all data. A statistician, supervisory thesis committee, and advisory group were consulted to verify the analyses of the data and minimize potential biases. A reflective journal and an audit trail were kept. As required by the UBC Behavioral Research Ethics Board (2012), data will be kept for five years before destroying. All hard copy paper data will be shredded and computer files data will be erased.

3.2.6. Data Analysis Procedures. Data analyses were carried out for six months using the free, statistical computing software R Studio (Version 3.1.2). Descriptive and inferential
statistics were used to analyze all the key variables by gender and as a total sample. Descriptive statistics involved percentages, means, and standard deviations to determine the frequency distributions and assess heterogeneity (Polit & Beck, 2012). Inferential statistics provided a method for drawing tentative conclusions about the general population with the collected data from the sample (Polit & Beck). A t-test is a parametric procedure used to test group differences between two means while a chi-square ($x^2$) test of independence was used to compare group differences in proportions (Polit & Beck). The level of statistical significance was set at 0.05 to minimize Type I Error, the probability of incorrectly rejecting a true null hypothesis or a false positive conclusion (Polit & Beck). The study’s power was set at a conventional standard of 0.80 or 20% risk of Type II Error, the probability of incorrectly rejecting a false null hypothesis or a false negative conclusion (Polit & Beck).

To answer Research Question 1, the data were analyzed in two groups, males and females, to describe and test the differences in demographic and health characteristics between gender groups. Gender is a nominal-level variable used to stratify the rest of the selected key variables; males were coded as “0” (reference) and females as “1”. Age in years is a ratio-level variable analyzed to obtain mean with standard deviation. Age was also transformed into an ordinal-level variable to obtain the frequency in percentages between age groups using the following codes: “0” = 1-50, “1” = 51-60, “2” = 61-70, “3” = 71-80, “4” = 81-90, “5” = greater than 90. Age at diagnosis and duration in years of Parkinson’s disease are ratio-level variables analyzed to obtain means with standard deviations. Number of encounters with a primary care provider in a one-year and two-year period is ratio-level variable analyzed to obtain means with standard deviations. Residence type is a nominal-level variable analyzed to obtain frequency in percentages using the codes: “0” = urban and “1” = rural.
Body mass index (BMI) is a ratio-level variable analyzed to obtain means with standard deviations but also, transformed in an ordinal-level data using the codes: “0” = normal (18–24 kg/m²), “1” = underweight (less than 18.5 kg/m²), “2” = overweight (25–29 kg/m²), “3” = obesity (30 kg/m² or greater). Smoking status is a nominal-level variable analyzed to obtain frequency in percentages using the codes: “0” = never, “1” = present, “2” = past. The number of comorbidity with Parkinson’s disease is a ratio-level variable but categorized into four groups to obtain frequency in percentages using the codes: “0” = no comorbidity, “1” = 1 comorbidity, “2” = 2 comorbidities, “3” = 3 or greater comorbidities. The type of comorbidity with Parkinson’s disease is a nominal-level variable analyzed to obtain frequency in percentages using the codes: “0” = depression, “1” = hypertension, “2” = osteoarthritis, “3” = diabetes, “4” = chronic obstructive pulmonary disease, “5” = dementia, and “6” = epilepsy.

To answer Research Question 2, the data were analyzed to describe and test whether there were differences in the number and type of pharmacologic treatments for depression between men and women with concurrent diagnoses of Parkinson’s disease and depression. The number of pharmacologic treatments for comorbid depression is a ratio-level variable but also categorized into four groups to analyze for frequency in percentages by gender using the codes: “0” = no medication, “1” = 1 medication, “2” = 2 medications, “3” = 3 or greater medications. The type of pharmacologic treatments for comorbid depression is an ordinal-level variable analyzed for frequency in percentages by gender. The type of pharmacologic treatments for comorbid depression was categorized using the following codes: “0” = no depression medications, “1” = selective serotonin reuptake inhibitor, “2” = tricyclics and tetracyclics, “3” = serotonin norepinephrine reuptake inhibitors, “4” = serotonin antagonist and reuptake
inhibitors, “5” = atypical antipsychotics, “6” = monoamine oxidase inhibitors, “7” = bipolar medications, and “8” = benzodiazepines and related hypnosedatives.

Poisson and logistic regression were also carried out to further examine where there were any gender differences in the recorded number and type of pharmacologic treatments for depression in Parkinson’s disease while controlling for the number of encounters with a primary care provider in a two-year period. A Poisson regression model data yields the rate ratio of a dependent variable given two or more independent variables (Vittinghoff, Glidden, Shiboski, & McCulloch, 2005) while a logistic regression is a statistical procedure that analyzes relationships between one or more independent variables and a categorical dependent variable (Polit & Beck, 2012). In the current study, the main independent variable was gender: men and women with concurrent diagnoses of Parkinson’s disease and depression. The main dependent variables were the recorded number and type of pharmacologic treatments for comorbid depression in a two-year period between September 30, 2012 and 2014) in the CPCSSN database. The main covariate was the number of encounters with a primary care provider in a two-year period, which used a log-2 scale in the Poisson and logistic regressions. A log-2 scale offered control for the variations in the number of encounters, particularly to account for some outliers influencing the regression models (R. White, personal communication, June 29, 2015). There was no evidence of overdispersion in the residuals of the Poisson regression, suggesting the required model assumption of equal variance and mean (Vittinghoff et al., 2005) was met and this was verified by the statistician (R. White, personal communication, April 2, 2015).

3.2.7. Advisory Group. An advisory group was formed to provide interpretation about the study’s findings. Their interpretation offered a way in which to triangulate the results; triangulation refers to the use of multiple data sources and/or methods with the aim of validating
and strengthening conclusions of the study results (Polit & Beck, 2012). Triangulation in this study provided a more complete and contextualized portrait of primary care practice for those patients with Parkinson’s disease. The eligibility criteria included primary care providers from the Alberta and British Columbia CPCSSN nodes and the recruitment process for advisory group members occurred within a two-month period.

There was a semi-structured discussion in order to discuss and seek feedback on the results. Primary care providers were also asked on the potential role of nurses in depression treatments associated with Parkinson’s disease. Each primary care provider was contacted via email and/or telephone using recruitment scripts (Appendix E) to obtain consent for a 45-minute discussion at a mutually agreed time and location. Demographic characteristics were obtained: participant’s name, age, gender, type of profession, and years of practice (Appendix D). All procedures were approved by the UBC Behavioral Ethics Board (2012).

3.2.8. Validity of Measures: Rigor. A validity taxonomy consisting of four aspects to strengthen research design was utilized: external validity, internal validity, statistical conclusion validity, and construct validity (Polit & Beck, 2012). The four aspects of validity identified threats and strategies which enhanced rigor in this study.

External validity refers to “the degree to which study results can be generalized to settings or samples other than the one studied” (Polit & Beck, 2012, p. 727). The study’s results were limited to the available data from the participating primary care providers in CPCSSN. There were potential differences in the delivery of primary care between provinces and territories and further, the health care system of Canada may differ from other countries. Despite the limitations, this study was the first of its kind using the CPCSSN database and provided foundational knowledge on patients with Parkinson’s disease in primary care across Canada.
Internal validity refers to “the degree to which it can be inferred that the experimental intervention (IV), rather than uncontrolled, extraneous factors, is responsible for the observe effects” (Polit & Beck, 2012, p. 731). The strategies that strengthened internal validity in this study include the explicit description of data analyses and the triangulation of results with the statistician, supervisory thesis committee, and advisory group. Reflective journals and audit trail held the analytical line of reasoning up for scrutiny.

Statistical conclusion validity is “the degree to which inferences about relationships from a statistical analysis of the data are correct” (Polit & Beck, 2012, p. 743). The consultation with a statistician assisted in determining the appropriate sample size needed to detect differences between groups using a significance level of 0.05 and a power of 0.80. Hence, all 11 practice based research networks across Canada were included to obtain adequate the sample size and strengthen the statistical conclusion validity of the study results.

Construct validity refers to “the validity of inferences from observed persons, settings, and interventions in a study to the constructs that these instances might represent; with an instrument, the degree to which it measures the construct under investigation” (Polit & Beck, 2012, p. 723). The construct validity of the study was strengthened by using Ferrans et al.’s (2005) HRQoL model as theoretical framework to guide and support the selection of key variables that affect health related quality of life in people with Parkinson’s disease. Conceptual definitions were provided on main terms and key variables including depression in Parkinson’s disease, primary care settings, and types of medications for depression. Treatment diffusion was a potential threat since depression treatments linked with Parkinson’s disease might be blurred due to off-label uses of some medications as well as the potential incomplete electronic medical records in CPCSSN database.
Chapter Four: Findings

Chapter Four is organized to answer the two main research questions and the respective hypotheses outcomes based on the results of descriptive and inferential statistics.

4.1. Study Sample: Demographic and Health Characteristics

Drawing on the data available between September 30, 2012 and 2014 from CPCSSN, Table 2 summarizes the demographic and health characteristics of patients with a diagnosis of Parkinson’s disease by gender and as a total sample. There were a total of 1,824 patients with a diagnosis of Parkinson’s disease who had at least one encounter with a primary care provider in a two-year period. Seven patients (0.4%) were excluded because they were recorded as deceased and an additional two patients (0.1%) were excluded due to the lack of recorded gender data. Thus, the analyses were based on 1,815 patients: 996 men (54.9%) and 819 women (45.1%).

The age of the patients ranged from 14 to 105 years old with the mean distribution being older (M = 74.6, SD = 12.4). The mean age at diagnosis and duration of Parkinson’s disease were 71.3 years old (SD = 12.6) and 3.3 years (SD = 2.8), respectively. The average number of encounters with a primary care provider was 7.5 in a one-year period and 15.5 in a two-year period. The majority of patients (82.0%, n = 1433) were living in urban areas.

The average BMI of patients was 26.7 kg/m²; 37.5% (n = 320) of those with recorded BMI were overweight. The majority of patients (55.3%, n = 431) with recorded smoking status had never smoked but about one in three had a history of smoking with men more likely to smoke than women in the past. Most patients with Parkinson’s disease (83.6%, n = 1517) also had one or more comorbidity relative to the conditions monitored in CPCSSN. The most frequent comorbidities were hypertension (n = 973), depression (n = 578), and osteoarthritis (n = 572). Men had significantly fewer diagnoses of depression and osteoarthritis than women.
Table 2. Recorded demographic and health characteristics of patients with a diagnosis of Parkinson’s Disease in the Canadian Primary Care Sentinel Surveillance Network (N = 1,815)

<table>
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<tr>
<th>Characteristic</th>
<th>Male (n = 996), %</th>
<th>Female (n = 819), %</th>
<th>Total (n = 1,815), %</th>
</tr>
</thead>
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<tr>
<td>Age†, mean (SD)</td>
<td>74.1 (11.8)</td>
<td>75.1 (13.4)</td>
<td>74.6 (12.4)</td>
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<tr>
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</tr>
<tr>
<td>&gt;90</td>
<td>4.0</td>
<td>8.2</td>
<td>5.9</td>
</tr>
<tr>
<td>Age at diagnosis of Parkinson’s disease†, mean (SD)</td>
<td>70.9 (11.7)</td>
<td>71.8 (12.6)</td>
<td>71.3 (12.6)</td>
</tr>
<tr>
<td>Duration of Parkinson’s disease in years†, mean (SD)</td>
<td>3.3 (2.8)</td>
<td>3.4 (2.8)</td>
<td>3.3 (2.8)</td>
</tr>
<tr>
<td>Encounters with a primary care provider, mean (SD)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-year period</td>
<td>7.2 (9.2)</td>
<td>7.9 (10.1)</td>
<td>7.5 (9.6)</td>
</tr>
<tr>
<td>2-year period</td>
<td>14.7 (16.1)</td>
<td>16.3 (17.3)</td>
<td>15.5 (16.7)</td>
</tr>
<tr>
<td>Residence type†</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>82.9</td>
<td>81.3</td>
<td>82.0</td>
</tr>
<tr>
<td>Rural</td>
<td>17.1</td>
<td>18.8</td>
<td>18.0</td>
</tr>
<tr>
<td>Body mass index† (n = 853), mean (SD)</td>
<td>27.0 (4.8)</td>
<td>26.2 (5.6)</td>
<td>26.7 (5.2)</td>
</tr>
<tr>
<td>Normal (18–24)</td>
<td>29.8</td>
<td>38.9</td>
<td>33.8</td>
</tr>
<tr>
<td>Underweight (≤ 18)</td>
<td>0.2</td>
<td>2.2</td>
<td>1.1</td>
</tr>
<tr>
<td>Overweight (25–29)</td>
<td>41.8</td>
<td>31.9</td>
<td>37.5</td>
</tr>
<tr>
<td>Obese (≥30)</td>
<td>28.2</td>
<td>27.0</td>
<td>27.7</td>
</tr>
<tr>
<td>Smoking status† (n = 779)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>49.6</td>
<td>63.4</td>
<td>55.3</td>
</tr>
<tr>
<td>Current</td>
<td>10.4</td>
<td>11.6</td>
<td>10.9</td>
</tr>
<tr>
<td>Past</td>
<td>40.1</td>
<td>25.0</td>
<td>33.8</td>
</tr>
<tr>
<td>Number of comorbidities*, mean (SD)</td>
<td>1.7 (1.2)</td>
<td>1.9 (1.3)</td>
<td>1.8 (1.3)</td>
</tr>
<tr>
<td>0</td>
<td>16.9</td>
<td>15.9</td>
<td>16.4</td>
</tr>
<tr>
<td>1</td>
<td>30.1</td>
<td>28.6</td>
<td>29.4</td>
</tr>
<tr>
<td>2</td>
<td>28.2</td>
<td>25.3</td>
<td>26.9</td>
</tr>
<tr>
<td>3+</td>
<td>24.8</td>
<td>30.3</td>
<td>27.3</td>
</tr>
<tr>
<td>Type of comorbidity‡ (n = 1,517)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hypertension</td>
<td>62.8</td>
<td>65.8</td>
<td>64.1</td>
</tr>
<tr>
<td>Depression*</td>
<td>34.2</td>
<td>42.8</td>
<td>38.1</td>
</tr>
<tr>
<td>Osteoarthritis*</td>
<td>31.3</td>
<td>45.4</td>
<td>37.7</td>
</tr>
<tr>
<td>Dementia</td>
<td>29.6</td>
<td>28.2</td>
<td>29.0</td>
</tr>
<tr>
<td>Diabetes</td>
<td>19.6</td>
<td>33.7</td>
<td>26.0</td>
</tr>
<tr>
<td>COPD*</td>
<td>17.6</td>
<td>11.3</td>
<td>14.8</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>3.1</td>
<td>4.1</td>
<td>3.6</td>
</tr>
</tbody>
</table>

SD = standard deviation; COPD = chronic obstructive pulmonary disease.

Note: Excluded deceased cases (0.4%) and cases without recorded gender (0.1%). Analysis based on N = 1,815.
† Missing data: Age, Age at Diagnosis of Parkinson’s Disease, Duration of Parkinson’s Disease, and Residence Type had < 4.0% missing data; Body Mass Index: 53.0%, Smoking Status: 57.1%.
‡ Column percentage is >100% given that people could have more than one chronic condition.
* Significance by gender defined as P < .05 using t-test and chi-square of independence test.
4.2. Pharmacologic Treatments for Depression in Parkinson’s Disease

Table 3 describes the pharmacologic treatments for a diagnosis of depression among men and women with Parkinson’s disease and depression in a two-year period as recorded in CPCSSN. The following analyses were based on 578 patients (49.0% men) with concurrent diagnoses of Parkinson’s disease and depression.

The mean age of patients with Parkinson’s disease and depression was 71.9 years old (SD = 12.1). While some (41.8%, n = 242) had a diagnosis of depression before Parkinson’s disease, about 58.1% (n = 336) of patients had a diagnosis of depression within a year and after Parkinson’s disease. The average number of encounters with a primary care provider for patients with Parkinson’s disease and depression was 8.5 in a one-year period and 17.5 in a two-year period. In contrast, patients with a diagnosis of Parkinson’s disease but without a concurrent diagnosis of depression had a lower mean number of encounters with a primary care provider; 7.0 (SD = 9.9) encounters in a one-year period and 14.5 (SD = 16.9) encounters in a two-year period (data not shown in Table 3).

The average number of depression medications for patients with Parkinson’s disease and depression was 1.8, whereby one out of every three patients had one or two medications. The most common type of medications for those with a diagnosis of depression was selective serotonin reuptake inhibitors, prescribed to over half of the total patients with Parkinson’s disease and depression. Benzodiazepines and related hypnosedatives followed closely with approximately 47.2% (n = 273) of patients being prescribed this type of medications. Amitriptyline, the tricyclic antidepressant recommended in the Canadian Guidelines on Parkinson’s Disease (Parkinson Society Canada, 2012), was prescribed to 4.5% (n = 26) of patients with Parkinson’s disease and depression in a two-year period as recorded in CPCSSN.
**Table 3. Recorded depression medication prescriptions for depression management in patients with a diagnosis of Parkinson’s Disease and Depression in the Canadian Primary Care Sentinel Surveillance Network (N = 578)**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Male (n = 283), %</th>
<th>Female (n = 295), %</th>
<th>Total (n = 578), %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at diagnosis of Depression, mean (SD)</td>
<td>71.8 (11.9)</td>
<td>72.0 (12.3)</td>
<td>71.9 (12.1)</td>
</tr>
<tr>
<td>Pre-diagnosed of Parkinson disease</td>
<td>42.8</td>
<td>41.0</td>
<td>41.9</td>
</tr>
<tr>
<td>Post-diagnosed of Parkinson’s disease</td>
<td>57.2</td>
<td>58.6</td>
<td>58.1</td>
</tr>
<tr>
<td>Duration of Depression in years, mean (SD)</td>
<td>5.0 (3.1)</td>
<td>4.8 (3.2)</td>
<td>4.9 (3.2)</td>
</tr>
<tr>
<td>Encounters with a primary care provider, mean (SD)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-year period</td>
<td>8.3 (9.1)</td>
<td>8.6 (8.5)</td>
<td>8.5 (8.8)</td>
</tr>
<tr>
<td>2-year period</td>
<td>17.2 (16.5)</td>
<td>17.7 (15.6)</td>
<td>17.5 (16.1)</td>
</tr>
<tr>
<td>Number of medications for depression, mean (SD)</td>
<td>1.7 (1.2)</td>
<td>1.9 (1.2)</td>
<td>1.8 (1.2)</td>
</tr>
<tr>
<td>0</td>
<td>15.5</td>
<td>12.2</td>
<td>13.8</td>
</tr>
<tr>
<td>1</td>
<td>26.9</td>
<td>30.8</td>
<td>28.9</td>
</tr>
<tr>
<td>2</td>
<td>33.9</td>
<td>27.8</td>
<td>30.8</td>
</tr>
<tr>
<td>3+</td>
<td>23.7</td>
<td>29.2</td>
<td>26.5</td>
</tr>
<tr>
<td>Type of medications for depression</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Selective serotonin reuptake inhibitors</td>
<td>49.5</td>
<td>54.9</td>
<td>52.2</td>
</tr>
<tr>
<td>Benzodiazepines and related hypnosedatives</td>
<td>48.5</td>
<td>45.9</td>
<td>47.2</td>
</tr>
<tr>
<td>Atypical antipsychotics</td>
<td>30.4</td>
<td>32.9</td>
<td>31.7</td>
</tr>
<tr>
<td>Serotonin norepinephrine reuptake inhibitors</td>
<td>15.9</td>
<td>18.3</td>
<td>17.1</td>
</tr>
<tr>
<td>Serotonin antagonist and reuptake inhibitors</td>
<td>15.6</td>
<td>10.5</td>
<td>13.0</td>
</tr>
<tr>
<td>Tricyclics and tetracyclics</td>
<td>7.4</td>
<td>12.2</td>
<td>9.9</td>
</tr>
<tr>
<td>Amitriptyline†</td>
<td>6.0</td>
<td>3.1</td>
<td>4.5</td>
</tr>
<tr>
<td>Bipolar medications</td>
<td>8.5</td>
<td>10.2</td>
<td>9.3</td>
</tr>
<tr>
<td>Monoamine oxidase inhibitors</td>
<td>1.8</td>
<td>1.4</td>
<td>1.6</td>
</tr>
<tr>
<td>No depression medication</td>
<td>15.5</td>
<td>12.2</td>
<td>13.8</td>
</tr>
</tbody>
</table>

SD = standard deviation.
† Tricyclic recommended in Canadian Guidelines on Parkinson’s Disease (Parkinson Society Canada, 2012).

### 4.2.1. Poisson and Logistic Regression Models for Number and Type of Medications.

Table 4 shows that the rate for the number of medications for depression was 1.08 times in women compared to men after controlling for the number of encounters with a primary care provider in a two-year period. The rate ratio of 1.08 suggested that women had a non-significant 8.0% higher rate for the number of medications than men (95% CI = 0.95-1.22, \( p = 0.23 \)).

Adjusting for the number of encounters with a primary care provider revealed a significant 11.0% increased in the rate for number of medications for every two-fold in the number of encounters over a two-year period (RR = 1.11, 95% CI = 1.06-1.16, \( p < 0.001 \)).
Table 4. Encounter-adjusted Poisson regression for the recorded Number of Medications for Depression by Gender in patients with a diagnosis of Parkinson’s Disease and Depression (N = 578)

<table>
<thead>
<tr>
<th>Dependent Variable</th>
<th>Difference in Gender (male reference 1.00)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>RR</td>
<td>95% CI</td>
<td>P Value</td>
</tr>
<tr>
<td>Number of Medications</td>
<td>1.08</td>
<td>0.95-1.22</td>
<td>0.23</td>
</tr>
</tbody>
</table>

RR = Rate Ratio; 95% CI = Confidence Intervals (lower bound-upper bound); P Value = Probability Value.
Note: Gender served as the main independent variable and number of encounters with a primary care provider in a two-year period served as a covariate using a log-2 scale in the regression model; * Significance defined as P < .05.

Table 5 shows that there were no statistically significant odds differences in each type of medications for depression between men and women after adjusting for number of encounters with a primary care provider in a two-year period. Despite non-significance by gender, the odds ratios suggested a pattern that women were more likely than men to be prescribed the following type of medications: selective serotonin reuptake inhibitors, benzodiazepines and related hypnosedatives, atypical antipsychotics, serotonin norepinephrine reuptake inhibitors, tricyclics and tetracyclics, and bipolar medications. In contrast, the odd ratios for serotonin antagonist and reuptake inhibitors as well as monoamine oxidase inhibitors suggested that women were less likely than men to be prescribed these medications after adjusting for the number of encounters with a primary care provider in a two-year period.

Table 5. Encounter-adjusted Logistic regressions for the recorded Type of Medications for Depression by Gender in patients with a diagnosis of Parkinson’s Disease and Depression (N = 578)

<table>
<thead>
<tr>
<th>Dependent Variable</th>
<th>Difference in Gender (male reference 1.00)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>OR</td>
<td>95% CI</td>
<td>P Value</td>
</tr>
<tr>
<td>Selective serotonin reuptake inhibitors</td>
<td>1.25</td>
<td>0.90-1.73</td>
<td>0.19</td>
</tr>
<tr>
<td>Benzodiazepines and related hypnosedatives</td>
<td>1.11</td>
<td>0.80-1.54</td>
<td>0.55</td>
</tr>
<tr>
<td>Atypical antipsychotics</td>
<td>1.12</td>
<td>0.79-1.59</td>
<td>0.52</td>
</tr>
<tr>
<td>Serotonin norepinephrine reuptake inhibitors</td>
<td>1.18</td>
<td>0.77-1.83</td>
<td>0.45</td>
</tr>
<tr>
<td>Serotonin antagonist and reuptake inhibitors</td>
<td>0.64</td>
<td>0.39-1.04</td>
<td>0.07</td>
</tr>
<tr>
<td>Tricyclics and tetracyclics</td>
<td>1.73</td>
<td>0.99-3.10</td>
<td>0.06</td>
</tr>
<tr>
<td>Bipolar medications</td>
<td>1.22</td>
<td>0.69-2.16</td>
<td>0.49</td>
</tr>
<tr>
<td>Monoamine oxidase inhibitors</td>
<td>0.76</td>
<td>0.19-2.90</td>
<td>0.68</td>
</tr>
</tbody>
</table>

OR = Odds Ratio; 95% CI = Confidence Intervals (lower bound-upper bound); P Value = Probability Value.
Note: Gender served as the main independent variable and the number of encounters with a primary care provider in a two-year period served as a covariate using a log-2 scale in the regression model; * Significance defined as P < .05.
4.3. Summary of the Advisory Group’s Feedback on Study Results

Table 6 shows the summary of the advisory group’s feedback on the interpretations of results. A series of individual 45-minute telephone meetings were carried out within one month. There were five primary care providers (40.0% men, 60.0% women) who were all over 30 years old and currently practicing as family physicians in Alberta or British Columbia, Canada. They had varying years of clinical practice (40.0% - 6 to 10 years, 20.0% - 11 to 15 years, 40.0% - over 20 years) and were all participating sentinels in CPCSSN.

<table>
<thead>
<tr>
<th>Demographic and health characteristics of men and women with a diagnosis of Parkinson’s disease</th>
<th>Number and type of medications for depression in men and women with Parkinson’s disease and depression</th>
<th>Implications of findings for primary care and nursing</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Good overview of characteristics; sample were mostly older adults</td>
<td>- High prevalence of SSRIs and BDZs may be due to current prescription trends</td>
<td>- High prevalence of comorbid depression need to be routinely assessed</td>
</tr>
<tr>
<td>- Results of residence type might be reflective of Canadian population and/or sentinels’ locations</td>
<td>- BDZs and TCAs have adverse side effects in the elderly</td>
<td>- Insufficient evidence to support TCAs, particularly Amitriptyline, and there is a need for more randomized controlled trials</td>
</tr>
<tr>
<td>- Obesity needs monitoring; overweight BMI range may be protective in elderly</td>
<td>- Amitriptyline may be more used for insomnia or nerve pain</td>
<td>- Multiple medications (polypharmacy) need to be recognized due to adverse side effects</td>
</tr>
<tr>
<td>- Discuss prevalence of comorbidities with past work on patients with Parkinson’s disease and/or older patients</td>
<td>- Regression results are non-significant; but there is a pattern of higher rate and odds in women than men</td>
<td>- Nurses have the scope to assess medication side effects and comorbidities</td>
</tr>
<tr>
<td>- Limitation: missing data on some variables might be reflective of providers not routinely recording data; potential difficulty in diagnosing chronic conditions versus aging process</td>
<td>- Limitation: medications assessed assume they are for depression, which is not always the case; analyses do not consider reasons, dosage, and duration of medication prescriptions</td>
<td></td>
</tr>
</tbody>
</table>

BMI = Body Mass Index; SSRIs = Selective Serotonin Reuptake Inhibitors; BDZs = Benzodiazepines; TCAs = Tricyclic Antidepressants

Note: There were 5 family physicians (40.0% men) who were all >30 years old and practicing in Alberta or British Columbia, Canada with varying years of clinical practice. Feedback was based on individual 45-minute meetings.

The advisory group found the results informative as it provided an overview of the demographic and health characteristics of men and women with Parkinson’s disease as well as the pharmacologic treatments for depression among those with comorbid depression. They pointed out that the patients were an older sample who had a high rate of encounters with primary care providers. To contextualize the findings, the providers suggested comparing the
prevalence of Parkinson’s disease and its comorbidities with previous evidence while also acknowledging the limitations of missing data on some variables, which could be explained by the providers’ practices who might not routinely record certain data. Two providers queried that the high proportion of patients in urban areas might be reflective of the geographic distribution of Canadian population and/or the sentinels’ practice locations. Though an obesity BMI range still requires monitoring, one provider discussed the protective role of being overweight in the elderly.

The providers indicated that the high prevalence of certain medications might be due to the current prescription trends in treating depressive symptoms and they felt it was important to discuss the existing evidence on adverse side effects of benzodiazepines and tricyclics in older adults. Despite non-significance in the number and type of medications by gender, the providers recognized a pattern that women received higher rate and odds than men and they indicated that they did not often prescribe tricyclics in the elderly. Two providers pointed out that the reasons, dosage, and duration of the medications were not assessed; thus, they suggested acknowledging the assumption that the medications were prescribed for depression in this study.

The advisory group recognized the high prevalence of depression in Parkinson’s disease and suggested that comorbid depression needs to be assessed routinely and comprehensively in primary care. Though Canadian guidelines recommend Amitriptyline, all the providers felt there is insufficient evidence for its routine use and more randomized controlled trials are necessary. They suggested that the potential combination of medications to treat comorbidities in Parkinson’s disease warrant important attention and it is within the nurses’ scope of practice to assess these medications and comorbidities.
Chapter Five: Discussion

Chapter Five discusses the primary study results and interpretations drawn from the findings relative to the current literature and the advisory group’s feedback. The strengths, limitations, and implications of the findings for nursing practice and education are discussed. Recommendations for future research and dissemination of findings are also presented.

5.1. Discussion of Findings

This large retrospective cohort design study analyzed the available electronic medical records of patients with Parkinson’s disease who had at least one encounter with a primary care provider over a two-year period in CPCSSN. It is the first Canadian study to examine the demographic and health characteristics of men and women with Parkinson’s disease as well as the pharmacologic treatments among those with comorbid depression. The use of Ferrans et al.’s (2005) HRQoL model and the available data in CPCSSN supported the selection of the study’s key variables and provided a better understanding of the complexity of men and women with a diagnosis of Parkinson’s disease in primary care. The demographic and health characteristics informed the assumed reciprocal influences of individual and environmental characteristics as well as biological function, symptoms, and functional status domains in Ferrans et al.’s model.

5.1.1. Individual and Environmental Characteristics. There were a total of 1,815 patients with a diagnosis of Parkinson’s disease, roughly representing 0.3% of the total patients in CPCSSN within the study period. This prevalence is higher than the 0.2% estimate of Parkinson’s disease in the 2010/2011 Canadian Community Health Survey (Wong et al., 2014a). While previous work similarly suggested that Parkinson’s disease is more common in men than women, the mean diagnosis age of Parkinson’s disease found in this study showed an older sample of patients compared to the typical age onset of 50-75 years old (Moore & Seeney, 2007;
Muangpaisan et al., 2011; Taylor et al., 2007). The sample’s demographic characteristics, including gender, current age, age of diagnosis and duration of Parkinson’s disease, indicated basic but important individual attributes assumed to influence the biological vulnerability of patients to health complications and the extent to which they are able and be satisfied to function in daily activities (Ferrans et al., 2005). Notably, these older patients were found to have a higher number of encounters with a primary care provider in one-year and two-year periods compared to the average visit rate of 3 to 5 visits per year in the general older populations (Murray, Davies, & Boushan, 2007). Though there was no significant gender difference found in the number of encounters, Murray et al. similarly found a pattern that women have increased visits compared to men. This is an important finding given that the interaction with primary care providers is a social environmental characteristic that can affect continuity of health care treatments (Ferrans et al.). As the proportion of older populations continues to grow in Canada, the high utilization of primary care services by patients with Parkinson’s disease warrants recognition to ensure their health care needs are met.

5.1.2. Biological Function, Symptoms, and Functional Status Domains. Body mass index (BMI) is a risk factor that can be used as a simple screening tool to monitor weight status. Ferrans et al.’s (2005) HRQoL model indicated that body mass index is an example of physical health characteristic influencing the biological function of individuals. Among the patients with recorded BMI in this study, most were within the overweight category while a quarter of the patients were obese. Interestingly, there is some evidence that that an overweight BMI range in the elderly has been associated with lower mortality risk (Winter, MacInnis, Wattanapenpaiboon, & Nowson, 2014) while obesity, on the contrary, has been shown to have negative effects on the body as well as increase the risk of mental disorders, including depression (McCrea, Berger, &
King, 2012; Pilhatsch et al., 2013). Considering 38.1% of patients with Parkinson’s disease also had a diagnosis of depression in this study, the potential relationship between obesity and depression in Parkinson’s disease merits further investigations. Ferrans et al.’s HRQoL model regarded the psychological status of individuals as an important element of the symptoms domain and can impact overall quality of life.

The majority of patients with Parkinson’s disease also had one or more comorbidities relative to the chronic conditions monitored in CPCSSN, adding to the complexity in caring for these older patients. These comorbidities informed the domains of biological function, symptoms, and functional status in Ferrans et al.’s (2005) HRQoL model by revealing potential self-care and mobility limitations. The most common comorbidity was hypertension (64.1%); prior works reported similar high prevalence of hypertension in patients with Parkinson’s disease (Carey et al., 2015; Pressley et al., 2003). Pressley et al. found that when comparing patients with and without Parkinson’s disease, hypertension was prevalent in 66.1% and 58.0% of patients, respectively. By gender, the study findings on hypertension were higher compared to the general population over 65 years and older (45.7% men; 48.8% women), as reported by Statistics Canada (2014). The high prevalence of hypertension is necessary to recognize given that a recent systematic review by Carey et al. suggested that patients with concurrent diagnoses of Parkinson’s disease and cardiovascular conditions, such as hypertension, had further decline in their cognitive function beyond the deficits caused by Parkinson’s disease alone.

The finding that 38.1% of patients had concurrent diagnoses of Parkinson’s disease and depression was comparable to past work, which reported depression occurring up to 40-50% of cases in patients with Parkinson’s disease (Hermanns et al., 2012; Parkinson Society Canada, 2012; Shearer et al., 2012). Notably, it has been shown the general lifetime prevalence of
depression among 65 years and older in Canada is roughly between 11% and 20% (Wong et al., 2014b). The significant gender difference in the prevalence of depression found in this study is lower than what is found in the Canadian population but nevertheless adds to existing evidence that depression diagnosis is higher in women than men (Hinton et al., 2006; Unüitzer et al., 2003; Wong et al., 2014b). It is possible that the gender difference in the prevalence of depression diminishes with age (Patten et al., 2006), which may be reflective of the study’s older sample of patients with Parkinson’s disease and depression.

Findings on the prevalence of comorbid dementia and diabetes were comparable to previous work on patients with Parkinson’s disease (Pressley et al., 2003). The prevalence of osteoarthritis, COPD, and epilepsy in Parkinson’s disease is not well-established in the literature but the study findings can be compared to older adults in the general population. The prevalence of osteoarthritis and the significant gender difference found are consistent with existing evidence; there are more women affected with osteoarthritis than men by age 70-74 years (Kopec et al., 2007). Halbert et al. (2006) reported in a global systematic review that the prevalence of individuals aged 65 and older with COPD is similar to the patients with comorbid COPD in this study. Although epilepsy in Parkinson’s disease was found to be the lowest relative to the other chronic conditions in CPCSSN, it is important to consider that epilepsy is only present in 0.4-0.7% of Canadians aged 65 and over (Tellez-Zenteno, Pondal-Sordo, Matijevic, & Wiebe, 2004).

It was encouraging to find that about 86.2% of patients with Parkinson’s disease and depression had at least one medication for the treatment of depressive symptoms in the two-year period. This finding supports previous evidence demonstrating that the use of medications for treating depression in general is increasing in the Canadian population (Simpson, Meadows, Frances, & Patten, 2012). However, the statistically non-significant results cannot support the
alternative hypothesis posed at the outset of this study, predicting that women were likely to have a higher number of medications than men given the high prevalence of depression diagnosis and utilization of primary care in women (Hinton et al., 2006; Unützer et al., 2003; Wong et al., 2014b).

The most frequently prescribed type of medications for depression appeared to be selective serotonin reuptake inhibitors and there was a lack of statistically significant odds difference between men and women with Parkinson’s disease and depression. Compared to a national American Veteran Affairs database study by Chen et al. (2007), they also found that selective serotonin reuptake inhibitors were the most common antidepressants taken by patients with Parkinson’s disease and depression. Possible explanations for the high frequency could be the current prescription trends and lower side-effect profile compared to other types of medications, such as tricyclics, which have anticholinergic effects that potentially increase the risk of falls in older populations (Troeung et al., 2013).

Yet, the use of selective serotonin reuptake inhibitors for depression in patients with Parkinson’s disease remains debatable in the literature. Past evidence suggested that certain selective serotonin reuptake inhibitors, such as paroxetine, may magnify the motor symptoms in Parkinson’s disease (Ceravolo et al., 2000; Jiménez-Jiménez et al., 1994). More recent meta-analyses revealed that tricyclics might be more effective for depression in Parkinson’s disease but also acknowledged that further randomized controlled trials are warranted to suggest their routine prescriptions (Liu et al., 2013; Rocha et al., 2013; Troeung, et al.). Consistently, the Canadian Guidelines for Parkinson’s Disease recommended the tricyclic Amitriptyline for depression but recognized it may only be possibly effective (Parkinson Society Canada, 2012). Notably, there was a low proportion (4.5%) of patients with Parkinson’s disease and depression
prescribed Amitriptyline in a two-year period in CPCSSN. The inconsistencies in efficacy and apparent difference in the prevalence of types of medications, specifically selective serotonin reuptake inhibitors and tricyclics, suggest a need for more randomized controlled trials to determine the most appropriate medications for depression in Parkinson’s disease.

Benzodiazepines and related hypnosedatives were prescribed to 47.2% of patients with Parkinson’s disease and depression. To date, large scale studies reported that these medications are highly prescribed to older populations with about 54.0% using them daily despite the consistent evidence of a two-fold risk for adverse psychomotor events, falls and hip fractures, and motor vehicle accidents in the elderly (Allain, Bentué-Ferrer, Polard, Akwa, & Patat, 2005; McMillan et al., 2013; Simon & Ludman, 2006). The high prescription of benzodiazepines and related hypnosedatives, which followed closely to the prevalence of selective serotonin reuptake inhibitors, deserves careful consideration by primary care providers to minimize the risk of adverse outcomes in patients with Parkinson’s disease who already deal with progressively debilitating motor symptoms, including postural instability (Alves et al., 2008).

5.2. Strengths and Limitations

This study had strengths and limitations important to reflect upon. One of the strengths was that the scientific literature logically supported the research problem in that within Canadian primary care, there was a need to describe the demographic and health characteristics of men and women with Parkinson’s disease as well as to examine gender differences in the pharmacologic treatments for comorbid depression. The research problem had significance to nursing since majority of the patients with Parkinson’s disease are diagnosed and treated in primary care.

Ferrans et al.’s (2005) Health-Related Quality of Life model is a notable conceptual framework that appropriately informs and integrates the biological and psychological aspects
contributing to quality of life, which is critical in patients with Parkinson’s disease and its comorbid conditions, particularly depression. The methodological use of a retrospective cohort design and secondary analysis allowed efficient collection and analysis of large amount of data from CPCSSN. According to Muller (2014), the use of electronic medical records has the potential to move primary care research forward by affording the possibility of providing an overview of the primary care practice workload and a sufficient sample size that might otherwise be difficult to acquire for research. Results from a recent systematic review suggested that electronic medical records can have positive impacts on primary care structures and processes, such as improved legibility and accessibility of records (Holroyd-Leduc, Lorenzetti, Straus, Sykes, & Quan, 2011). In addition to enhancing the interpretations of the results, the advisory group, who were also sentinels, had the opportunity to be involved and provide valuable and contextualized feedback on data they contributed in CPCSSN.

This study was not without limitations. Findings were limited to the patients with Parkinson’s disease in the participating sentinels in CPCSSN within a two-year period; thus, may not be representative of the entire population living with Parkinson’s disease within the each province as well as to the rest of Canada and other countries. Further, the prevalence of patients’ residence type is likely reflective of the geographic distribution of the sentinels which were mostly located in urban settings (Williamson et al., 2013). Utilizing electronic medical records have potential critical drawbacks including inaccuracies in diagnosis of diseases and lack of comprehensiveness in all aspects of patient care (Muller, 2014). Despite Williamson et al.’s (2014) validation study on the CPCSSN case definitions and diagnostic algorithms, each case definition refers to lifetime prevalence of the chronic disease and for depression, there was no delineation between chronic and episodic depression.
The record of symptoms and diagnoses is a combination of what the patient reported and what the primary care provider chose to record, leading to incomplete depiction of patient status (Muller, 2014). In the context of CPCSSN, there were large percentages of patients without BMI and smoking status data, which hindered the potential relationships between the two health characteristics in men and women with Parkinson’s disease. Health data, such as family history and severity of chronic conditions, were not recorded in CPCSSN and in turn, limited the study’s key variables. The comorbidities were also limited to the eight chronic conditions monitored by CPCSSN. The domains of general health perceptions and overall quality of life in Ferrans et al.’s (2005) HRQoL model were not fully addressed since CPCSSN did not collect patient health perceptions. Finally, the medications were assumed to be prescribed categorically for depression as well as restricted to the medications recorded by primary care providers in a two-year period.

5.3. Implications for Nursing Practice and Education

The study findings have implications for nursing practice and education relevant to primary care but also in acute care settings to recognize the value of continuity of care. Granted that there were limitations, this study addressed the knowledge gaps on the demographic and health characteristics of men and women with a diagnosis of Parkinson’s disease across Canada as recorded in CPCSSN. Examining the primary care service delivery of medications for depression as a comorbid condition to Parkinson’s disease revealed inconsistencies with the type of medications recommended in the Canadian Guidelines for Parkinson’s Disease (Parkinson Society Canada, 2012). It is, thus, critical that primary care providers take the opportunity to comprehensively assess for comorbid depression and better understand the type of medications effective for treating depression in Parkinson’s disease. Higher level research, including meta-
analyses, systematic reviews, and randomized controlled trials, can be beneficial to sufficiently support the use of tricyclics, particularly Amitriptyline, for comorbid depression.

The findings lend support for the creation of better decision-support tools that can promote a critical review of comorbidities and respective medication history to minimize the risk for polypharmacy among patients with Parkinson’s disease and depression. Nurses can also be valuable resources in primary care; it is within the nurses’ scope of practice, whether working in primary care or acute care settings, to continually assess the medications that are most appropriate for patients with Parkinson’s disease and depression to facilitate a patient-centered care while adhering to the Canadian guidelines. The minor and adverse side-effects of the different types of medications for comorbid depression need to be monitored in the elderly given the conflicting evidence on the efficacy of selective serotonin reuptake inhibitors and tricyclics as well as the high prevalence of benzodiazepines and related hypnosedatives. Nurses, family physicians, and other providers, such as pharmacists and neurologists, can work together to create appropriate guidelines as a potential population-level intervention to help patients manage their Parkinson’s disease and depression simultaneously.

It is essential that primary care providers, including nurses, be educated on the risks and complications that arise from Parkinson’s disease and learn how to discern changes in health status. Findings in this study revealed a higher prevalence of depression compared to the general older populations and can even predate the diagnosis of Parkinson’s disease. Other comorbidities, such as hypertension and osteoarthritis, were also common with significant difference in prevalence by gender. It would be beneficial to have ongoing educational sessions built in nursing curriculums and acute settings to promote continuity of care and provide opportunities for growth in knowledge and advance nursing practice beyond primary care.
5.4. Recommendations for Future Research

This study provided foundational knowledge useful for future research on men and women with Parkinson’s disease and of those who also have a diagnosis of depression in Canadian primary care. It is vital that future studies continue to use methodological procedures that will optimize generalizability of new research findings, which include using valid sample size calculations to reduce the risk of false negative results. Further research would be useful to determine whether there are differences in certain dosage and duration of medications for treating depression associated with Parkinson’s disease. It would also be advantageous to go beyond the study’s two-year period since some patients might have been prescribed medications in the past. The surveillance of multi-morbidity in conjunction with polypharmacy in patients with Parkinson’s disease can be investigated further through longitudinal large-scale studies. Finally, rigorous qualitative studies can shed light on the knowledge and decision-making processes of Canadian primary care providers in treating depression, including the combination of pharmacologic and non-pharmacologic treatments, as they encounter men and women with Parkinson’s disease and depression.

5.5. Dissemination of Findings

The dissemination of the study findings to the target audiences is a key element for knowledge translation and exchange. The completed research study will be made available for distribution through academic library systems, including Open Access Journals. There will be initiatives taken to publish the study results to appropriate research journals that can reach out health care professionals caring for patients with Parkinson’s disease and depression within primary care settings. Potential research journals include New England Journal of Medicine, Annals of Family Medicine, Canadian Medical Association Journal, and Lancet. There will also
be attempts to be featured on the CPCSSN News and UBC Applied Science News websites. The study results will be presented to the Primary Health Care Team as well as the Centre for Health Services and Policy Research Team that are both directed by Dr. Wong in UBC.

5.6. Summary and Conclusions

The use of a pan-Canadian primary care sentinel surveillance network data provided a novel way to examine the demographic and health characteristics of patients with Parkinson’s disease as well as the difference in depression treatments between men and women with Parkinson’s disease and depression. Parkinson’s disease consists of motor and non-motor features that need to be recognized and managed by primary care providers. As found in this study, Parkinson’s disease affects the older aging populations with slightly more prevalent in men. Depression remains a common psychological comorbidity more frequent in women and it is mostly treated by selective serotonin reuptake inhibitors. There were no significant difference in the number and type of medications for depression by gender even after adjusting for the high number of encounters with a primary care provider but a pattern suggested that women may be more likely to be prescribed certain types of medications.

Findings highlight the potential need for more resources and decision-making tools to guide primary care providers in treating comorbid depression. Nurses can be valuable resources and they have a scope of practice that can competently care for these patients. Current Canadian guidelines offer useful recommendations but higher level studies are still required to sufficiently support the best treatments for depression in men and women with Parkinson’s disease. While more population-level research on Parkinson’s disease is needed in Canadian primary care, this study provided groundwork on the theoretical and practical knowledge for health care providers to holistically care and positively influence the quality of life of people with Parkinson’s disease.
References


Menec, V., Black, C., Roos, N. P., Bogdanovic, B., & Reid, R. (2000). *Defining practice populations for primary care: methods and issues*. Manitoba Centre for Health Policy and Evaluation, Department of Community Health Sciences, Faculty of Medicine, University of Manitoba.


Appendix A

Type of Data in the Canadian Primary Care Sentinel Surveillance Network
# Appendix B

## List of Medications for Depression by Classification and Generic Name

<table>
<thead>
<tr>
<th>Medication Classification</th>
<th>Generic Name of Medication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Selective serotonin reuptake inhibitors</td>
<td>Citalopram</td>
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<tr>
<td></td>
<td>Escitalopram</td>
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<tr>
<td></td>
<td>Fluoxetine</td>
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<td></td>
<td>Fluvoxamine</td>
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<tr>
<td></td>
<td>Paroxetine</td>
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<tr>
<td></td>
<td>Sertraline</td>
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<tr>
<td>Tricyclics and tetracyclics</td>
<td>Amitriptyline</td>
</tr>
<tr>
<td></td>
<td>Amoxapine</td>
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<tr>
<td></td>
<td>Butriptyline</td>
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<td></td>
<td>Clomipramine</td>
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<tr>
<td></td>
<td>Desipramine</td>
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<td></td>
<td>Doxepin</td>
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<td></td>
<td>Imipramine</td>
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<td></td>
<td>Maprotiline</td>
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<td></td>
<td>Nortriptyline</td>
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<td></td>
<td>Protriptyline</td>
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<tr>
<td></td>
<td>Trimipramine</td>
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<tr>
<td>Serotonin norephinephrine reuptake inhibitors</td>
<td>Desvenlafaxine</td>
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<td></td>
<td>Duloxetine</td>
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<tr>
<td></td>
<td>Venlafaxine</td>
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<tr>
<td>Serotonin antagonist and reuptake inhibitors</td>
<td>Trazodone</td>
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<tr>
<td>Atypical antipsychotics</td>
<td>Aripiprazole</td>
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<tr>
<td></td>
<td>Bupropion</td>
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<tr>
<td></td>
<td>Mirtazapine</td>
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<td></td>
<td>Quetiapine</td>
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<tr>
<td>Monoamine oxidase inhibitors</td>
<td>Isocarboxazid</td>
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<td></td>
<td>Moclobemide</td>
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<tr>
<td></td>
<td>Phenelzine</td>
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<tr>
<td></td>
<td>Selegilene</td>
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<tr>
<td></td>
<td>Tranylcypromine</td>
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<tr>
<td>Bipolar medications</td>
<td>Lithium</td>
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<tr>
<td></td>
<td>Carbamazepine</td>
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<tr>
<td></td>
<td>Divalproex</td>
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<tr>
<td></td>
<td>Lamotrigine</td>
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<tr>
<td></td>
<td>Valproate</td>
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<tr>
<td>Benzodiazepines and related hypnosedatives</td>
<td>Alprazolam</td>
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<tr>
<td></td>
<td>Bromazepam</td>
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<tr>
<td></td>
<td>Chlordiazepoxide</td>
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<td>Clonazepam</td>
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<td>Clorazepate</td>
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<td>Oxazepam</td>
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<td>Temazepam</td>
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<td></td>
<td>Triazolam</td>
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<tr>
<td></td>
<td>Zopiclone</td>
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</table>
Appendix C

Primary Care Provider’s Consent Form

THE UNIVERSITY OF BRITISH COLUMBIA

Consent Form

Primary Care Providers of People with Parkinson’s Disease

Study Team:

Principal Investigator: Dr. Sabrina Wong RN PhD  Phone: [phone number]

Co-Investigator: Kimberly Singian RN BSN  Phone: [phone number]

This research study is part of a thesis for Kimberly Singian’s graduate degree in the Master of Science in Nursing (MSN) at the University of British Columbia (UBC).

Purpose: You are invited to participate in this research study because we want to learn more about your thoughts and interpretations on our key findings regarding patients with Parkinson’s disease across the Canadian Primary Care Sentinel Surveillance Network (CPCSSN).

Procedure: The study will involve a 45 minute group discussion consisting of primary care providers to serve as an advisory group. You will be asked to respond to questions on the interpretations of the study’s key findings in relation to the demographics and health characteristics of patients with Parkinson’s disease and the pharmacologic treatments for depression among patients with concurrent diagnoses of Parkinson’s disease and depression. You will also be asked on the potential roles of nurses and/or nurse practitioners in depression treatment associated with Parkinson's disease.

Results: The results of this study will be reported in a graduate thesis and may be presented in conferences as well as published in academic journal articles, such as Open Access Journals.

Potential Risks: Participating in the advisory group is voluntary. There are no potential harms to you. Please let one of the study investigators know if you have any question and/or concerns.

Potential Benefits: The results may help primary care providers to gain knowledge and further understand the complexity of caring for patients with Parkinson’s disease and depression.
Confidentiality: You will not be identified. All information will be reported in an aggregated format. Your name will not be used in any written reports of the completed study and any information that can personally identify you will be kept confidential. The discussion notes taken will be kept in a locked office and password-protected computer files. The discussion notes will be kept for future research purposes for 5 years before being destroyed.

Payment: An honorarium of $20.00 CAD for the time you take to be in this advisory group will be offered. Parking costs will be reimbursed.

Contact Information: If there are questions or concerns regarding this study or your participation, you may call Kimberly Singian at [phone number] or Dr. Sabrina Wong at [phone number]. If you have any concerns regarding your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at (604) 822-8598 or if long distance e-mail RSIL@ors.ubc.ca or call toll free 1-877-822-8598.

Participant: Taking part in this study is voluntary. You have the right to refuse to participate in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason and without any negative impact on your practice.

Consent: Your signature below indicates that you have received a copy of this consent form for your own records. Your signature indicates that you consent to participate in this study. Upon providing consent, please fill out the attached primary care provider demographic form.

I have read and received a copy of this informed consent form.

Participant's Name (Please Print Clearly)

Signature of Participant    Date
Appendix D

Primary Care Provider’s Demographic Form

THE UNIVERSITY OF BRITISH COLUMBIA

Primary Care Provider Demographic Form

Name: ________________________________________________________________

Contact Email/Number: ________________________________________________

Sentinel Location (if applicable): ________________________________________

Age:
1. ___ 0 – 30 years old
2. ___ 31 – 40 years old
3. ___ 41 – 50 years old
4. ___ 51 – 60 years old
5. ___ 60 and older

Gender:
1. ___ Male
2. ___ Female

Profession Type:
1. ___ Physician
2. ___ Nurse Practitioner

Years of Practice:
1. ___ 0 – 5 years
2. ___ 6 – 10 years
3. ___ 11 – 15 years
4. ___ 16 – 20 years
5. ___ 20 and over
Appendix E

Primary Care Provider Recruitment Scripts

Sample Letter/Email Recruitment Script (to be sent after contacted by Network Director)

Dear [primary care provider name],

My name is Kimberly Singian and I am a University of British Columbia School of Nursing master’s student working with Dr. Sabrina Wong. My thesis work uses data from the Canadian Primary Care Sentinel Surveillance Network to examine the characteristics of those who are diagnosed with Parkinsonism. I am also examining the pharmacologic treatment for those Parkinson’s patients with depression. Dr. Sabrina Wong suggested I contact you as a potential advisory group member that will be part of my master’s study.

If you decide to participate in this study, you will be asked to take part in a 45 minute discussion (either face-to-face or over the telephone) with other sentinels. You will be asked for your thoughts on the key findings of this study.

As a token of appreciation, I would like to provide you with $20.00 CAD for the time you take to be in this study.

Participating in the advisory group is completely voluntary. If you would like to participate or have questions about the study, please email or contact me at [email address and phone number] or Dr. Sabrina Wong at [email address and phone number].

Thank you very much for your consideration.

Sincerely,

Kimberly Singian, RN, BSN
Sample Telephone Recruitment Script

Hello [primary care provider name]

My name is Kimberly Singian and I am a graduate student from the School of Nursing at the University of British Columbia. Dr. Sabrina Wong suggested I contact you as a potential advisory group member. I am conducting my graduate research study on patients diagnosed with Parkinson’s disease using data from the Canadian Primary Care Sentinel Surveillance Network.

If you decide to participate in this study, you will be asked to take part on a 45 minute discussion (either face-to-face or over the telephone/GoToMeeting conference call) with other primary care providers to serve as an advisory group. You will be asked to respond to questions on the interpretations of the key findings from my study.

As a token of appreciation, I would like to provide you with $20.00 CAD for the time you take to be in this study. [For in-person meeting, you will be provided refreshments and reimbursements for travel and parking.]

Participating in the advisory group is completely voluntary. If you would like to participate, we can email you more information. If you need more time to decide if you would like to participate, you may also call or email at [phone number and email address] or Dr. Sabrina Wong at [phone number and email address].

Do you have any questions for me at this time?

Thank you so much.