RISK FACTORS, TRENDS, HEALTH CARE AND GENERAL LIFE SATISFACTION FOR SELECT NEUROLOGICAL CONDITIONS AMONG AN AGING POPULATION IN CANADA

A Thesis
Submitted to the
College of Graduate and Postdoctoral Studies
In Partial Fulfillment of the Requirements
For the
Degree of Doctor of Philosophy
In the School of Public Health
University of Saskatchewan
Saskatoon

By

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ABSTRACT

There is an increasing number of people with neurological conditions. These people are living longer due to advances in critical care medicine and increasing survival and life expectancy rates among an aging population. As a result, neurological conditions and their attendant disabilities impact over 3.7 million people living in Canada and account for large health care expenditures, both by the publicly funded health system and through out-of-pocket payments by individuals with the conditions. Our main objective is to discover, other factors besides age, that affect the quality of life for Canadians living with neurological conditions. We use nationally representative population based survey data to identify risk factors, trends, health care and general life satisfaction for select neurological conditions found among Canadians. In order to inform health systems planning and direction of financial resources, policy and services, especially amidst grim predictions on the overall burden of these conditions on the Canadian economy, we examine specific neurological conditions (Alzheimer’s disease (AD)/dementia, Parkinson’s disease (PD), stroke effects, migraine headaches, multiple sclerosis (MS), cerebral palsy, epilepsy, amyotrophic lateral sclerosis (ALS), Huntington's disease, Tourette’s syndrome, dystonia, muscular dystrophy, hydrocephalus, spina bifida, brain and spinal cord tumors, and brain and spinal cord injuries), either independently or collectively in four distinct studies.

In the first study, chapter 3, we confirmed through our systematic review and meta-analysis that toxic occupational exposures are significant risk factors for the development of Parkinson’s disease especially that confirmed by a neurologist or nurse using standardized diagnostic methodology.

The second study analyzed the trends in AD/dementia prevalence by age, gender, education and geographic regions and found increasing prevalence across all strata of the community, with more men than women living with AD/dementia in the community. Increases in prevalence over the twenty-year period were less among those with higher levels of education and in the 45-64 age category, while prevalence was higher in the 65-79 age category and ballooned in the 80+ age categories of both men and women.

The third study assessed the relationship between self-reported unmet care needs and general health care satisfaction, satisfaction with physician and satisfaction with hospital services among Canadians with neurological conditions. We found that patient satisfaction was positively influenced by quality and availability of provincial and received care and being satisfied with life in general while unmet health care needs and receiving emergency services at the hospital had a negative impact on patient satisfaction.

The final study which examined the association between spirituality/religiosity and general life satisfaction among Canadians with neurological conditions found a protective relationship between spiritual values providing strength to face everyday difficulties, regular attendance at religious services and self-perceived physical and mental health and satisfaction with life in general.

The final take-home messages from our findings is that a population-based approach and a coordinated holistic system of care are needed for primary prevention of neurological conditions and the enhanced quality of life among the patients.

ACKNOWLEDGEMENTS

My highest praise is reserved for my Heavenly Father who sustained me and my family on our move to a new country to pursue my studies. My survival and strength through this time of adjustment are founded in His ever keeping care, and the love and sacrifice of my supportive husband and children, Andrew, Justin-Andrew and Sadie-Jade Richards.

I am very appreciative of my Supervisor, Dr. Carl D'Arcy who was never too busy for consultation, despite my never giving prior warning of my intent to interrupt his busy schedule. I am that much wiser for your mentorship, guidance and constructive feedback.

I extend gratitude to my thesis advisory committee chaired by Dr. Michael Szafron and comprised of Drs. Xiangfei Meng, Mary-Ellen Lebrecque, and Marwa Farag, as well as external examiner Dr. Shahin Shooshtari. Your patience, insightful suggestions and timely advice and responses were fundamental to my research process and completion of this work.

I am grateful to the School of Public Health and the Western Regional Training Centre (WRTC) for financial support for my academic pursuits. I am also thankful to the Saskatchewan Research Data Centre (SKY-RDC) for providing me with access to the data required for me to complete this thesis. I would also like to thank the Data Analyst, Dr. Reuben Mercado at SKY-RDC for facilitating my use of this protected data for the completion of my analysis and to Saskatchewan Polytechnic who supported my timely completion of this thesis.

I acknowledge my siblings Kayla, Marc, Kurt, Gayon, and Duane and my many cousins, aunts and uncles who believed in me and inspired and motivated me to keep going during my moments of doubt and lack of belief in my abilities. My young friends, Renae and Denae, and Principal Kryshna Hylton, and friend Ilene Pusey who cared for our children when I needed time away to concentrate on my academic goals, I am tremendously grateful for your kindness.

To my parents, Lloyd and especially Sadie Chambers, from whom I inherited a love and hunger and thirst for knowledge, and whom as educators, knowing the value of a solid academic foundation, planted the tenets of excellence and hard work within my young mind, I will never tire of acknowledging you for the virtues you have faithfully and patiently imparted.

DEDICATION

To my mother who lives with Lewy body dementia and whose brilliant mind and witty discourse I so thoroughly miss, and to my father, who taught me that disability is not a dream killer and never a deterrent to success, and who today, despite being diagnosed and de-diagnosed with Parkinson's disease, enjoys a rich quality of life.

To my spouse, Andrew Richards who followed me across many miles, leaving the warm climate of Jamaica to face the struggles of starting life over in a new country and my children Justin-Andrew and Sadie-Jade who have lived more years with their mother as a student in a different country than they have in the country of their birth.

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LIST OF ABBREVIATIONS

AB	Alberta
AD	Alzheimer's disease/dementia
ALS	amyotrophic lateral sclerosis
BC	British Columbia
CAI	computer assisted interviewing
CAPI	computer assisted personal interviewing
CATI	computer assisted telephone interviewing
CCHS	Canadian Community Health Survey – Annual Component
CCHS-2010	Canadian Community Health Survey – Annual Component, 2010
CCHS-2011	Canadian Community Health Survey – Annual Component, 2011
CI	confidence intervals
DALYs	disability adjusted life years
ER	emergency room
GLS	general life satisfaction
ICD	international classification of disease
MB	Manitoba
MOOSE	Meta-analysis of Observational Studies in Epidemiology
MS	multiple sclerosis
NB	New Brunswick
NEU	neurological conditions
NJ	New Jersey
NL	Newfoundland
NOS	Newcastle–Ottawa Scale
NPHS	National Population Health Surveys
NS	Nova Scotia
NT	Northwest Territories

NU	Nunavut
ON	Ontario
OR	Odds ratio
PD	Parkinson’s disease
PEI	Prince Edward Island
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-analysis
QC	Quebec
RR	Relative risk
SCI	spinal cord injury
SK	Saskatchewan
SKY-RDC	Saskatchewan Research Data Centre
SRPB	spiritual, religious and personal beliefs
UCN	unmet health care needs
UOR	unadjusted odds ratio
USA	United States of America
YT	Yukon

CHAPTER 1 – INTRODUCTION

1.1 The impact of neurological conditions

Neurological conditions are a major contributor to disability in the Canadian population. Approximately 3.77 million Canadians live with neurological conditions. Of this number, 170,000 are cared for in institutions (1). Most neurological conditions are long term, meaning they develop from injury or impairment to the nervous system, resulting in life long impacts (2, 3). These conditions, many of which are incurable and worsen overtime, are associated with symptoms and functional impairments that are daily challenges to individuals and their families (4). These challenges which include and are not limited to impaired cognition i.e., memory and capacity to think; paralysis or weakened muscles; loss of coordination and sensation; pain; seizures and confusion; have life-altering effects for individuals with the conditions (1, 4, 5).

Some neurological conditions are reported to have shared risk factors such as inherited biological characteristics (sex, age, genetic susceptibility), exposure to environmental and occupational toxins, and lifestyle choices (smoking, nutritional choices, alcohol consumption), social characteristics such as socio-economic status, cultural effects of ethnic backgrounds which may overlap with biological and behavioral factors (6). Shared risk factors for the more common neurological conditions, Parkinson's disease (PD) and Alzheimer's disease/dementia (AD), include genetics or family history, sex, head trauma, lower levels of education and exposure to environmental toxins (6-11). Smoking, hypertension, and high cholesterol (7, 12, 13) seem to increase the risk of AD/dementia while midlife adiposity, regular infections, and dietary practices including high animal fat intake have been reported to be linked to increased risk of PD (7, 8, 14).

Age has also been identified as a common risk factor for many of the other neurological conditions impacting Canadians. Neurological conditions are more common in the older population, impacting 5% to 55% of people 55+ years of age (15-17). Among adults aged 60 and over in all regions of the world, there is a rapidly rising risk of death with those 60 years of age having a 55% odds of dying before they reach 70 years old (15). By 2031, Canada's population is expected to grow to more than 40 million people with a shift in the age structure resulting in increased numbers of Canadian 65 years and older (4). This shift in population age structure is attendant with an increase in incidence of some of the more common neurological conditions such as AD/dementia and PD due to their significantly increased incidence among those over the age of 65 years (5), thereby contributing to an increased prevalence.

Through microsimulation modelling, it is projected that the total number of cases of AD/dementia will increase from 340,000 in 2011 to 674,000 in 2031, accounting for 334,000 new cases and a 5-year delayed age-specific incidence of 1.10 per 1,000 people, relative to baseline incidence rates. A further 1.13 per 1,000 incidence rate is projected among males and 1.07 per 1,000 people among females. In other words, the total number of cases of AD/dementia in males will increase from 142,000 in 2011 to 291,000 in 2031, and 198,000 to 383,000 in females over the same period (18).

Pringsheim, Fiest, and Jette, 2014, list the global incidence of Parkinson's disease in 65+ individuals as 36.5 per 100,000 person-years among males and 65.5 per 100,000 person-years among females (19). They also state that the pooled worldwide community-based prevalence of dementias including AD/dementia in 65+ individuals was 4.63 % and the region-specific community-based prevalence among those 65+ in North America was approximately 6.0% (19). They list the worldwide prevalence for the more common neurological conditions in Canada as follows: Tourette syndrome, 0.77%; Epilepsy, 5.96% (0.68% North American); PD, 0.32% (female 0.04% and male 0.07%); cerebral palsy, 0.22%; traumatic brain injury, 0.21% (0.17% North American); hydrocephalus, 0.14%; spina bifida, 0.05% (0.04% North American); brain tumors, 0.01%; dystonia, 0.005%; muscular dystrophy, 0.005%; spinal cord injury (SCI), 0.003% (0.004% North American); and Huntington's disease, 0.003% (19).

Similar to their range of prevalence and conditions, the overall burden of neurological conditions is increasingly multifaceted and transcends the health system. Because they are linked to a high risk of negative health outcomes, including mortality, disability, falls, institutionalization and hospitalization, they have a considerable impact, not only on those living with the conditions, but also their families, caregivers and employers (15, 20, 21). Neurological conditions present a huge financial burden globally and in 2016 was the major cause of worldwide disability adjusted life years (DALYs) (22). Furthermore, the economic impact of neurological conditions on Canada is great, due to direct health care expenditures (hospital care, physician care and drugs) and indirect costs such as death, long-term disability, and lost productivity (4, 23). The total pooled cost of neurological conditions including AD/dementia, PD, multiple sclerosis (MS), amyotrophic lateral sclerosis (ALS), brain tumors, epilepsy, migraine headaches, cerebral palsy, head injury, spinal cord injuries (SCI) and stroke effects (24) was estimated in 2007 to be $8.8 billion, which represented what would be 4.6% of the total attributable cost of illness ($192.8 billion) in Canada in 2008 (4, 5).

More recent estimates suggest that the annual total direct health care costs were higher among individuals with neurological conditions than those without those conditions. In 2014, the total direct health care costs estimated for Alzheimer's disease and other dementias was $527,494,000. Other estimated total direct health care costs included $208,679,000 for epilepsy, $120,358,000 for PD, and $17,720,000 for spinal cord injury (1). It is projected that by 2031, the total indirect economic cost, combining loss due to working-age premature death and disability for each neurological condition, will increase. This cost, depending upon the neurological condition, will range from $0.3 billion to $8.2 billion (1). The burdens of living with neurological conditions are not confined to the impacts on a country's economy. Those living with neurological conditions also face many challenges associated with disabilities that result from long term neurological conditions.

A major challenge common across people with neurological conditions is psychosocial difficulties, defined as deficiencies in mental and body functions under central nervous system control that result in activity limitations and participation restrictions (25, 26). Challenges with independent living, relationships, social interaction and occupations are examples of psychosocial difficulties that occur across neurological conditions (27). Common determinants of these challenges have been identified as approaches and care of health professionals, caregiver (usually family) attitudes and the availability of help and assistance (25). Impairments and psychosocial difficulties may significantly influence the physical and mental health, subsequent care and quality of life associated with neurological conditions (28). People with psychosocial difficulties, common to neurological conditions, have reported higher numbers of unmet health care needs (29-31) that may go unnoticed by health professionals (32).

Indeed, patients with select neurological conditions have identified that their greatest need is access to health care services that maintain relevance as their diseases progress (33-35). Access to such care influences health care utilization, patient satisfaction and quality of life (36). Quality health care access is influenced by four major factors: structural issues, which may be influenced by age and education; patient perception concerns, i.e., patient satisfaction with quality and availability of care; having access to regular source of care and emergency service use (health care utilization); and health outcomes such as self-perceived physical and mental health (37). Obstruction of any of the aforementioned four factors results in unmet health care needs (33, 38) and reduced quality of life.

Quality of life, as defined by the World Health Organization (WHO) is “an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (38). Quality of life is a broad concept and is impacted by the complex interplay among physical health, psychological well-being, personal beliefs, social relationships and their relationship to environmental factors (39). In keeping with that definition, activity and participation in social and lifestyle activities, and the ability to cope have been established as predictors of quality of life among those with neurological conditions (40).

On the other hand, life satisfaction is a concept related to quality of life and is a subjective measure of one’s quality of life as a whole (41, 42). Buetell, 2006, further explains life satisfaction as the “overall assessment of feelings and attitudes about one’s life at a particular point in time ranging from negative to positive” (43). In this thesis, we view life satisfaction as an individual’s measure of quality of life at a particular point in time. Spirituality has been demonstrated as a coping mechanism while living with neurological conditions. At points in time, it has provided meaning and sense to catastrophic life events, allowing individuals to find purpose to life circumstances, and experience increased life satisfaction amidst adversities (44).

The available knowledge and expertise regarding neurological conditions are as varied as each separate condition. However, the substantial and sometimes calamitous nature of the diseases have large scale impacts on those with neurological conditions, their families and care providers. The needs and gaps are far reaching in their effects and overlie physical and mental health. Though treatment mechanisms for each neurological condition may be different, the management of care for each in Canada is dependent upon the same intricate, complex and multifaceted designs of health and social services (45). As a result, a number of health regions across Canada have adopted best practices that incorporate the fundamental philosophies of the Expanded Chronic Care Model (45-47) to address psychosocial as well as physiological needs for improved outcomes across chronic conditions (46).

The Expanded Chronic Care Model incorporates population health promotion and prevention into the management of chronic disease. It seeks to decrease the burden of chronic disease, by reducing the impact on those who have a disease and also supporting people and communities to be healthy (46). This model of care is important to the concepts examined in this thesis in relation to Canadian living with neurological condition. An integrated approach to the development of policies and public health prevention solutions for the management of neurological conditions as a whole, mirroring that of the Expanded Chronic Care Model is necessary to reduce the burdens to families, health systems and the economy, associated with these conditions.

1.2 The context of this research

More people are living longer with neurological conditions due to advances in critical care medicine and increasing survival and life expectancy rates among an aging population (48, 49). This means that there is an increase in the number of aging persons living with the debilitating impacts of neurological conditions including multiple disabilities (50) and a range of physical, social, and psychological complications (51, 52). As a consequence, these individuals require services and care such as timely information, support and rehabilitation, and may need the usage of assistive devices and appliances (52). There is evidence in the literature to suggest that, despite these needs, people with neurological conditions continue to experience poorer health and are at greater risk of developing secondary health problems and report unmet needs as well as barriers and delays in receiving the care and services that they require (48). These unmet health care needs, coupled with the progressive and lifelong nature of most of these conditions may have a significant effect on healthcare utilization (4, 49).

In addition, unmet health care needs reduce quality of life of both patients and caregivers (52) and have been associated with decreased patient satisfaction with healthcare services (53, 54). Patient satisfaction has been demonstrated as an indicator of quality of care, which in turn has an impact on quality of life. While there is much more information on unmet health care needs, health care utilization, patient satisfaction and their effects on quality of life for other chronic conditions or select neurological conditions, there is a gap in the literature of Canadian studies on neurological conditions as a group (as is necessary for the assessment of a chronic care model). Principles of self-management are emphasized in the expanded chronic care model. This model of care, which takes into consideration psychological outcomes such as positive coping, has an impact on quality of life for those living with chronic conditions (55). Quality of life is enhanced among those with spirituality and/or religious faith (56). For those for whom it is relevant, spirituality and religious faith are important coping resources for living with chronic conditions. Even among the more secular societies, spirituality and religious faith have been reported to provide emotional well-being, preserve self-esteem, and lead to a better tolerance of pain and other symptoms (57-60). However, most studies on neurological conditions have focused mainly on links between spirituality and physical health, with fewer studies on neurological conditions measuring the influence of spirituality on indicators of psychological functioning, such as life satisfaction (1).

Despite the expected rise in incidence of neurological conditions and associated health care costs and caregiver burdens, there is a lack of studies highlighting recent trends in prevalence of the more common conditions. For example, recent trend data is lacking for AD/dementia in Canada by age, gender, education and regions. Such knowledge is important for informed health systems planning and direction of financial resources and services, especially amidst grim predictions on the overall burden of these conditions on the Canadian economy. In relation to estimates of incidence and prevalence of neurological conditions in Canada, only one study identified provided data for all provinces and territories (61, 62). Although prevalence estimates exist, they may not be applicable to all Canadian jurisdictions.

Notwithstanding the abundance of information on risk factors, health care utilization and economic burden, this information does not thoroughly explain the impact on the quality of life measures associated with living with neurological conditions (23) among Canadians, especially those in the 65+ age categories. As well, there are unique effects of neurological conditions related to spiritual needs (62) and unmet healthcare needs that impact health care and general life satisfaction, that are not widely described in the literature.

The predominant theme of this research is to examine, in addition to age, what other factors affect the quality of life for Canadians living with neurological conditions. In this research, we conduct a systematic review of the literature and examine population based survey data, which is nationally representative, to identify risk factors, trends, health care and general life satisfaction for select neurological conditions found among Canadians. This thesis focuses on reducing the existing gaps in research on the experiences of Canadians living with select neurological conditions. We examine specific neurological conditions [AD/dementia, PD, stroke effects, migraine headaches, MS, cerebral palsy, epilepsy, ALS, Huntington's disease, Tourette’s syndrome, dystonia, muscular dystrophy, hydrocephalus, spina bifida, brain and spinal cord tumors, and brain and SCI (62)], either independently or collectively in specific studies, depending on the availability of data and the need to protect confidentiality while retaining large enough sample sizes to maintain study power. This thesis is composed of four substantive chapters that:

- Conduct a systematic review and meta-analysis of existing literature examining the association between toxic occupational exposures and PD using longitudinal studies.
- Analyze the trends in AD/dementia prevalence by age, sex, education and geographic regions using data from national Canadian health surveys.
- Assess the relationship between self-reported unmet care needs and (1) general health care satisfaction, (2) satisfaction with physician and (3) satisfaction with hospital services among Canadians with neurological conditions
- Examine the effects of sociodemographic factors, physical and mental health and spirituality on general life satisfaction (GLS) in Canadians with neurological conditions, using data from the Canadian Community Health Survey.

The major chapters in this thesis are linked by (1) the commonalities of the neurological conditions studied, (2) the fact that these conditions together account for a huge burden to the health system, the Canadian economy and the society and, (3) neurological conditions get progressively worse over time and are accompanied by psychosocial difficulties. It is anticipated that the major chapters of this thesis will contribute to the ongoing dialogue about how the government of Canada as a whole and particularly the health ministries and services can better meet the specific health needs of an aging population, who by nature of being, will continue to be impacted by select chronic neurological conditions.

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CHAPTER 2 – METHODS AND PROCEDURES

2.1 Study designs

In this thesis, two study designs and various epidemiological methods are employed in the assessment of secondary survey data and a review of existing literature. It is comprised of four major studies, each separate and independent, and a closing chapter on the general implications for program and policy development and future research that may need to be undertaken.

In Chapter 3, a systematic review and meta-analysis is conducted. This review of longitudinal studies was done using the Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA) guidelines (1). This study design is advantageous in that most sources of bias and heterogeneity can be statistically examined while measuring the sensitivity of statistically significant results. It presents reliable estimates of the impacts of exposures or interventions, so that robust inferences can be made. (2). Thus, representing the strongest source of evidence for policy makers and health systems to keep abreast of comprehensive solutions to questions or challenges. Noteworthy limitations are loss of information on essential outcomes, potential publication bias, heterogeneity, and the combination of evidence from a combination of studies. Because the quality of these studies may vary, care has to be taken in the interpretation of the results as they may not be generalizable to entire populations, and may be more suitable to subsets of people within a population (2). Due to the variability of the quality of systematic reviews, readers are limited in their ability to assess strengths and weaknesses of the reviews (3).

Cross-sectional study designs are used in Chapters 4, 5 and 6. These study designs were employed because they yield information that is representative of the Canadian population. While they provide very valuable information on prevalence and associated risk factors, are advantageous in that they are relatively inexpensive, are less time-consuming and present the opportunity for examining many risk factors and outcomes, cross sectional study designs are limited in providing for causal inferences (4). Therefore, the results of analysis using cross-sectional study designs should be interpreted with caution, because different participants may be interviewed at each cross section in time, making it difficult to determine whether changes in prevalence represent a trend or are due to differences between separate groups of survey respondents. In addition, in cross-sectional studies, data on independent and dependent variables are collected simultaneously, making it impossible to differentiate cause and effect between exposure and outcome variables. This violates Bradford Hill's temporal criterion of causality.

The cross-sectional surveys used in this thesis employ complex designs. The sample design of the NPHS was shaped by a number of factors aimed at improving the precision of survey estimates. These included stratified sampling by provinces and cluster sampling within the provinces in proportion to their population sizes based on household Census. This type of sampling is advantageous because it allows for calculation of descriptive frequencies by province, the production of sample weights that allows computation of nationwide estimates of parameters (5).

2.2 Data Sources

For the systematic review and meta-analysis in Chapter 3, search strategies were used to conduct an electronic search for published articles in databases such as Medline/PubMed, EMBASE, Toxnet, LILACS, and Cochrane Library. Reference lists in eligible articles and grey literature were vetted to find the most comprehensive articles for inclusion in the review. Also, a manual search was done on other resources for additional relevant studies. Eligibility of articles was determined by established inclusion and exclusion criteria.

This thesis also includes analyses from Statistics Canada's cross-sectional data from anonymized Master Microdata Files with restricted access through the Saskatchewan Research Data Centre (SKY-RDC) and Public Use Microdata Files (PUMF) with free electronic access to the public. The anonymized Master microdata files accessible through the Research Data Centre (RDC) contain most of the confidential original content collected during the survey period, and additional variables derived post data collection, while the publicly accessible, PUMF, limits the possibility of identifying individual survey respondents due to the aggregation and removal of variables that could be identifying characteristics (6).

The first 12-month cycle of the National Population Health Survey (NPHS) started in June 1994 and it was conducted every other year following. It was designed to provide information to guide health policy and system development and evaluation due to increasing financial pressures on the Canadian health system (7). The survey produced both periodic cross-sectional and longitudinal data including demographic content and modules on health status, chronic conditions, health services utilization and determinants of health, among other topics (7).

The CCHS began in 2000 as a joint initiative of the Canadian Institute of Health Information (CIHI), Statistics Canada, Health Canada and the Public Health Agency of Canada. Similar to the NPHS, the CCHS provides population-based data on health determinants, health care utilization and health status (8). At the onset, the survey was conducted every two years, providing data from across the nation, provinces and health regions, until 2007 when this data began to be collected annually. The CCHS data is comprised of three major modules: (1) common content that is composed of cored and themed information that is asked of all participants annually, with some modules from the common content collected for two years and alternate between two to four years, (2) optional content that varies year over year, according to the information needs of provinces or territories and, (3) Rapid Response content that is accessible to organizations who wish to have national estimates on an evolving or particular issue connected to the health of the general population (9).

In chapter 4, our analysis of trends in prevalence across various strata of the Canadian community was conducted using the PUMF NPHS 1994-95, 1996-97 and 1998-99 and restricted SKY-RDC anonymized master files of the Canadian Community Health Survey-Annual Components, 2000-2014.

In Chapter 5, the restricted SKY-RDC anonymized master file of the CCHS – 2010 was used in the multivariate model building process to determine predictors of patient satisfaction. The CCHS-2010 was used because the data contained one-year unique common content on health care utilization: unmet health care needs (UCN) and neurological conditions (NEU) and the optional content on patient satisfaction (10), all of interest in this study. Respondents with neurological conditions who received health care services and completed the optional module on patient satisfaction as well as the unique common content on unmet health care needs resided in the province of Ontario.

Chapter 6 utilized the restricted SKY-RDC anonymized master files of the CCHS - 2011 to examine predictors of one of the components of quality of life, general life satisfaction. The CCHS-2011 anonymized Master Files were used for this study because it is the latest survey containing responses on all major variables of interest in this study: common content on general life satisfaction, the one-year unique common content on neurological conditions and the optional content on spiritual values (11). Respondents with neurological conditions who reported on general life satisfaction and completed the optional module on spiritual values resided in the provinces of New Brunswick (NB) and Manitoba (MB).

2.3 Statistical Analysis

Demographic and clinical characteristics such as age, gender, marital status, educational status, income level, etc., of Canadians living with selected neurological conditions, were examined through descriptive analysis (Chapter 5 and 6).

Quantitative meta-analysis was done in the systematic review (Chapter 3). Meta-analysis was applied to pool estimates from previous studies to determine the strength of association between toxic occupational exposures (electromagnetic, metal and pesticides) and Parkinson's disease. This increases study power in comparison to single, separate studies, allowing for measurement of consistency of effect across different samples (12).

Age and sex standardization of prevalence estimates using the 2001 census data was used to calculate prevalence estimates of Alzheimer's disease/dementia by age, sex, highest level of education, and geographical region, over a twenty-year period, from 1994-2014 (Chapter 4).

Univariate and multivariate logistic regression models were performed for dichotomous outcome variables in Chapter 5 and 6. Table 2-1 summarizes the study designs of the individual studies included in this thesis.

Chapters 4, 5, and 6 utilized data from complex surveys. To account for this survey design, weighted analysis was completed by applying sampling weights to our data set. In consultation, it was decided not to proceed with bootstrapping due to the very small sample size of the population for each study.

Table 2- 1 Summary of study designs in this thesis

Title of Study	Study design	Method & Analysis	Age category of participants
Chapter 3- Toxic Occupational Exposures and their Association with Parkinson’s Disease: A systematic Review and Meta-Analysis	Meta-analysis	Systematic Review Meta-Analysis	16+ years
Chapter 4- Trends in prevalence of self-reports of Alzheimer’s disease/dementia, among 45+ individuals in Canada, 1994-2014	Cross-sectional	Descriptive analysis Trend Analysis	45+ years
Chapter 5- Unmet Health Care Needs: Factors predicting Satisfaction with Health Care Services among Canadians with Neurological Conditions using data from the Canadian Community Health Survey, Annual Component, 2010	Cross-sectional	Descriptive analysis Logistic Regression	12+
Chapter 6- An exploration of the sociodemographic factors and select measures of spirituality/religiosity that predict general life satisfaction among Canadians with neurological conditions	Cross-sectional	Descriptive analysis Logistic Regression	12+

2.4 References

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CHAPTER 3 – TOXIC OCCUPATIONAL EXPOSURES AND THEIR ASSOCIATION WITH PARKINSON'S DISEASE: A SYSTEMATIC REVIEW WITH META-ANALYSIS

A version of this chapter will be submitted for journal publication review.

3.1 Abstract

Background: Parkinson's disease (PD) is the second most common age associated neurodegenerative condition contributing to a doubling of disease burden from 1990 to 2016. Previous epidemiological studies highlight exposure to environmental and occupational toxins as significant risk factors for PD. However, most studies have been cross-sectional and are of varying quality, utilizing questionnaires or other methods of recall, introducing bias. In this study, our aim is to (1) determine the strength of association between overall toxic occupational exposures and three types of toxic occupational exposure (metals, electromagnetic and pesticides) and the occurrence of Parkinson's disease and (2) understand the relationship between toxic occupational exposures and PD by diagnostic methods.

Methods: A search was conducted of EMBASE, PubMed/Medline, Toxnet, LILACS, and Cochrane Library databases for longitudinal studies which included an assessment of toxic occupational exposure, Parkinsonian or related disorders, diagnosed by international classification of diseases (ICD) codes, medical records or confirmation by a neurologist or nurse, and published in English language for the period January 1990 to March 2019. Pooled relative risk (RR) estimates were produced using random effects models.

Results: Twenty-four articles were used in the analyses. The pooled RR between toxic occupational exposures and PD was 1.15 (95% confidence interval (CI) 1.06–1.24), and 1.03 (95% CI 0.91–1.16) between electromagnetic exposure and PD, while the pooled RR between PD and metal and pesticide exposure were 1.07 (95% CI 0.92–1.24) and 1.41 (95% CI 1.20–1.65), respectively. The pooled RR for methods of diagnosis and their associations with PD were: confirmation by a neurologist or nurse, 2.17 (95% CI 1.32-3.54); medical records, 1.06 (95% CI 0.92-1.21); and ICD codes, 1.14 (95% CI 1.03-1.26).

Conclusions: Our systematic review provides robust evidence that toxic occupational exposures particularly to pesticides are significant risk factors for PD especially that diagnosed by neurologists or nurses using standardized methods. This evidence supports the need for (1) general prevention efforts targeted to those in occupations that expose them to occupational chemicals or toxins and (2) using a reliable standardized approach by a specialist is important for

the accurate confirmation of PD and establishing accurate estimates of risk of PD through toxic occupational exposures.

3.2 Introduction

Population growth worldwide coupled with increasing life expectancy in current years result in more people reaching ages where neurological disorders are most prevalent (1, 2). Parkinson's disease (PD) is one such example, as it is the second most common age associated adult neurodegenerative condition, following Alzheimer's disease (AD)/dementia (3). The worldwide burden of the disease more than doubled over 26 years, from 2.5 million patients in 1990 to 6.1 million patients in 2016. This increase is attributed to longer disease duration, a result of living longer with disease, and possible changes in environmental risk factors (4). The pathology of PD includes the degeneration of dopaminergic neurons along with the accumulation of Lewy bodies in select regions of the central and peripheral nervous system (5). This type of neurological involvement in PD results in a progressive movement disorder. Signs of PD involve severe motor dysfunction and may include slow movement, postural instability and rigidity, resting tremors, anxiety, depression and cognitive decline in tandem with disease progression (6, 7).

Epidemiologic studies have highlighted that residing in rural communities, consuming well water, farming, and exposure to chemicals, metals, electromagnetic fields were significantly associated with PD (6, 8-9). There have been variable results in investigations of occupation as a potential risk factor for PD. Some occupations may serve as proxies to harmful exposures to environmental factors. For e.g. farming acts as the vehicle to pesticide exposure, while welding is the conduit to metal exposures. Therefore, it is the toxic occupational exposures rather than particular occupations that have been explored in more recent studies (10) that have been found to be associated with Parkinson's disease.

There is an abundance of evidence in the literature (11-16) to suggest that toxic occupational exposure is strongly linked with Parkinson's disease. The most common toxic occupational exposures in the literature (17) in order of rank have been pesticides (18-20), metals (21), and extremely low frequency electromagnetic fields (22). Most studies on pesticide exposure suggest a significant association between pesticide use and PD risk, while there have been variations in the direction of the association between toxic occupational exposures to metal and electromagnetic fields.

Most of the review studies that demonstrate a link between toxic occupational exposures and Parkinson's disease have not been rigorous in excluding studies of lower scientific quality or those that have not applied the Meta-analysis of Observational Studies in Epidemiology (MOOSE) recommendations (23). Most studies are cross sectional or case-control, which have the potential for recall bias and are less reliable in establishing causality. Cross-sectional studies are disadvantageous in exploring links between toxic occupational exposures and Parkinson's disease, due to prevalence-incidence or Neyman bias (24). Any toxic occupational exposure that would have resulted in death would have been under-represented among those with the disease (25), especially in the case of PD which is a longer-lasting and progressive disease. On the other hand, there are fewer systematic reviews with meta-analyses on cohort studies demonstrating the impact of toxic occupational exposures on the prevalence of PD. In addition, to limited systematic reviews and meta-analysis on high quality longitudinal studies, toxic occupational exposure in most cross sectional or case-control studies have generally been measured via questionnaires or other recall methods, which may introduce bias.

The objective of this study is to (1) determine the strength of association between overall toxic occupational exposures and three types of toxic occupational exposure (metals, electromagnetic and pesticides) and the occurrence of PD and (2) understand the relationship between toxic occupational exposures and PD by sources of diagnostic information. The focus of this study is on longitudinal studies which use robust means of assessing toxic exposures and outcome (PD) as these are more advantageous than case-control studies in determining relative risk as well as establishing incidence. Our analysis is based on sub-analyses according to three categories of toxic occupational exposure and methods of diagnosis.

This study adds updated information that helps to clarify the nature and strength of the relationship between the more common types of toxic occupational exposures and PD and summarizes a comparison of the results in one study. One advantage of this study is that it demonstrates which subgroups of occupational exposures result in greater risks of PD. This study differs from more recent longitudinal systematic reviews on toxic occupational exposures in that it focuses on methods of diagnosis of PD and includes more recently published studies. It is anticipated that more recent studies would include those of better quality. Such findings can help to inform where interventions would be most effective in reducing risks of exposures leading to Parkinson’s disease.

3.3 Methods – Systematic review and meta-analysis

The systematic review and meta-analysis was conducted according to the PRISMA guidelines, 2009 revision (26), and the Meta-analysis of Observational Studies in Epidemiology (MOOSE) recommendations (23). All studies included in the analysis were of high quality based on our assessment criteria (Appendix C).

3.3.1 Search strategy

Publications were identified by a computerized search on EMBASE, PubMed/Medline, Toxnet, LILACS, and Cochrane. These databases were searched because they include publications on environmental toxins and toxic occupational exposures and public health or general health outcomes. The search was conducted for the period January 1990 to March 2019 using varying combinations of the following key words: prospective, retrospective, historical, cohort study, occupation, occupational, horticulture, pesticide applicators, pesticide(s), herbicides, insecticides, fungicides, mining, bauxite, aluminum, manufacturing workers, Parkinson, Parkinsonism, and Parkinsonian. Reference lists of the eligible articles and grey literature were also searched for additional studies. The review was limited to studies published in English in peer-reviewed journals. All titles or abstracts were screened to determine the eligibility of the publication for inclusion in the review.

3.3.2 Inclusion and exclusion criteria

A publication was evaluated for further review if the following inclusion criteria were met: (1) workers were identified as vulnerable to toxic occupational exposure (farmers, gardeners, greenhouse workers, pesticide applicators, shipbuilders, utility workers, railway employers, nurses exposed to airborne metals etc.); (2) the outcome included Parkinsonian disorders or related diseases (cited as Parkinson's disease, Parkinsonism); (3) original data from a cohort design was presented; 4) inclusion of a statistical indicator (relative risk, odds ratio, hazard ratio) or original data to estimate the relationship between occupational exposure and PD;

and 5) controlled for potential confounders by using statistical adjustment in the analysis or matching in the study design. Studies were excluded if they were experimental studies, or focused only on genetic data or if they were published in languages other than English. Studies were excluded if they did not identify Parkinson's disease cases or provide sufficient data to determine an estimator of relative risk (RR) and its confidence interval (CI) for PD. Age was not an inclusion/exclusion criterion in our study.

3.3.3 Data collection and quality assessment

Full-text of all articles for studies that initially met our inclusion criteria were retrieved for further examination. Two authors [TC-R and YS] independently determined eligibility of articles for inclusion in the review, with consultation and discussion to resolve any dichotomy in suitability of articles. Data on the first author's name, publication year, cohort characteristics, age at enrollment, sample size, occupational chemical exposure assessment, as well as disease definition were extracted independently (3). We compared the results of this exercise and obtained consensus before performing the meta-analysis. The Newcastle–Ottawa Scale (NOS) criteria was used to characterize study quality (27).

3.3.4 Statistical analyses

We grouped toxic occupational exposures according to the different and specific types: electromagnetic exposures, metal exposures and pesticides exposures. We also grouped occupational exposures according to methods used to assess outcomes: International Classification of Diseases (ICD) codes, medical records (self-reported diagnosis of PD or PD identified in medical records with no specific ICD code), and neurologists'/nurses' confirmation of PD. Meta-analyses were conducted using rate ratios (RR) for all included prospective studies.

Summary effect estimates and their corresponding 95% CIs were calculated using the DerSimonian and Laird random-effects model which incorporated the amount of variances produced by differences between and within studies, and also taking the results of heterogeneity test into consideration (28). Statistical heterogeneity between studies was quantified using Cochran's Q test and the I^2 statistic. The significance of the Q test was indicated by a corresponding p value lower than 0.05. I^2 with a value of 0% indicates no observed heterogeneity, with 25% as low, 50% as moderate, and 75% as high heterogeneity (29). Sensitivity analysis assessed the influence of lower quality studies on overall estimates by recalculating RRs with the exclusion of lower quality studies for each sub-group analysis.

Publication bias was evaluated by inspection of funnel plots visually and Egger's test statistically (30-31). Comprehensive Meta-Analysis, version 2.2 (Biostat Inc, Englewood, NJ, USA) was used to analyze the data. We considered p values that were less than 0.05 statistically significant. All statistical tests were two-sided.

3.4. Results

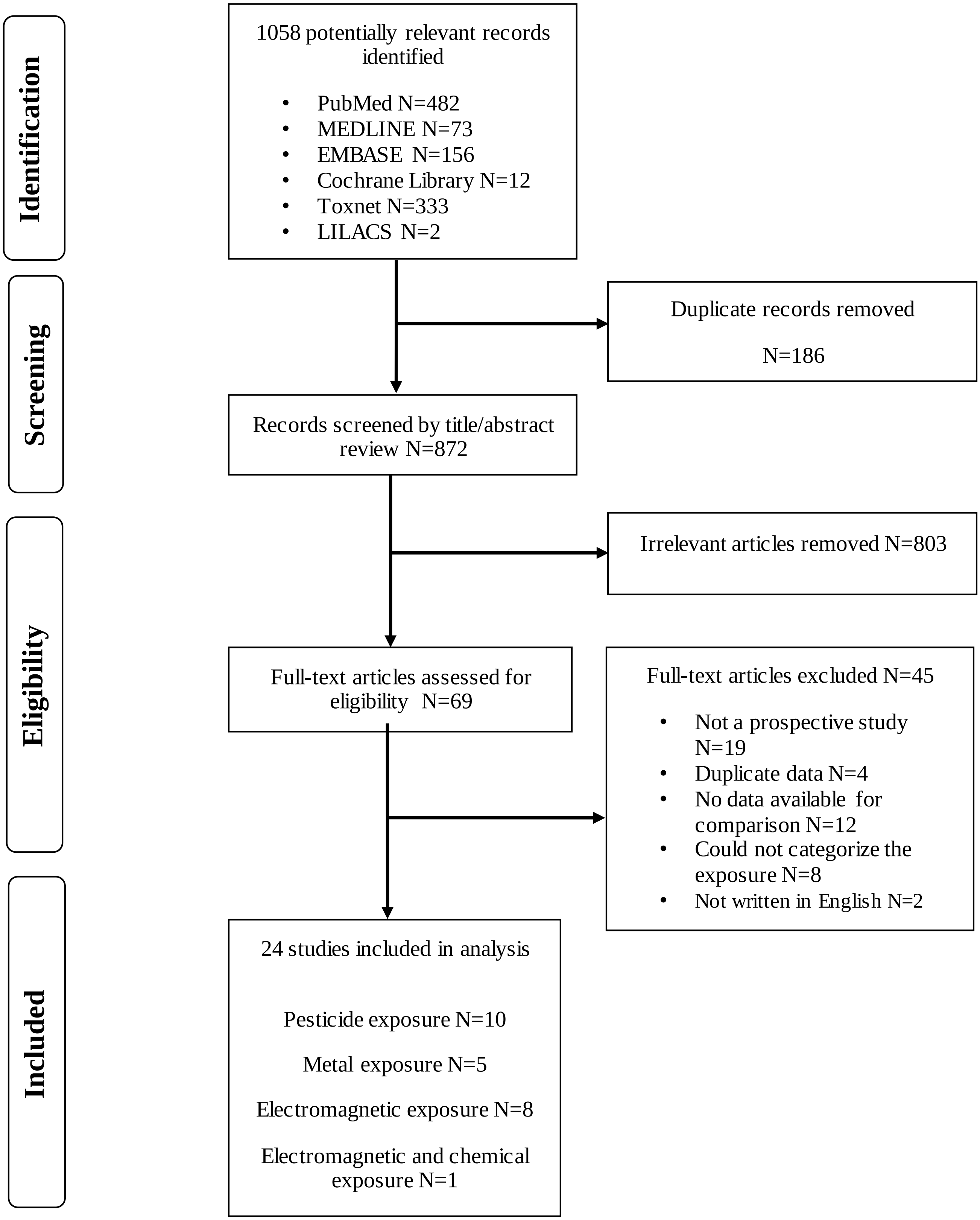
3.4.1 Meta-analysis

3.4.1.1 Selection of articles

To maximize the number of relevant publications retrieved, the search process included a combination of MeSH terms using applicable key words or title search related to "Parkinson's Disease," and "herbicides," "pesticides", "fungicides", "insecticides", "heavy metals" "electromagnetic fields" (Appendix A).

Figure 3-1 outlines the search process. We identified 1058 relevant titles in our initial search. This number was reduced to 872 titles following exclusion of duplicates. An additional 803 articles were discarded after the title/abstract review which resulted in 69 potentially relevant full text articles screened. Another 45 articles were removed after failing to meet inclusion criteria, resulting in a final list of 24 articles that met the criteria for meta-analysis and were included in the study. Figure 3-1 indicates reasons for exclusion from the study during full-text screening.

Figure 3- 1 PRISMA flowchart – Toxic occupational exposures and Parkinson’s disease



Twenty-four articles met our inclusion criteria. Data from the selected articles were extracted and kept electronically for easy retrieval for additional analysis. The extracted data included authors, year of publication, cohort characteristics, sample size, exposure, and outcome of interest, assessment of exposure and outcome, and other relevant information (Table 3-1). The twenty-four articles that were included in the analysis are fully referenced in Appendix B.

Table 3-1 provides a detailed summary of the study characteristics of the articles included in the review. Sample sizes ranged from 284 to 5,138,648, with a total sample size of 9,570,178 for all 24 studies included in the analysis. A total of 5,606,328 males and 3,911,099 females and 52,751 unclassified for sex were included in the study from countries such as the USA including Hawaii, Denmark, South Korea, England and Wales, Switzerland, Sweden, France, The Netherlands, and Australia.

A modified NOS assessment scale was utilized in assessment of the quality of the included studies. The original scale was modified to separate tools developed for cohort and case-control studies after it was tested on systematic reviews. We used the modified scale developed for cohort studies in our quality assessment. The quality assessment was based on the external and internal validity of the studies. External validity included representativeness of the population, cohort representative of the target population and demonstration that outcome of interest was not present at start of study. Internal validity included assessment of exposure (security of records and validity of information), assessment of outcome (length and adequacy of follow up, and acceptable case definition and/or assessment), comparability of study design including appropriate control of confounding (Appendix C).

Table 3- 1 Summary of study characteristics

First Author and Year	Cohort Characteristics	Age (yrs.) at Enrolment	No. of Subjects (male/female)	Exposures	Exposure Assessment	PD Diagnosis	Quality Assessment
Fryzek et al., 2005	Retrospective cohort; 1977 to 2002; Danish metal-manufacturing employees.	37	27,839/0	Occupation (metals)	Self-administered questionnaire of occupational histories.	ICD8, code-342.0 and ICD10, code-G20.	Fair
Palacios et al., 2014	Prospective cohort of US nurses; 1976 with biennial questionnaires.	30-55	0/121,701	Occupation (metals)	National Air Toxics Assessments on exposures to select metals.	Self-reporting verified by medical record.	Good
Park et al., 2006	Retrospective cohort; 1970 and 2002; South Korean shipbuilding employees.	n/a	38,560/0	Occupation (manganese)	Airborne manganese concentration.	ICD10, code-G20-G26 as the primary or auxiliary diagnosis were used.	Good
Tüchsen et al., 2000	Prospective cohort; 1981 to 1993; Danish agricultural workers.	20-59	90,430/38,505	Occupation (pesticides)	Occupational groups (farming, horticulture, forestry and related fields).	ICD-8, code-342.	Good
Johansen et al., 2000	Retrospective cohort; employees of Danish utility companies between 1900 and 1993 and the Danish National Register of Patients 978 to 1993.	18-66	24,580/5,781	Occupation (electromagnetic)	Utility workers employment records, Danish Supplementary Pension Fund and the files of the public payroll administration of all Danish counties.	ICD-8, code-342.99.	Good
Beard et al., 2003	Retrospective cohort; 1935 to 1996; field officers, office staff or laboratory staff for the Board of Tick Control, Australia.	n/a	1,984/0	Occupation (pesticides)	Board of Tick Control records indicating chemical usage.	Insurance and death records; mailed questionnaire.	Fair
Willis et al., 2010	Retrospective cohort; medicare part A beneficiaries enrolled since 1995, living in the United States in the year 2003.	n/a	2,685,857/ 2,452,791	Metals	Toxic Release Inventory facility location and onsite metal release and waste management activities.	ICD-9, code 332.0, 332.1 and 333.0	Good

Sorahan and Kheifets, 2007	Employees of the former Central Electricity Generating Board of England and Wales; 1971-1993.	n/a	72,954/11,043	Occupation (electromagnetic)	Occupational exposures were assessed by the EMF Research Section of the National Grid Company.	ICD-8 and ICD-9.	Good
Röösli et al., 2007	Swiss railway employees; 1972 to 2002.	n/a	20,141/0	Occupation (electromagnetic)	Electromagnetic measurements and modelling.	ICD-8 and ICD-10.	Fair
Sorahan and Mohammed, 2014	Employees of the former Central Electricity Generating Board of England and Wales; 1973-2010.	n/a	62,825/10,226	Occupation (electromagnetic)	Exposure assessments for power stations and transmission workers.	ICD-8, code 342 and ICD-10, code-G 20-21, and G25.9.	Fair
Baldi et al., 2003	Elderly people, aged 65 years or older, living at home or in an institution in Gironde, southwestern France was followed from 1987.	≥ 65	1,122/1,670	Pesticides	Detailed occupational histories from specific questionnaires.	Trained neurologist confirmation of a diagnosis of Parkinson's disease.	Good
Feldman et al., 2011	Prospective cohort; Swedish men s followed for up to 43 years.	44	20,225/0	Occupation (pesticides)	A job exposure matrix (JEM) based on occupation at baseline.	National Patient Register (NPR) and the Cause of Death Register (CDR).	Good
Pedersen et al., 2017	Employees of private and public utility companies in Denmark 1900-1993.	16-66	32,006/0	Occupation (electromagnetic)	A job-exposure matrix.	ICD-8 and ICD-10.	Good
Brouwers et al., 2014	A sub cohort of the Netherlands Cohort Study followed up for cause-specific mortality; 1986-2003.	55-69	58,279/62,573	Occupation (electromagnetic)	Occupational history questionnaire	ICD-9, code 332.0 and ICD-10, code-G20.	Good
Engel et al., 2001	A cohort study; men exposed to pesticides; 1972-1976.	69.6 (49-96)	310/0	Occupation (pesticides)	Self-administered questionnaire on pesticide use.	Unified Parkinson's disease rating scale (UPDRS).	Fair
Petrovitch et al., 2002	Prospective cohort; men of Japanese ancestry living on the island of Oahu, Hawaii; 1965-1996.	53.0 (45-68)	7,986/0	Occupation (pesticides)	Self-reported years of work on plantations and exposure to pesticides.	Hospitalization records and verification of diagnosis by neurologist.	Fair

Kenborg et al., 2012	Retrospective cohort: Danish steel production workers; 1964-1984	16–66	10,058/1	Occupation (metals)	A mailed questionnaire.	ICD-8: 342; ICD-10: G20, ICD-8: 342.1; ICD-10: G21, ICD-10: G22	Fair
Kenborg et al., 2012	Prospective cohort; Danish professional gardeners;1977-2008.	≥35	3,124/0	Occupation (pesticides)	Danish Union of Gardeners membership delineated exposure to pesticides.	ICD-8, code 342 and ICD-10 code G20.	Good
Wastensson et al., 2006	Prospective cohort; Swedish diphenyl-impregnated paper production workers; 1954 to 1970.	44-55	264/20	Occupation (pesticides)	Company files and trade union cards that indicated job titles and time of employment.	Neurologist identified cases based on signs and response to levodopa treatment.	Fair
Ascherio et al., 2006	Prospective cohort; US farmers; enrolled in 1993-1997, and followed in 1997-2001.	male: 63.7 (41-90); female: 62.0 (40-85)	86,404/97,786	Pesticides	Questionnaire on occupation and exposure to selected chemicals or dusts.	Questionnaire; medical records of treating neurologists that confirmed PD.	Fair
Kamel et al., 2006	Prospective cohort; restricted use pesticide-applicators; enrolled in 1993-1997, and followed in 1999-2003.	n/a	52751 (sex undefined)	Occupation (pesticides)	Questionnaires on pesticide exposure.	Self-reported PD diagnosis by a physician at enrollment and follow-up.	Good
Park et al., 2005	Retrospective cohort of National Occupational Mortality Surveillance System; 1992-1998 .	n/a	1,683,783/930,563	Occupation (electromagnetic, pesticides)	Job exposure matrix and occupational classification by proportionate mortality rates.	ICD:331.0.	Good
Håkansson et al., 2003	Prospective cohort; Swedish engineering industry workers; 1985-1996.	35	537,692/180,529	Occupation (electromagnetic)	Job exposure matrix and occupational classification from Nordic version of the International Standard for Classification of Occupations (ISCO).	ICD-9, code 332.0.	Good
Savitz et al., 1998	A cohort mortality study electric utility workers between 1950 and 1986.	n/a	139,905/0	Occupation (electromagnetic)	Job histories and occupational categories.	ICD 8, code 342 and ICD-9, code 331.0.	Fair

The reviewed articles were categorized according to (1) occupational exposures and (2) methods of outcome assessment. Each category had several groups, occupational exposures: (a) overall toxic exposures (b) electromagnetic exposures; (c) metal exposures; and (d) pesticide exposures and methods of outcome assessment: (a) ICD codes, (b) medical records and (c) confirmation by neurologists/nurse. Some articles examined more than one type of toxic exposure leading to inclusion in multiple separate analyses. When broken down by types of toxic exposures, a total number of 35 studies were analyzed. We report on these studies first looking at overall toxic exposures, followed by electromagnetic studies, metal studies, and finally, pesticide studies.

Twenty-four articles [32-55] used longitudinal study designs to examine the relationship between toxic occupational exposures and Parkinson's disease. Most of these studies used the ICD codes in varying classifications, medical records or neurologists' confirmation to ascertain PD diagnosis (Table 3-1). Figure 3-2 shows the individual studies, pooled estimates, and funnel plots for (a) all toxic occupational exposures and (b) electromagnetic exposures; (c) metal exposures; and (d) pesticide exposures. A random effects model was used to calculate the summary effect estimates and their corresponding 95% confidence intervals (CIs).

3.4.1.2 Relationship between toxic occupational exposures and PD

The pooled RR (Table 3-3) for toxic occupational exposures among study subjects diagnosed with PD was 1.15 (95% CI 1.06–1.24, $\chi 2 = 10.75$, $I^2 = 0.00\%$, $p = 0.001$) indicating that any toxic occupational exposure is a significant risk factor for PD as those with a history of exposure were 1.15 times more likely to be diagnosed with PD than those without history of toxic exposures. The Egger's test ($p=0.217$) and funnel plot in Figure 3-2a indicated that there was no evidence of heterogeneity or publication bias for overall toxic occupational exposures.

3.4.1.2.1 Relationship between occupational electromagnetic exposures and PD

Nine articles [36, 39-41, 44-45, 53-55] were used to examine the relationship between electromagnetic exposures and PD. PD diagnosis was assessed through ICD codes. Six studies reported an association between PD and occupational electromagnetic exposures, while the other three studies did not find an association. A random effects model was used. Figure 3-2b shows the individual study and pooled estimates, and funnel plots. The pooled RR (Table 3-3) for PD for those who were occupationally exposed to electromagnetic forces as opposed to those who were not was 1.03 (95% CI 0.91–1.16, $\chi 2 = 0.22$, $I^2 = 12.55\%$, $p = 0.642$). This indicates that those working in occupations where they were exposed to electromagnetic fields were 1.03 times more likely to develop PD than those who were not exposed to magnetic fields in their occupations.

As demonstrated in Figure 3-2b, the funnel plot shows that all studies were within the 95% confidence interval domain. There was no evidence of heterogeneity or publication bias (Egger's test, $p = 0.418$). The influence of study quality on overall estimates was assessed by omitting lower quality studies from the analysis. The analysis yielded an electromagnetic exposure RR of 1.02 (95% CI 0.85 -1.25), clearly demonstrating that occupational electromagnetic exposure was a risk factor for Parkinson's disease.

3.4.1.2.2 Relationship between occupational metal exposures and PD

Fourteen articles [32, 33a-h, 34, 38a-c] were used to examine the relationship between metal exposures and PD. PD diagnosis was assessed through ICD codes and medical records. Nine studies reported an association with occupational metal exposures and PD, with one study reporting a significant association, while five studies did not report an association. A random effects model was used. Figure 3-2c demonstrates the individual study, pooled estimates, and funnel plots. The pooled RR for PD (Table 3-3) for those who were occupationally exposed to metals as opposed to those who were not was 1.07 (95% CI 0.92–1.24, $\chi 2 = 0.76$, $I^2 = 0.00\%$, $p = 0.385$). This indicates that those occupationally exposed to metals were 1.07 times more likely to develop PD than those who were not exposed to magnetic fields in their occupations.

As demonstrated in Figure 3-2c, the funnel plot shows that all studies were within the 95% confidence interval domain. There was no evidence of heterogeneity or publication bias (Egger's test, $p = 0.329$). Sensitivity analysis yielded metal exposure RR of 1.08 (95% CI 0.92 - 1.27), clearly demonstrating that occupational metal exposure was a risk factor for Parkinson's disease.

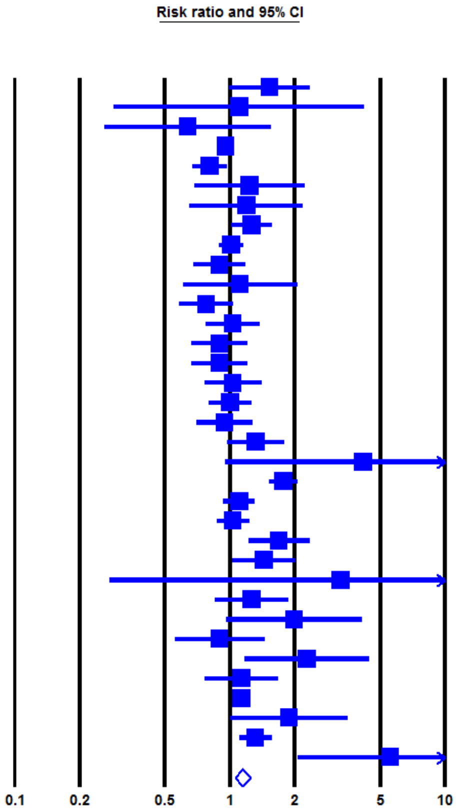
3.4.1.2.3 Relationship between occupational pesticide exposures and PD

Twelve articles [35, 37, 42-44, 45-48, 50-53] were used to examine the relationship between metal exposures and PD. PD diagnosis was assessed through ICD codes, insurance, medical and death records, neurologist or nurse's confirmation of self-reported diagnosis and one mailed questionnaire. Eleven of the twelve studies reported an association between occupational pesticide exposure and PD, with half of the associations being significant. A random effects model was used. Figure 3-2d shows the individual study and pooled estimates, and funnel plots. The pooled RR (Table 3-3) for PD for those who were occupationally exposed to pesticides as opposed to those who were not was 1.41 (95% CI 1.20–1.65, $\chi 2 = 16.99$, $I^2 = 26.24\%$, $p = 0.000$). This indicates that those working in occupations where they were exposed to pesticides were at significant increased risk or 1.41 times more likely to develop PD than those who were not occupationally exposed to pesticides.

As demonstrated by the funnel plot in Figure 3-2d, all studies were within the 95% confidence interval domain. However, there was moderate heterogeneity and publication bias (Egger's test, $p = 0.003$). Sensitivity analysis yielded pesticide exposure RR of 1.28 (95% CI 0.99 -1.62), clearly demonstrating that occupational pesticide exposure was a risk factor for Parkinson's disease.

Figure 3-2 a Relationship between overall toxic occupational exposures and PD

Study name	Subgroup within study	Risk ratio	Lower limit	Upper limit	Z-Value	p-Value
Brouwers et al., 2014a	Electromagnetic exposures	1.540	1.002	2.366	1.971	0.049
Håkansson et al., 2003	Electromagnetic exposures	1.110	0.292	4.214	0.153	0.878
Johansen et al., 2000	Electromagnetic exposures	0.640	0.263	1.558	-0.983	0.325
Park et al., 2005a	Electromagnetic exposures	0.960	0.883	1.044	-0.958	0.338
Pedesen et al., 2017	Electromagnetic exposures	0.810	0.673	0.975	-2.232	0.026
Röösli et al., 2007	Electromagnetic exposures	1.240	0.693	2.219	0.724	0.469
Savitz et al., 1998	Electromagnetic exposures	1.200	0.657	2.191	0.594	0.553
Sorahan and Kheifets, 2007	Electromagnetic exposures	1.270	1.027	1.571	2.205	0.027
Sorahan and Mohammed, 2014	Electromagnetic exposures	1.020	0.902	1.153	0.317	0.751
Fryzek et al., 2005	Metal exposures	0.900	0.687	1.178	-0.766	0.444
Kenborg et al., 2012a	Metal exposures	1.120	0.609	2.059	0.365	0.715
Palacios et al., 2014a	Metal exposures	0.780	0.587	1.036	-1.718	0.086
Palacios et al., 2014b	Metal exposures	1.040	0.782	1.383	0.269	0.788
Palacios et al., 2014c	Metal exposures	0.900	0.667	1.214	-0.689	0.491
Palacios et al., 2014d	Metal exposures	0.900	0.667	1.214	-0.689	0.491
Palacios et al., 2014e	Metal exposures	1.040	0.771	1.402	0.257	0.797
Palacios et al., 2014f	Metal exposures	1.010	0.806	1.265	0.087	0.931
Palacios et al., 2014g	Metal exposures	0.950	0.710	1.271	-0.346	0.730
Palacios et al., 2014h	Metal exposures	1.330	0.984	1.797	1.856	0.064
Park et al., 2006	Metal exposures	4.187	0.959	18.282	1.904	0.057
Willis et al., 2010a	Metal exposures	1.780	1.535	2.064	7.642	0.000
Willis et al., 2010b	Metal exposures	1.110	0.940	1.310	1.233	0.218
Willis et al., 2010c	Metal exposures	1.040	0.880	1.230	0.459	0.646
Ascherio et al., 2006	Pesticides exposures	1.700	1.228	2.354	3.197	0.001
Baldi et al., 2003	Pesticides exposures	1.450	1.040	2.021	2.194	0.028
Beard et al., 2003	Pesticides exposures	3.300	0.280	38.916	0.948	0.343
Brouwers et al., 2014b	Pesticides exposures	1.270	0.859	1.878	1.198	0.231
Engel et al., 2001	Pesticides exposures	2.000	0.976	4.099	1.893	0.058
Feldman et al., 2011	Pesticides exposures	0.900	0.558	1.451	-0.432	0.666
Kamel et al., 2006	Pesticides exposures	2.300	1.188	4.454	2.470	0.014
Kenborg et al., 2012b	Pesticides exposures	1.140	0.774	1.680	0.663	0.508
Park et al., 2005b	Pesticides exposures	1.140	1.086	1.196	5.342	0.000
Petrovitch et al., 2002	Pesticides exposures	1.900	1.016	3.555	2.008	0.045
Tüchsen et al., 2000	Pesticides exposures	1.320	1.113	1.565	3.198	0.001
Wastensson et al., 2006	Pesticides exposures	5.600	2.084	15.050	3.416	0.001
		1.146	1.056	1.243	3.278	0.001



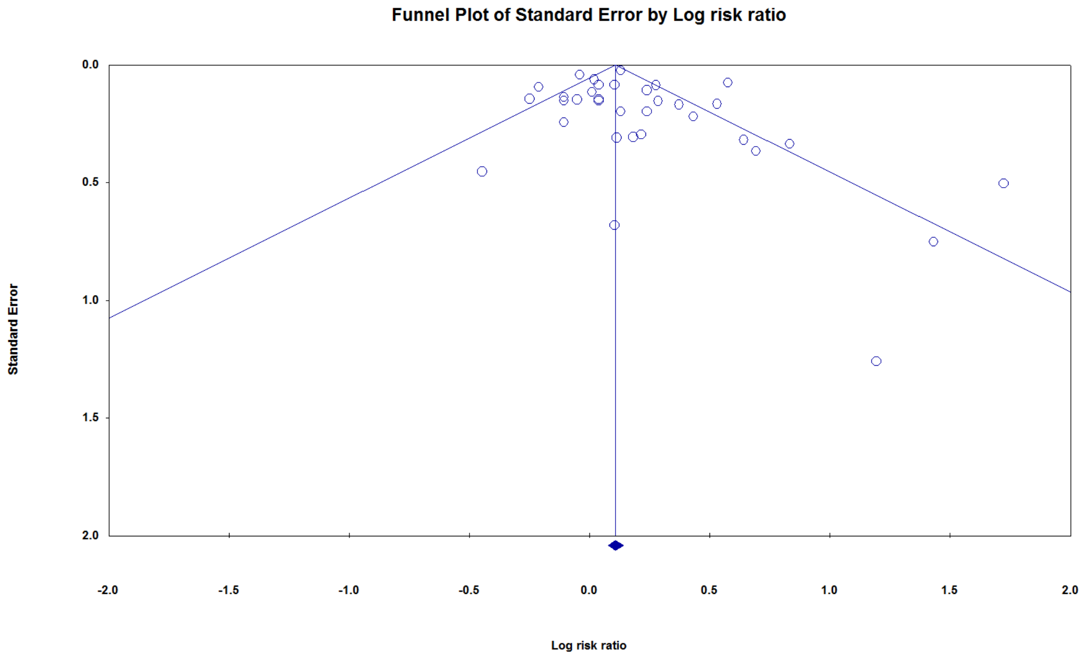
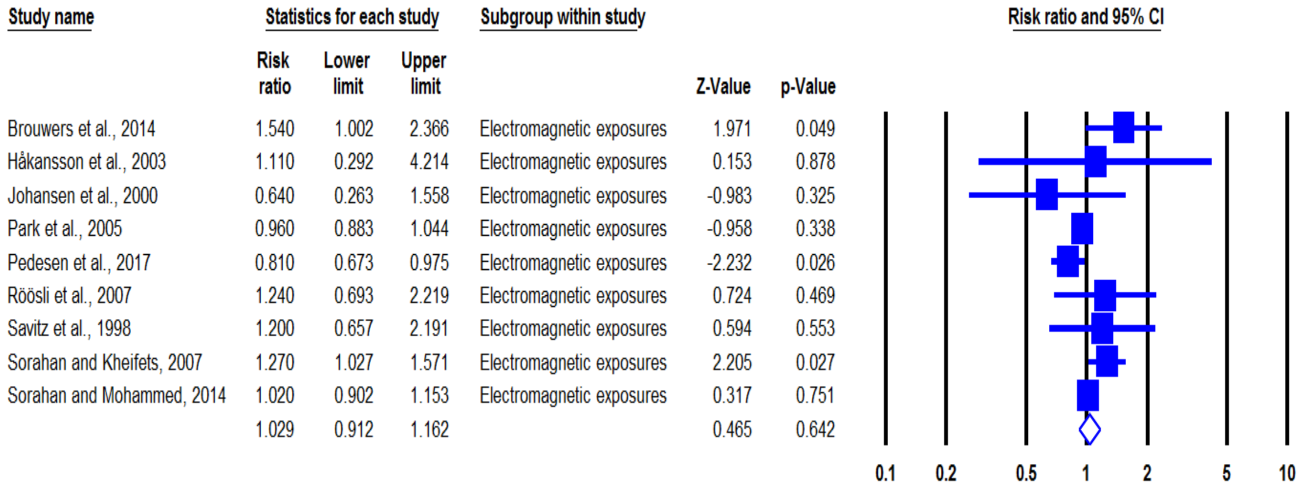


Figure 3-2 b Relationship between occupational electromagnetic exposure and Parkinson's disease



Study name	Statistics for each study			Subgroup within study		
	Risk ratio	Lower limit	Upper limit		Z-Value	p-Value
Brouwers et al., 2014	1.540	1.002	2.366	Electromagnetic exposures	1.971	0.049
Håkansson et al., 2003	1.110	0.292	4.214	Electromagnetic exposures	0.153	0.878
Johansen et al., 2000	0.640	0.263	1.558	Electromagnetic exposures	-0.983	0.325
Park et al., 2005	0.960	0.883	1.044	Electromagnetic exposures	-0.958	0.338
Pedesen et al., 2017	0.810	0.673	0.975	Electromagnetic exposures	-2.232	0.026
Röösli et al., 2007	1.240	0.693	2.219	Electromagnetic exposures	0.724	0.469
Savitz et al., 1998	1.200	0.657	2.191	Electromagnetic exposures	0.594	0.553
Sorahan and Kheifets, 2007	1.270	1.027	1.571	Electromagnetic exposures	2.205	0.027
Sorahan and Mohammed, 2014	1.020	0.902	1.153	Electromagnetic exposures	0.317	0.751
	1.029	0.912	1.162		0.465	0.642

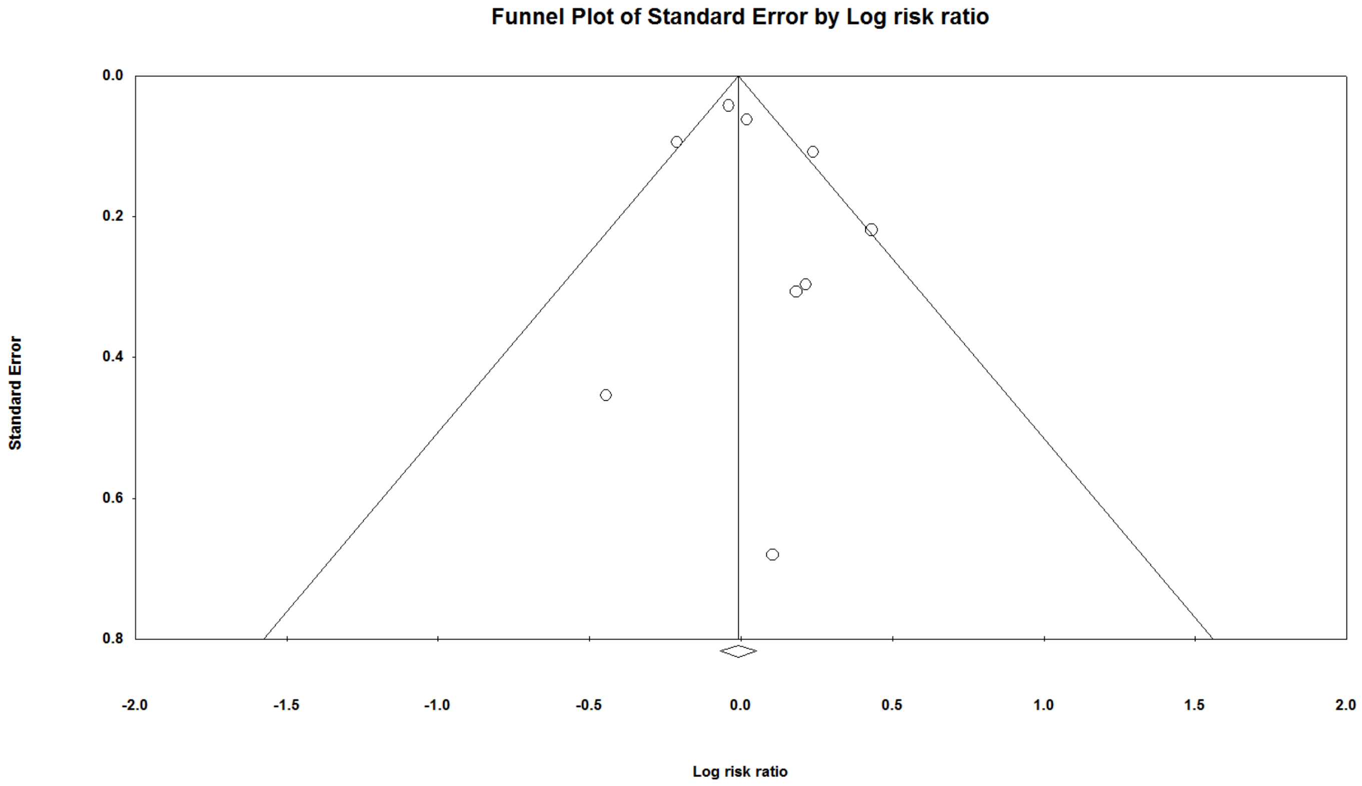
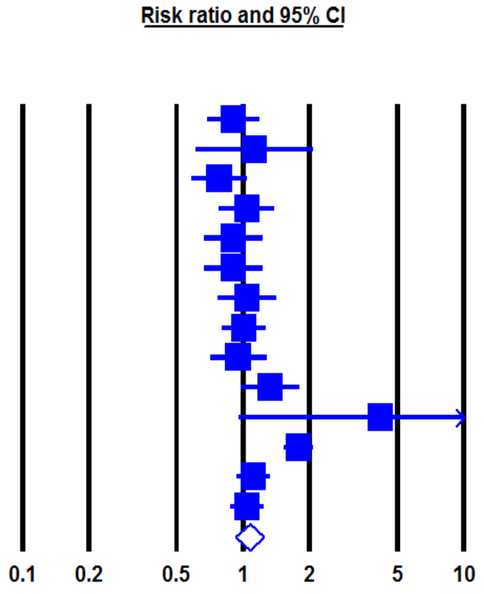


Figure 3-2 c Relationship between occupational metal exposure and Parkinson’s disease

Study name	Subgroup within study	Risk ratio	Lower limit	Upper limit	Z-Value	p-Value
Fryzek et al., 2005	Metal exposures	0.900	0.687	1.178	-0.766	0.444
Kenborg et al., 2012a	Metal exposures	1.120	0.609	2.059	0.365	0.715
Palacios et al., 2014a	Metal exposures	0.780	0.587	1.036	-1.718	0.086
Palacios et al., 2014b	Metal exposures	1.040	0.782	1.383	0.269	0.788
Palacios et al., 2014c	Metal exposures	0.900	0.667	1.214	-0.689	0.491
Palacios et al., 2014d	Metal exposures	0.900	0.667	1.214	-0.689	0.491
Palacios et al., 2014e	Metal exposures	1.040	0.771	1.402	0.257	0.797
Palacios et al., 2014f	Metal exposures	1.010	0.806	1.265	0.087	0.931
Palacios et al., 2014g	Metal exposures	0.950	0.710	1.271	-0.346	0.730
Palacios et al., 2014h	Metal exposures	1.330	0.984	1.797	1.856	0.064
Park et al., 2006	Metal exposures	4.187	0.959	18.282	1.904	0.057
Willis et al., 2010a	Metal exposures	1.780	1.535	2.064	7.642	0.000
Willis et al., 2010b	Metal exposures	1.110	0.940	1.310	1.233	0.218
Willis et al., 2010c	Metal exposures	1.040	0.880	1.230	0.459	0.646
		1.068	0.920	1.240	0.869	0.385



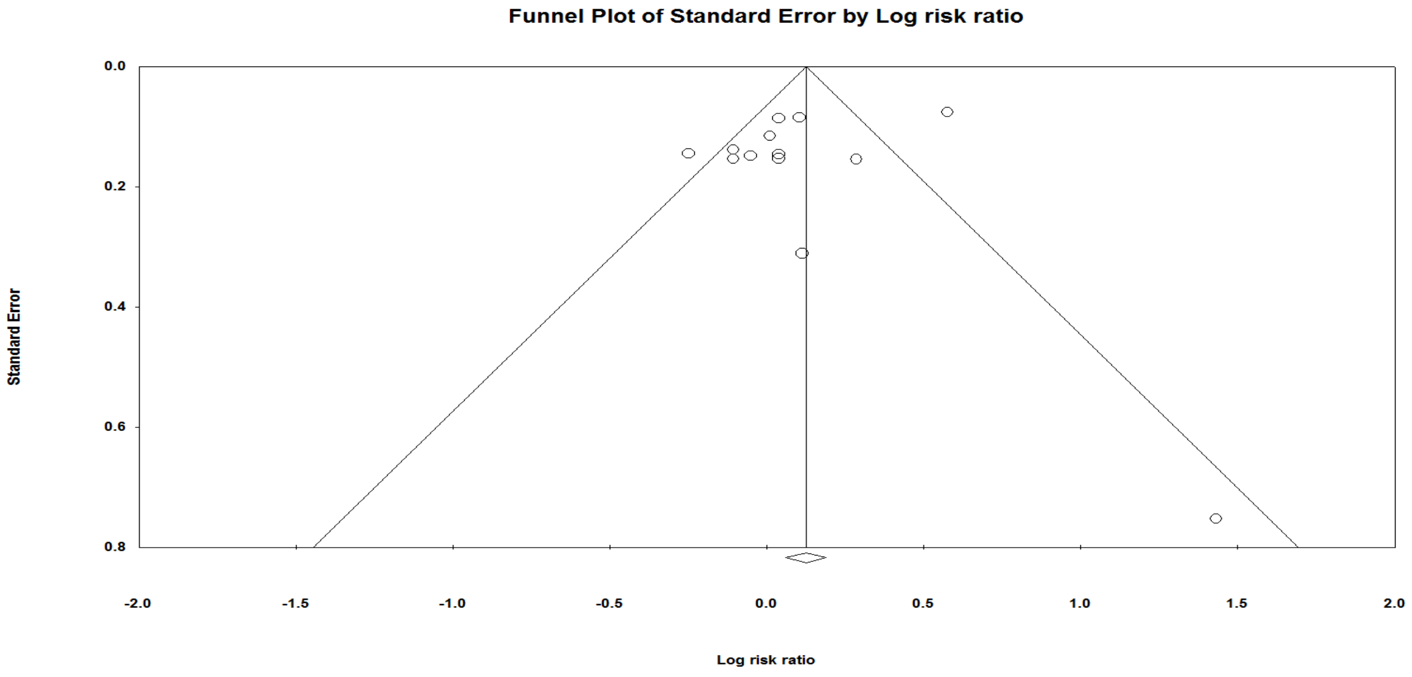
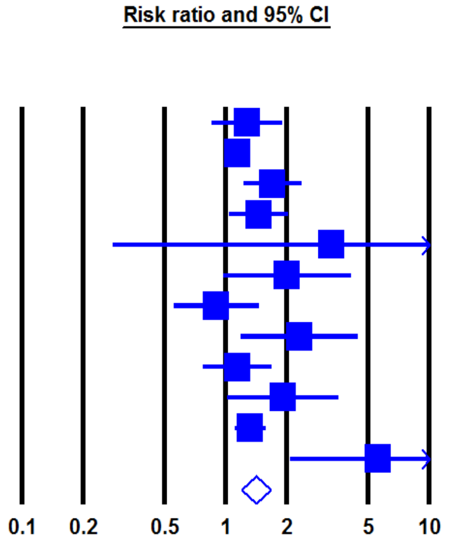
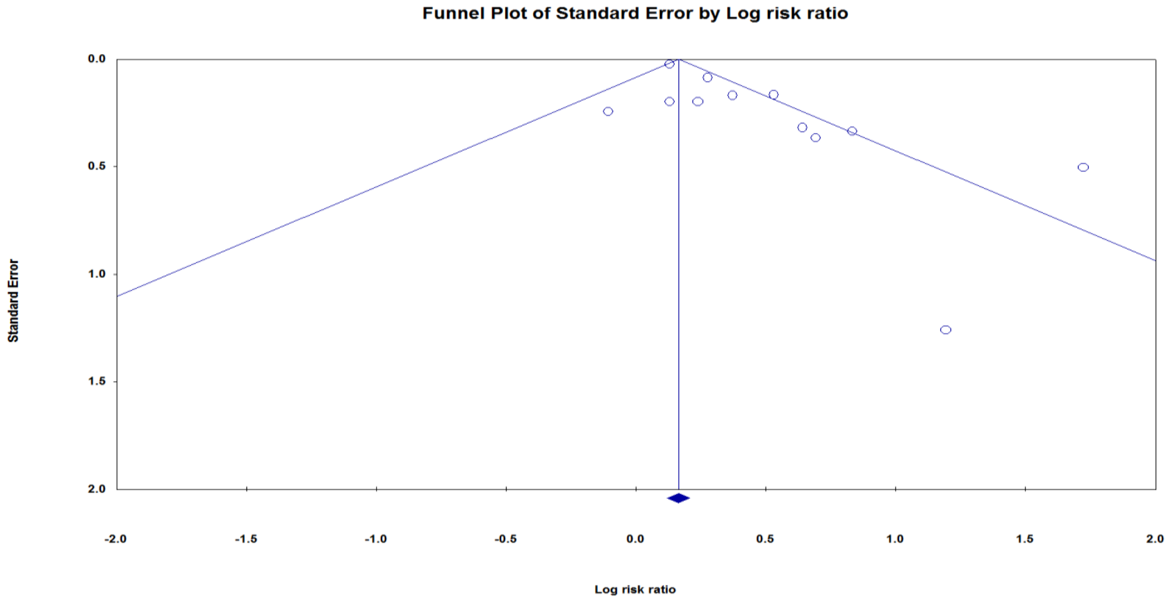


Figure 3-2 d Relationship between occupational pesticide exposure and Parkinson's disease

Study name	Subgroup within study	Statistics for each study				
		Risk ratio	Lower limit	Upper limit	Z-Value	p-Value
Brouwers et al., 2014	Pesticides exposures	1.270	0.859	1.878	1.198	0.231
Park et al., 2005	Pesticides exposures	1.140	1.086	1.196	5.342	0.000
Ascherio et al., 2006	Pesticides exposures	1.700	1.228	2.354	3.197	0.001
Baldi et al., 2003	Pesticides exposures	1.450	1.040	2.021	2.194	0.028
Beard et al., 2003	Pesticides exposures	3.300	0.280	38.916	0.948	0.343
Engel et al., 2001	Pesticides exposures	2.000	0.976	4.099	1.893	0.058
Feldman et al., 2011	Pesticides exposures	0.900	0.558	1.451	-0.432	0.666
Kamel et al., 2006	Pesticides exposures	2.300	1.188	4.454	2.470	0.014
Kenborg et al., 2012	Pesticides exposures	1.140	0.774	1.680	0.663	0.508
Petrovitch et al., 2002	Pesticides exposures	1.900	1.016	3.555	2.008	0.045
Tüchsen et al., 2000	Pesticides exposures	1.320	1.113	1.565	3.198	0.001
Wastensson et al., 2006	Pesticides exposures	5.600	2.084	15.050	3.416	0.001
		1.406	1.196	1.653	4.122	0.000





3.4.1.3 Relationship between toxic occupational exposures and PD by diagnostic methods

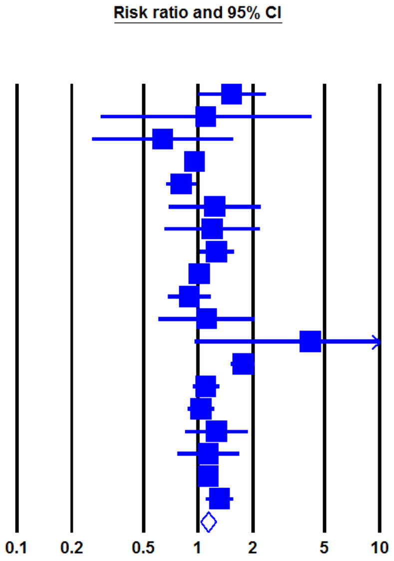
When the relationship between toxic occupational exposures and PD was analyzed according to methods of diagnosing PD, the pooled RR, 2.17 (95% CI 1.32-3.54, $\chi 2 = 9.49$, $I^2 = 7.83\%$, $p = 0.002$) was highest and significant in those whose diagnosis was confirmed by a neurologist or nurse using standardized assessment methods. The lowest pooled RR was 1.06 (95% CI 0.92-1.21, $\chi 2 = 0.62$, $I^2 = 8.54\%$, $p = 0.002$). This represented an insignificant association between toxic occupational exposures and PD diagnosis confirmed through medical records.

There was a significant association between toxic occupational exposure and PD diagnosis confirmed by ICD codes, RR 1.14 (95% CI 1.03-1.26, $\chi 2 = 6.45$, $I^2 = 8.09\%$, $p = 0.011$) (Figure 3-3 and Table 3-3). The Egger's test (p=0.676; 0.228; and 0.217) and funnel plots in Figure 3-3 indicated that there was no evidence of heterogeneity or publication bias for toxic occupational exposures leading to PD diagnosed through ICD codes, medical records, and confirmation by neurologist/nurse, respectively.

Figure 3-3 a Relationship between overall toxic occupational exposures and PD diagnosed by ICD codes

Study name	Subgroup within study	Risk ratio	Lower limit	Upper limit	Z-Value	p-Value
Brouwers et al., 2014a	ICD codes	1.540	1.002	2.366	1.971	0.049
Håkansson et al., 2003	ICD codes	1.110	0.292	4.214	0.153	0.878
Johansen et al., 2000	ICD codes	0.640	0.263	1.558	-0.983	0.325
Park et al., 2005a	ICD codes	0.960	0.883	1.044	-0.958	0.338
Pedesen et al., 2017	ICD codes	0.810	0.673	0.975	-2.232	0.026
Röösli et al., 2007	ICD codes	1.240	0.693	2.219	0.724	0.469
Savitz et al., 1998	ICD codes	1.200	0.657	2.191	0.594	0.553
Sorahan and Kheifets, 2007	ICD codes	1.270	1.027	1.571	2.205	0.027
Sorahan and Mohammed, 2014	ICD codes	1.020	0.902	1.153	0.317	0.751
Fryzek et al., 2005	ICD codes	0.900	0.687	1.178	-0.766	0.444
Kenborg et al., 2012a	ICD codes	1.120	0.609	2.059	0.365	0.715
Park et al., 2006	ICD codes	4.187	0.959	18.282	1.904	0.057
Willis et al., 2010a	ICD codes	1.780	1.535	2.064	7.642	0.000
Willis et al., 2010b	ICD codes	1.110	0.940	1.310	1.233	0.218
Willis et al., 2010c	ICD codes	1.040	0.880	1.230	0.459	0.646
Brouwers et al., 2014b	ICD codes	1.270	0.859	1.878	1.198	0.231
Kenborg et al., 2012b	ICD codes	1.140	0.774	1.680	0.663	0.508
Park et al., 2005b	ICD codes	1.140	1.086	1.196	5.342	0.000
Tüchsen et al., 2000	ICD codes	1.320	1.113	1.565	3.198	0.001
		1.137	1.030	1.256	2.539	0.011

(Statistics for each study)



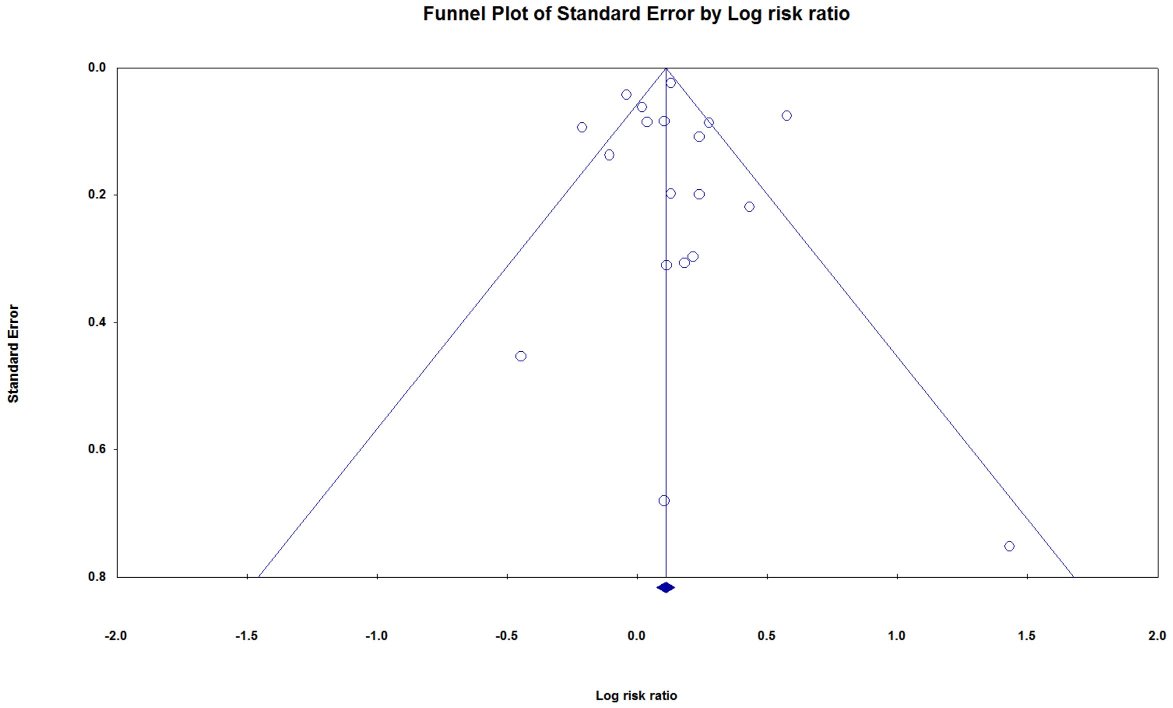
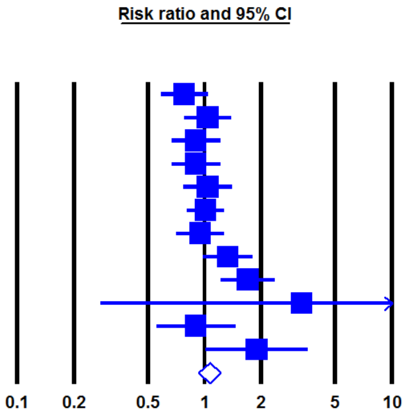


Figure 3-3 b Relationship between overall toxic occupational exposures and PD diagnosed by medical records

Study name	Subgroup within study	Statistics for each study				
		Risk ratio	Lower limit	Upper limit	Z-Value	p-Value
Palacios et al., 2014a	Medical records	0.780	0.587	1.036	-1.718	0.086
Palacios et al., 2014b	Medical records	1.040	0.782	1.383	0.269	0.788
Palacios et al., 2014c	Medical records	0.900	0.667	1.214	-0.689	0.491
Palacios et al., 2014d	Medical records	0.900	0.667	1.214	-0.689	0.491
Palacios et al., 2014e	Medical records	1.040	0.771	1.402	0.257	0.797
Palacios et al., 2014f	Medical records	1.010	0.806	1.265	0.087	0.931
Palacios et al., 2014g	Medical records	0.950	0.710	1.271	-0.346	0.730
Palacios et al., 2014h	Medical records	1.330	0.984	1.797	1.856	0.064
Ascherio et al., 2006	Medical records	1.700	1.228	2.354	3.197	0.001
Beard et al., 2003	Medical records	3.300	0.280	38.916	0.948	0.343
Feldman et al., 2011	Medical records	0.900	0.558	1.451	-0.432	0.666
Petrovitch et al., 2002	Medical records	1.900	1.016	3.555	2.008	0.045
		1.057	0.921	1.214	0.787	0.431



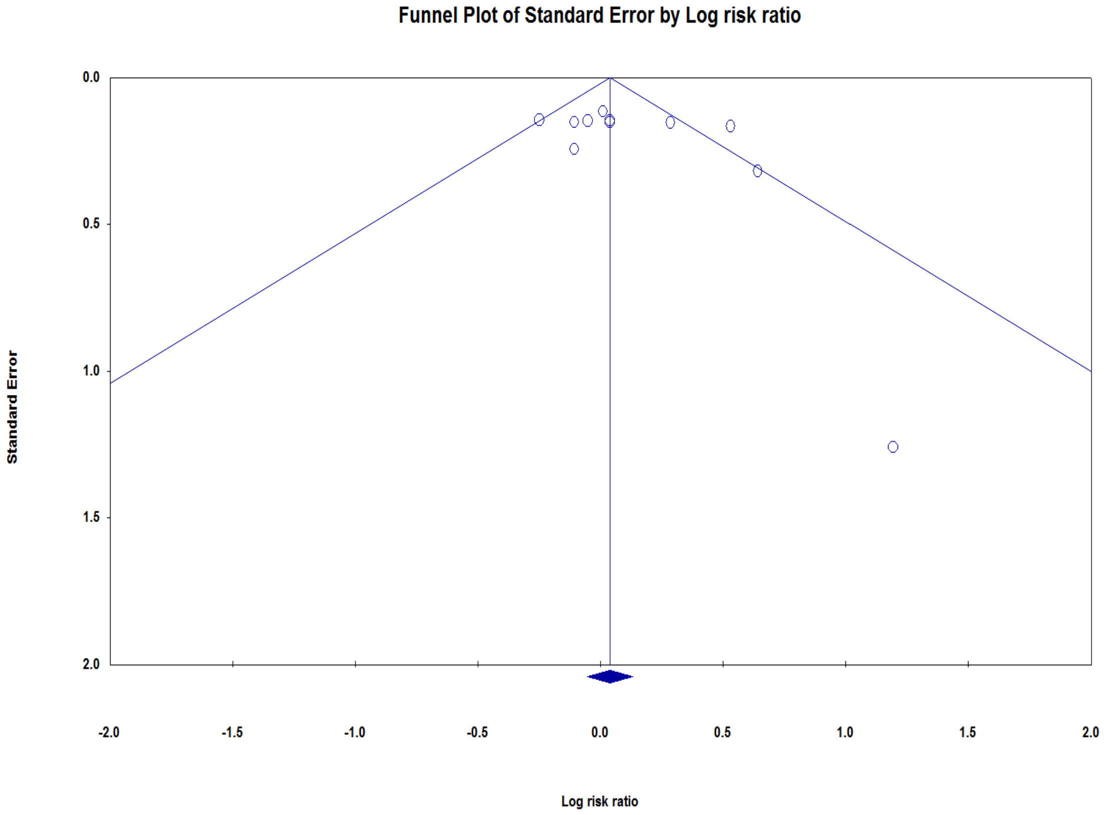
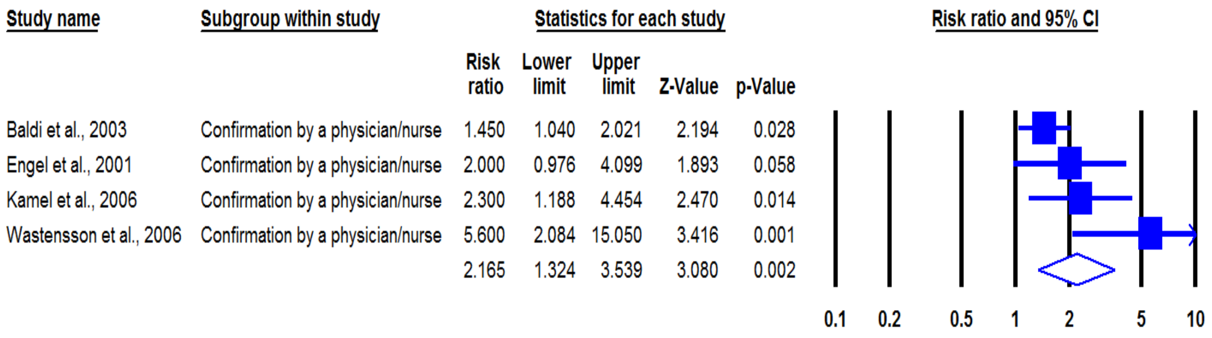
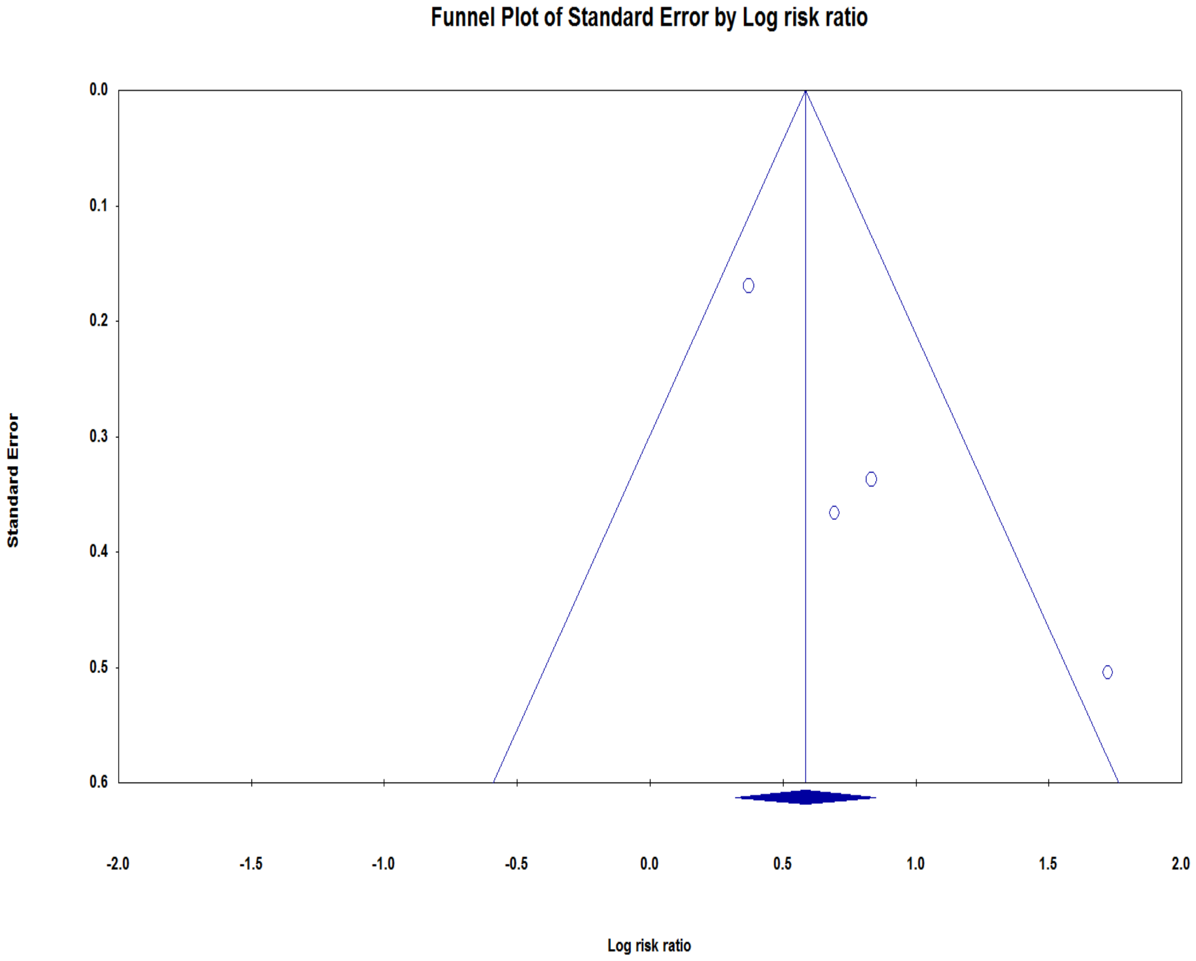


Figure 3-3 c Relationship between overall toxic occupational exposures and PD confirmed by neurologist or nurse



Study name	Subgroup within study	Risk ratio	Lower limit	Upper limit	Z-Value	p-Value
Baldi et al., 2003	Confirmation by a physician/nurse	1.450	1.040	2.021	2.194	0.028
Engel et al., 2001	Confirmation by a physician/nurse	2.000	0.976	4.099	1.893	0.058
Kamel et al., 2006	Confirmation by a physician/nurse	2.300	1.188	4.454	2.470	0.014
Wastensson et al., 2006	Confirmation by a physician/nurse	5.600	2.084	15.050	3.416	0.001
		2.165	1.324	3.539	3.080	0.002



3.4.1.4 Summary of findings

The major finding of our analyses is that, though all toxic occupational exposures result in increased risk of being diagnosed with PD, those individuals working in occupations where they are exposed to pesticides are at significant risk and are most likely to be diagnosed with PD (Table 3-2). The strongest association between toxic occupational exposure and PD was observed in those whose PD diagnosis was confirmed by a neurologist or nurse.

Table 3- 2 Summary of results of meta-analysis

Study Group	Risk ratios (RR)	95% Confidence interval (CI)	p-value
Toxic Occupational Exposures			
Overall exposures	1.15	1.06-1.24	0.001
Electromagnetic exposures	1.03	0.91-1.16	0.642
Metal Exposures	1.07	0.92-1.24	0.385
Pesticide exposures	1.41	1.20-1.65	<0.001
Diagnostic Methods			
ICD Codes	1.14	1.03-1.26	0.011
Medical Records	1.06	0.92-1.21	0.431
Neurologists'/Nurse's Confirmation	2.17	1.32-3.54	0.002

We assessed heterogeneity and publication bias of the subgroups using Cochran's Q test and the I^2 statistic (Table 3-3). Pesticide exposures demonstrated low heterogeneity and significant risk for publication bias, while electromagnetic exposures, metal exposures and overall exposures showed no to low heterogeneity and insignificant risk for publication bias. No publication bias or heterogeneity was found among toxic occupational exposures.

Table 3- 3 Heterogeneity and publication bias results of subgroup meta-analyzed studies.

Study Groups	**Number of studies**	**Heterogeneity**			**Publication Bias**	
		Q-value	df (Q)	I^2	t value	P value (two-tailed)
Occupational Exposures						
Overall exposures	35	46.08	34.000	26.219	1.261	0.217
Electromagnetic exposures	9	9.148	8.000	12.548	0.860	0.418
Metal exposures	14	10.519	13.000	0.000	1.016	0.329
Pesticide exposures	12	14.913	11.000	26.237	3.526	0.003
Diagnostic methods						
ICD codes	19	19.585	18.000	8.093	0.425	0.676
Medical records	12	12.027	11.000	8.537	1.284	0.228
Confirmation by a neurologist/nurse	4	3.255	3.000	7.829	1.261	0.217

3.5 Discussion

This meta-analysis demonstrated that people in occupations where there were toxic exposures had a greater risk of being diagnosed with PD when compared to those who had no toxic occupational exposures. Of a total of 35 studies, 26 studies (74.3%) suggested increased risk of PD due to toxic occupational exposures. The pooled RR between any type of toxic occupational exposure and PD was 1.15 (95% CI 1.06-1.24). For select types of toxic occupational exposures, the RRs were: electromagnetic exposure, RR =1.03 (95% CI 0.91-1.16); metal exposure RR=1.07 (95% CI 0.92-1.24); and pesticide exposure RR= 1.41 (95% CI 1.06-1.65). Specific studies that reported an increased risk of PD were published between 2000 and 2014, generally had larger sample sizes, well-defined exposure and outcome assessments as well as longer periods of follow-up.

Our results show toxic occupational exposures in general and exposure to electromagnetic fields, metals and pesticides as significant risk factors for PD. Several meta-analyses, using similar rigorous quality assessment criteria for exploring the association between various types of occupational exposures on PD diagnosis, support our finding that toxic occupational exposures are associated with an elevated risk of developing Parkinson's disease (6; 56; 57).

This study further confirms the association between toxic occupational exposures found in two earlier studies (17 & 58). The pooled RR for metal exposure, 1.07 (95% CI 0.92-1.24) reported in this review was greater than the RRs reported in one of the earlier studies (58) which showed a negative association between metal exposure and PD, RR 0.98 (95% CI 0.53-1.81) and 0.85 (95% CI 0.82-0.89). The pooled RR for electromagnetic exposure, 1.03 (95% CI 0.91-1.16) in this review was slightly greater than the RRs, 1.02 (95% CI 0.83-1.26) and 1.02 (95% CI 0.90-1.16), respectively reported in both earlier studies (17 & 58). The pooled RR for pesticide exposure, 1.41 (95% CI 1.20-1.65) in this review was lower than those reported in both earlier studies (17 & 58), 1.66 (95% CI 1.42-1.94) and 1.67 (95% CI 1.42-1.97), respectively. Despite being lower than the RRs for pesticide exposure reported for other studies, the RR for pesticide exposure in this study is consistent with the finding in the literature that exposure to pesticide results in a significantly higher risk of Parkinson's disease than any other toxic exposures.

Publication bias may have influenced the results for pesticide exposure, partially explaining the higher risk estimate. Studies published more recently, i.e. after 2005 showed no publication bias (p=0.249) and a slightly lowered risk when compared to studies published before 2005 (p=0.003). Though the heterogeneity was negligible, this could be attributable to control selection, differences in methods used to assess toxic occupational exposures, variations in study design, and length of follow-up (15).

What this study adds new to the literature is pooled risk estimates of PDs based on common types of toxic occupational exposure and diagnostic assessment of outcome. Our meta-analysis found that when studies were grouped according to outcome assessment methods, no publication bias was indicated and risk estimates were higher for those whose diagnosis was confirmed by a neurologist or nurse using standardized assessment methods. This finding may be attributable to the fact that disease has progressed significantly at this stage and there is no doubt about an accurate PD diagnosis for individuals in this group, indicating a strong association between toxic occupational exposures and PD.

3.5.1 Strengths and Limitations of the Current Study

A general limitation of meta-analyses is that risk estimates can only be calculated based on data from previously published studies. Such calculations will reproduce any intrinsic weaknesses in the study design of those publications (17). In addition, previous publications of meta-analyses on Parkinson's disease have included those studies identified as relevant, regardless of their quality. One limitation of this study is that occupational exposures were assessed through a variety of methods in published data, with little focus on the dosage of exposure. Based on the lack of uniformity of exposure, we selected risk estimates spanning many years of exposure to minimize heterogeneity. Another limitation of our study is that in several of the included publications, PD was diagnosed using ICD codes which include both PD and secondary parkinsonism (Table 3-1). Parkinsonism is caused by different pathophysiological mechanisms than Parkinson's disease and may be related to different occupational exposures and pathogenesis (56). However, this limitation was overcome by stratifying studies according to method of diagnosis as part of our meta-analysis, yielding increased risk for PD despite the method of diagnosis.

One strength of our study is that the meta-analysis included studies that were of high quality, having met our robust quality assessment criteria. Another strength is that we employed multiple methods to find all potential sources of publication bias; we stratified data to account for potential confounders and used varied methods of evaluating publication bias such as stratification by publication year, funnel plots and the Egger's test (17). Other strengths of our study include the large sample size from different regions of the world; longitudinal study designs; adequate periods of follow-up; relative recency of included studies; and the number of studies included in the analyses.

3.6 Conclusion

The results of review and meta-analysis in this study provide robust confirmation that overall toxic occupational exposures are significantly and strongly associated with the development of PD. Occupational pesticide exposure, in particular, showed a greater level of association with PD that was confirmed by a neurologist/nurse using standardized methods. This may suggest that the risk in the development of PD may be more markedly increased with the duration or frequency of exposure to pesticide (19), as opposed to exposure to metals and electromagnetic fields. As the findings of this study are consistent with those of previous high quality studies, additional studies with similar methodologies may not result in significantly novel findings. Further reviews and meta-analyses of longitudinal studies of high quality should focus on prospective designs, but with more definitive exposure assessments and PD diagnosis confirmed by a neurologist/movement disorder specialist using standardized guidelines.

3.7 References

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Appendix A: Search Strategy

The following MeSH terms and free terms related to “Parkinson’s Disease,” and “herbicides,” “pesticides”, “fungicides”, “insecticides”, “heavy metals” “electromagnets” were combined to retrieve the maximum number of relevant publications: (Idiopathic Parkinson’s Disease OR Lewy Body Parkinson Disease OR Lewy Body Parkinson’s Disease OR Primary Parkinsonism OR Idiopathic Parkinson Disease OR Parkinson’s Disease OR Parkinson Disease OR Parkinson Patients OR Parkinson Patient OR Parkinson’s Patients OR Parkinson’s Patient OR Paralysis Agitans) AND ((Herbicides OR Methyl Viologen OR Gramoxone OR Paragreen A OR paraquat OR paraquat poisoning OR paraquat poisoned patients OR paraquat poisoned patient OR paraquat intoxication OR paraquat concentration OR neurotoxicity of paraquat OR paraquat neurotoxicity OR fungicide toxicity OR insecticides OR fungicides OR agricultural chemicals) OR (heavy metals OR Actinium OR Americium OR Antimony OR Barium OR Berkelium OR Bismuth OR Cadmium OR Californium OR Cesium OR Cesium Isotopes + OR Chromium OR Chromium Isotopes + OR Cobalt OR Cobalt Isotopes + OR Copper OR Curium OR Einsteinium OR Fermium OR Francium OR Gallium OR Gallium OR Isotopes + OR Germanium OR Gold OR Gold Isotopes + OR Hafnium OR Indium OR Iridium OR Iron OR Iron Isotopes + OR Lawrencium OR Lead OR Manganese OR Mendelevium OR Mercury OR Mercury Isotopes + OR Molybdenum OR Neptunium OR Nickel OR Niobium OR Nobelium OR Osmium OR Palladium OR Platinum OR Plutonium OR Protactinium OR Radium OR Rhenium OR Rhodium OR Rubidium OR Ruthenium OR Silver OR Strontium OR Strontium Isotopes + OR Tantalum OR Technetium OR Thallium OR Thorium OR Tin OR Tungsten OR Uranium OR Vanadium OR Zinc OR Zinc Isotopes + OR Zirconium) OR (electromagnetic OR electromagnets OR electromagnetism)).

Appendix B: Data References

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Appendix C: A summary of the Newcastle-Ottawa Scale (NOS) quality assessment for selected studies

Assessment item	Study																							
	Fryzek (2005)	Palacios (2014)	Park (2006)	Tüchsen (2000)	Johansen (2000)	Beard (2003)	Willis (2010)	Sorahan &Kheifets (2014)	Röösli (2007)	Sorahan &Mohammed (2014)	Baldi (2003)	Feldman (2011)	Pedersen (2017)	Brouwers (2014)	Engel (2001)	Petrovitch (2002)	Kenborg[a] (2012)	Kenborg[b] (2012)	Wastensson (2006)	Ascherio (2006)	Kamel (2006)	Park (2005)	Håkansson (2003)	Savitz (1998)
Selection																								
1. Representativeness of the population																								
a) truly representative of the average, elderly, community-dwelling resident	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	1	0	0	0	0
b) somewhat representative of the average, elderly, community-dwelling resident	0	0	0	1	0	0	1	0	0	0	1	0	0	1	1	0	0	0	0	0	1	1	1	0
c) selected group of patients, e.g. only certain socio-economic groups/areas	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
d) no description of the derivation of the cohort	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
2. Selection of the non-intervention cohort																								
a) drawn from the same community as the intervention cohort	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
b) drawn from a different source	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
c) no description of the derivation of the non-intervention cohort	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
3. Ascertainment of intervention (exposure)																								
a) secure record (e.g. health care record)	1	1	0	1	1	1	1	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	1	1

b) structured interview	0	0	1	0	0	0	0	1	1	0	1	1	1	1	0	0	0	1	1	0	0	1	0	0
c) written self-report	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
d) other / no description	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
4. Demonstration that outcome of interest was not present at start of study																								
a) yes	0	1	1	1	1	0	1	0	0	0	1	0	1	0	0	1	1	1	0	1	1	0	0	0
b) no	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Comparability																								
1. Comparability of cohorts on the basis of the design or analysis																								
a) study controls for age, sex, marital status	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
b) study controls for any additional factors (e.g. socio-economic status, education)	0	1	0	0	1	1	1	1	0	1	1	1	1	1	1	1	0	1	0	1	1	1	1	1
Outcome																								
1. Assessment of outcome																								
a) independent blind assessment	0	0	0	0	0	0	0	0	0	0	1	0	0	0	1	1	0	0	1	0	0	0	0	1
b) record linkage	1	0	1	1	1	0	1	1	1	1	0	1	1	1	0	0	1	1	0	0	0	1	1	0
c) self-report	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
d) other / no description	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0

2. Was follow up long enough for outcomes to occur																								
a) yes, if median duration of follow-up >= 6 month	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
b) no, if median duration of follow-up < 6 months	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
3. Adequacy of follow up of cohorts																								
a) complete follow up: all subjects accounted for	0	0	1	0	0	0	0	0	0	0	0	0	1	0	0	0	1	0	1	0	0	0	0	0
b) subjects lost to follow up unlikely to introduce bias: number lost <= 20%, or description of those lost suggesting no different from those followed	1	1	0	0	0	1	0	1	1	0	1	0	0	1	0	0	0	0	0	0	1	0	0	0
c) follow up rate < 80% (select an adequate %) and no description of those lost	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
d) no statement	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Overall	5	6	6	6	6	5	7	6	5	5	8	6	7	7	5	5	5	6	5	5	6	6	6	5

Note: Kenborg[a]: Parkinson's disease among gardeners exposed to pesticides-a Danish cohort study; Kenborg[b]: Parkinson's disease and other neurodegenerative disorders among welders: a Danish cohort study.
For each component of the quality assessment, 1 denotes that the criterion has been met; 0 denotes that the criterion has not been met.

CHAPTER 4 – TRENDS IN PREVALENCE OF SELF-REPORTS OF ALZHEIMER'S DISEASE/DEMENTIA AMONG NON-INSTITUTIONALIZED INDIVIDUALS 45+IN CANADA, 1994-2014

A version of this chapter will be submitted for journal publication review.

The analysis presented in this paper was conducted at the Saskatchewan Research Data Centre (SKY-RDC) which is part of the Canadian Research Data Centre Network (CRDCN). The services and activities provided by the Saskatchewan Research Data Centre (SKY-RDC) are made possible by the financial or in-kind support of the SSHRC, the CIHR, the CFI, Statistics Canada, and the University of Saskatchewan. The views expressed in this paper do not necessarily represent the CRDCN's or that of its partners'.

4.1 Abstract

Background: The risk of developing Alzheimer's disease/dementia (AD) appears to be modified by a combination of demographic, lifestyle, and medical factors. Improved treatments of heart disease, hypertension and stroke have resulted in decreased mortality from these diseases and are expected to contribute to a decline in prevalence of AD/dementia. While there were 340,000 people living with dementia in 2011 with a projected doubling by 2031, there are few Canadian trend studies on prevalence of AD, the most common of the dementias. This study aims to (1) describe the trends in the overall prevalence of self-reported AD/dementia and in men and women in different age groups, educational levels and geographic areas in Canada from 1994 to 2014 and (2) assess what the observed trends mean in the context of the aging Canadian population and the health care system.

Methods: A trend analysis was conducted using data from the cross-sectional National Population Health Surveys, 1994/1995-1998/1999 and the Canadian Community Health Survey, 2001/2001-2014. Trends in age-sex standardized prevalence estimates were calculated and assessed over time.

Results: The overall prevalence of AD/dementia increased from 0.14 in 1994 to 0.80 in 2014 representing a 0.66% increase over the twenty-year period. The increasing trend in AD/dementia prevalence was found across all strata of the population and mostly among men aged 65 or older, those with lower levels of educational attainment and those living in Central Canada.

Conclusions: The overall prevalence of AD/dementia in the community increased over time. We conclude that the increase in prevalence is partly attributable to more people living longer in the community in Canada due to increased survival rates and early intervention for chronic conditions which are risk factors for AD/dementia. The high life expectancy and projected growth of the elderly population, and the findings of our study emphasize the importance of establishing effective community-based prevention strategies that focus on minimizing risk and optimizing protection as well as health system capacity strengthening and preparation for long-term care including increased demand for neurologists' services, increased associated disability and psychosocial difficulties, rising costs, caregiver burden.

4.2 Introduction

Alzheimer's disease (AD) is one of the most common types of dementias and neurological conditions. In 2006, there were 26.6 million people impacted globally by AD and related dementias (1). By 2050, the global prevalence of dementias including AD is expected to quadruple and 1 in 85 people is projected to be living with the disease (2). In Canada, there were 340,000 people living with dementia in 2011 with a projected doubling by 2031 (3). The economic burden on the Canadian health system is tremendous. In 2008, the total economic burden of care for dementia was approximately $15 billion. This cost is projected to increase to $153 billion by 2038 (4). The number of older persons with dementia living in the community is expected to steadily rise, exacerbated by a projected shortage of long-term care beds (5).

The risk of developing dementia appears to be modified by a combination of demographic, lifestyle, and medical factors. Diseases such as hypertension and diabetes contribute to cardiovascular and cerebrovascular diseases (2, 6, 7). Individuals with obesity and cardiovascular, and cerebrovascular diseases are at higher risk for dementia and AD (8, 9-11). Obesity has been linked with changes in the structure of the brain, resulting in cognitive decline, dementia and AD (12, 13).

Notwithstanding these risks, dementia is expected to decrease because there has been a significant decline in the incidence of stroke in recent decades. In Canada, improved treatments of heart disease, hypertension and stroke have resulted in decreased mortality from these diseases (14). One study identified increasing prevalence but decreasing incidence of AD/dementia in Saskatchewan (15). There is also evidence to suggest that the prevalence of AD/dementia is decreasing in younger cohorts and that these trends are likely to occur across developed countries (16, 17). On the other hand, there may be more individuals especially in the older population with increased risk of dementia due to advances in medical interventions which contribute to an improvement in survival after stroke, or an increased prevalence of underlying vascular disease despite not presenting with stroke or its effects (2).

Formal education and more wealth have been identified as protective for the risk of dementia (18). More years of formal education are associated with a reduced risk of dementia including AD. Over time, there has been an increase in the level of education among older adults impacting brain development and function, and better health behaviors. The general health advantages of having more education and social opportunities may have influenced the prevalence of AD/dementia (19, 20).

A diagnosis of Alzheimer's disease/dementia means cognitive impairment, dependency, caregiver burden, and premature death (21). Despite the depth of impact of AD/dementia on individuals and caregivers, Canadian studies focusing specifically on the trends of AD/dementia are lacking. Studies on the epidemiology of dementia generally provide estimates of overall dementia and are not specific to causes such as AD (22, 23). In addition, some studies have shown that AD/dementia is declining in the younger age cohorts and ballooning in the oldest old age categories, with prevalence projections focusing on those in the highest age categories, otherwise called the oldest old. This may lead to appropriating health care interventions to only a select group of people to the neglect of others who also may need to be targeted. Updated information on the trends of dementia specifically due to AD is needed in Canada if we are to ensure that adequate and appropriate resources are mobilized to deal with the needs of those with this condition and their families who are most times severely impacted. Such studies can also inform prevention strategies and approaches to management.

This study provides evidence on the prevalence of Alzheimer's disease/dementia at the population level. Estimates were derived from two *sets* of national health surveys over a 20-year period conducted by Statistics Canada during the period 1994 to 2014: The National Population Health Surveys (NPHS) and the Canadian Community Health Surveys (CCHS).

The objectives of this study are:

1. To describe the trends in the overall prevalence of self-reported AD/dementia and in men and women in different age groups, educational levels and geographic areas in Canada from 1994 to 2014.
2. To assess what the observed trends mean in the context of the aging Canadian population and the health care system.

4.3 Methods

4.3.1 Data Sources

Health surveys are conducted by Statistics Canada each year among randomly chosen individuals residing throughout Canada. In this study, we used data from 2 different but similar sets of Canadian health surveys. We examined data from the 10 provinces and where available the three territories of Canada: NL, NB, NS, PEI, QC, ON, MB, SK, AB, BC and NU, YT and NT. To allow ease of comparison across all twenty years, as well as graphical presentation, and maintenance of confidentiality of individual data, the provinces and territories were categorized into four regions: Eastern Canada (NL, NB, NS, PEI); Western Canada (MB, SK, AB and BC); Central Canada (QC and ON) and Territories (NU, YT and NT).

Our first source of data from 1994-1999 was the PUMF data from the NPHS which is both a cross-sectional as well as a longitudinal study carried out by Statistics Canada (24). The first phase of data collection in the NPHS took place in 1994 and served as both a cross sectional study and the starting part for a longitudinal study which ended in 2010/2011. The data was collected, as far as possible, using face-to-face interviews of a nationally representative cohort of 17,276 household residents. In the period covering 1994 to 1999, the NPHS survey collected cross-sectional data on a representative sample of the Canadian population every two years. However, the sample was selected from the 10 provinces only and did not include those living in the territories. Therefore, for the period 1994-1999, no data on Alzheimer's disease/dementia prevalence was reported for the territories.

The second source of data from 2000-2014 was the anonymized Master Files from the CCHS which replaced the NPHS and used similar sampling procedures as that survey. Unlike the NPHS, this survey included individuals living in the 10 provinces as well as the territories of Canada. Originally, CCHS surveys were conducted every 2 years, starting in 2001 (CCHS 1.1). Subsequent surveys were conducted in 2003 (CCHS 2.1), in 2005 (CCHS 3.1), and in 2007 (CCHS 4.1) (25). In those years, large sample sizes of approximately 130,000 respondents were interviewed. Significant changes were made to the survey design in 2007 to account for the structure of the Canadian population. As a consequence, the sample size was lowered to approximately 65,000, with data now being collected on an ongoing basis with annual releases. For surveys conducted after 2007, roughly one-half of the sample was interviewed in person and one-half by telephone using computer assisted telephone interviewing (25).

Both the NPHS and CCHS allow for proxy responses (information provided on behalf of others). These type of responses represented less than 10% of the total responses for all years of the surveys utilized in this thesis. As well, for the serious condition of Alzheimer's/dementia, there were no differences between estimates generated by proxy and non-proxy responses (26, 27). A survey weighting factor based on age groups, sex, marital status, educational levels, and provincial difference is supplied by Statistics Canada. Population estimates can be calculated from this weighting (24, 25). Ethics approval was not required for this study as it involved analysis of anonymized secondary survey data which contained no personal identifiers.

4.3.2 Measures of Alzheimer's disease/dementia

In all surveys between 1994 to 2014, the questions on Alzheimer's disease/dementia was similar: "Do you have Alzheimer's disease/other dementia diagnosed by a health professional?" Respondents aged 45 years and over with Alzheimer's disease/dementia were included in this analysis. In some instances, variable categories for provinces and territories, and educational level were collapsed to preserve confidentiality of data. Alzheimer's disease/dementia prevalence estimates were generated for 1994, 1996, 1998, 2001, 2003, 2005, 2007, 2008, 2009, 2010, 2011, 2012, 2013 and 2014.

AD/dementia prevalence was analyzed by age, sex, province of residence and educational level. We categorized respondents with AD/dementia according to their highest level of education such as "less than secondary", "secondary graduation", "some post-secondary", and post-secondary graduation". We further categorized respondents with AD/dementia into the four regions based on their province of residence. We also categorized age of AD/dementia respondents into three groups: 45–64; 65–79; and 80+, accounting for differences in sex.

4.3.3 Statistical analyses

The analyses of this study involved estimating frequencies and prevalence of AD/dementia by sex, age group, region of residence and educational level for each study population from 1994-2014. Data analysis of the CCHS Master Files was conducted under confidentiality restrictions of the SKY-RDC at the University of Saskatchewan. Population frequencies were estimated using Statistics Canada survey specific sampling weights. This was followed by the use of direct standardization to estimate prevalence to account for changes in the demographic structure of the population and population-weighted estimates over time. Standardization was performed based on the population size and age and sex distributions in 2001 to facilitate comparison of frequencies over time (28)). We treated AD/dementia values recorded as, “not stated”, “don’t know”, “not applicable” and “refusal” as missing values and excluded them from subsequent analyses.

AD/dementia prevalence was generated to reflect the age–sex groupings for each year included in the study. Stratified analyses were performed according to age groups, sex, region of residence and educational level to identify trends in Alzheimer’s/dementia prevalence over time. Study results are presented in both tabular and graphic forms. All analysis was conducted using STATA 14 (StataCorp LP, College, TX, USA).

4.4 Results

4.4.1 Trends in overall Alzheimer's disease/dementia prevalence in Canada

The overall prevalence of Alzheimer's disease/dementia increased from 1994 to 2014. There was a steady increase in prevalence from 1994 to 2001, with a significant rise in prevalence in 2003, followed by a decline in 2005 and 2010 and again in 2014 (Figure 4.1). Over the period 1994 to 2014, the highest prevalence rates were recorded in 2011 to 2013 with the highest standardized prevalence (1.06%) reported in 2013 (Table 4.1, Figure 4.1). In 2014, Alzheimer's/dementia prevalence at endpoint (0.80%) remained the same as it was at midpoint in 2007 (Table 4.1). Table 4.1 indicates that prevalence of Alzheimer's/dementia increased between the period 1994 to 2013, from 0.14% to 1.06%. This represented an increase of 0.92 percentage points.

Table 4- 1 Adjusted prevalence of Alzheimer's disease/dementia from 1994 to 2014

Survey Year	Alzheimer's/dementia Prevalence (%)
1994	0.14
1996	0.55
1998	0.54
2001	0.57
2003	0.81
2005	0.71
2007[1]	0.80
2008	0.85
2009	0.82
2010	0.78
2011	0.90
2012	0.94
2013	1.06
2014	0.80

[1] Midpoint

According to Figure 4.1, the Alzheimer's/dementia prevalence dipped below expected estimates in 1996 to 2008 and surpassed the expected estimates between 1999 to 2001. The period 2001-2012 saw an expected incline in overall AD/dementia prevalence (Figure 4.1). Though there was a plateau in overall AD/dementia prevalence between 1998 and 2001, overall prevalence of AD/dementia among Canadians 45-64 years of age was at an all-time high, with the steady increase in trend for that period reflected in the 65-79 and 80+ age categories (Figure

4-1, Table 4-2). Males accounted for the highest increase in overall AD/dementia prevalence between 1994-2014 (Figure 4-1, Table 4-2).

Figure 4- 1 The overall prevalence of Alzheimer’s disease/dementia in the Canadian health survey population, over the period 1994-2014

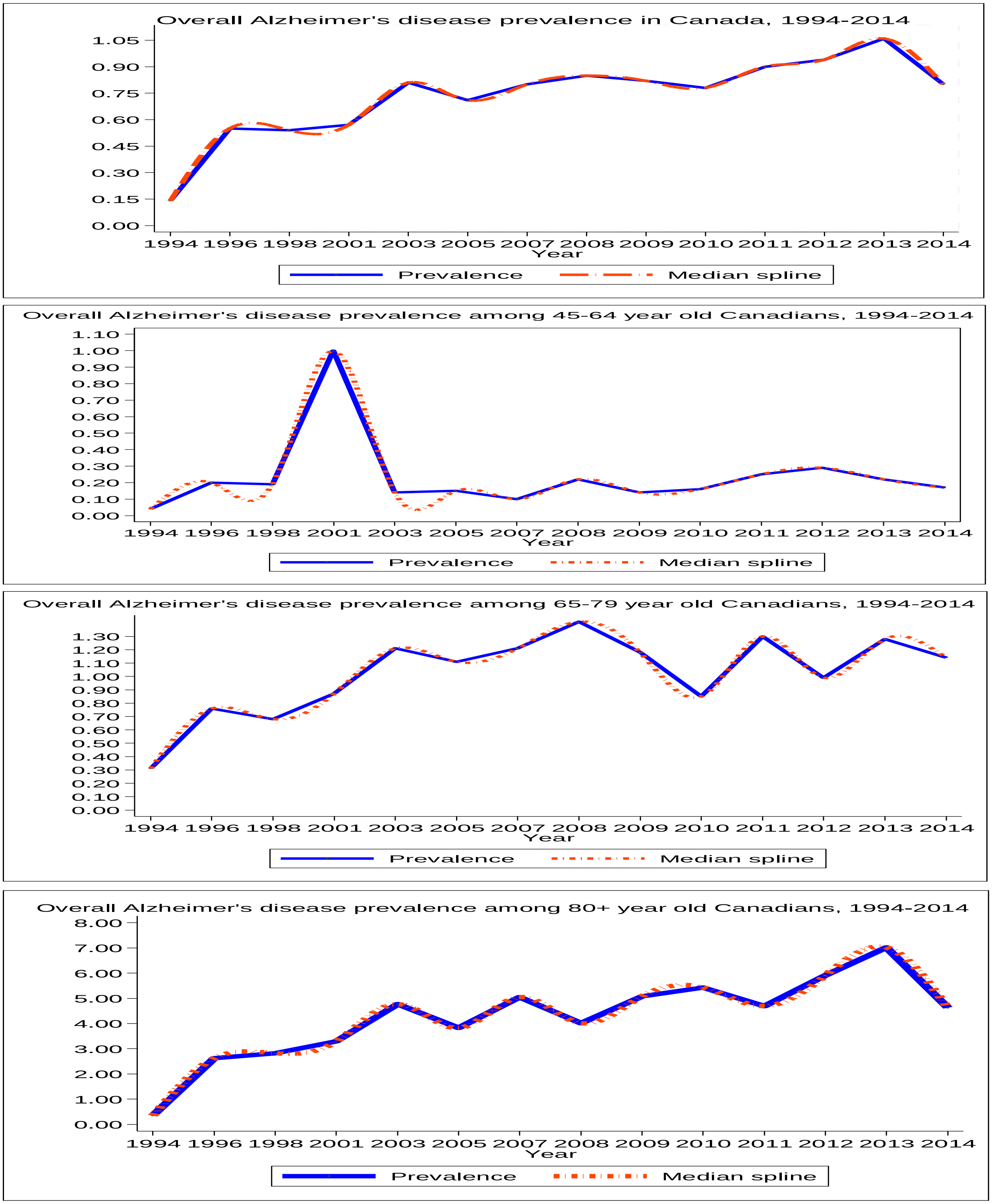


Table 4- 2 Trends in the prevalence of Alzheimer's disease/dementia diagnosed by a physician in Canadian health surveys over the period 1994-2014

	Adjusted percentage of persons with Alzheimer's disease/dementia and percentage change in trends 1994-2014														
	1994	1996	1998	2001	2003	2005	2007	2008	2009	2010	2011	2012	2013	2014	**Change (% pts[2])**
Men and Women															
45-64 yrs.	0.04	0.20	0.19	0.10	0.14	0.15	0.10	0.22	0.14	0.16	0.25	0.29	0.22	0.17	0.13
65-79 yrs.	0.31	0.76	0.68	0.87	1.21	1.11	1.21	1.41	1.18	0.85	1.30	0.99	1.28	1.14	0.83
80+ yrs.	0.34	2.62	2.82	3.29	4.77	3.82	5.05	4.01	5.08	5.43	4.69	5.91	7.02	4.63	4.29
Total std[1]	0.14	0.55	0.54	0.57	0.81	0.71	0.80	0.85	0.82	0.78	0.90	0.94	1.06	0.80	0.66
Women															
45-64 yrs.	0.03	0.26	0.25	0.06	0.12	0.17	0.12	0.21	0.10	0.12	0.11	0.34	0.25	0.11	0.08
65-79 yrs.	0.45	0.60	0.68	0.76	0.99	1.07	1.13	0.26	0.88	0.59	1.17	0.91	1.27	0.91	0.46
80+ yrs.	0.40	2.73	3.09	3.33	3.83	3.36	3.89	3.67	4.28	5.12	4.34	5.27	6.67	4.59	4.19
Total std[1]	0.18	0.61	0.66	0.59	0.74	0.74	0.79	0.86	0.75	0.76	0.84	1.01	1.20	0.79	0.61
Men															
45-64 yrs.	0.04	0.14	0.13	0.14	0.16	0.14	0.08	0.23	0.17	0.20	0.39	0.24	0.18	0.24	0.20
65-79 yrs.	0.16	0.95	0.67	1.01	1.47	1.16	1.30	1.60	1.52	1.17	1.46	1.09	1.30	1.43	1.27
80+ yrs.	0.22	2.41	2.29	3.33	6.62	4.71	7.33	4.67	6.65	6.04	5.37	7.16	7.70	4.70	4.48
Total Std[1]	0.08	0.48	0.40	0.54	0.88	0.67	0.82	0.84	0.90	0.79	0.96	0.86	0.91	0.81	0.73

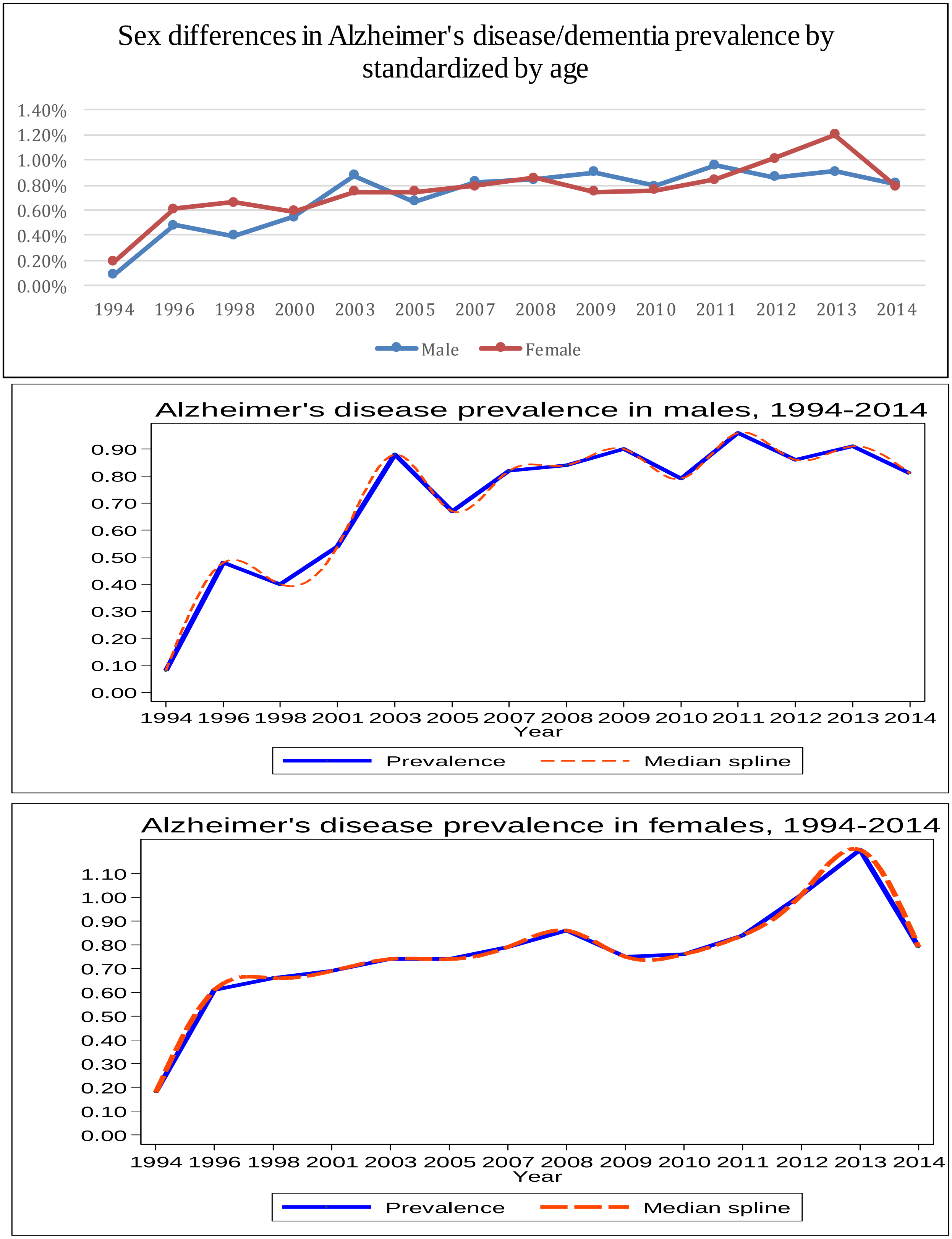
[1] Total prevalence for men and women, women, and men, standardized according to the age distribution in 2001

[2] Percentage points

4.4.2 Sex differences in the prevalence of Alzheimer’s disease/dementia

Figure 4-2 demonstrates that for the period 1994 to 2001, Alzheimer’s disease/dementia prevalence was higher in females than in males, followed by a lower AD/dementia prevalence in females than males in 2003, 2007, 2009-2011 and 2014. Female AD/dementia prevalence surpassed male AD/dementia prevalence in 2005, 2008, and 2013. We observed that for the entire period, 1994-2014, males experienced a higher increase in AD/dementia prevalence than females, though in latter years (2012 and 2013) the increase is much greater for females than for males. For both sexes, AD/dementia prevalence was slightly less than expected between 1996 and 1998 and higher than expected for males between 1998 and 2001. Female prevalence of AD/dementia was slightly lower than expected between 2012 and 2014 (Figure 4-2).

Figure 4- 2 The prevalence of Alzheimer's disease/dementia in Canada, by sex over the period 1994-2014.

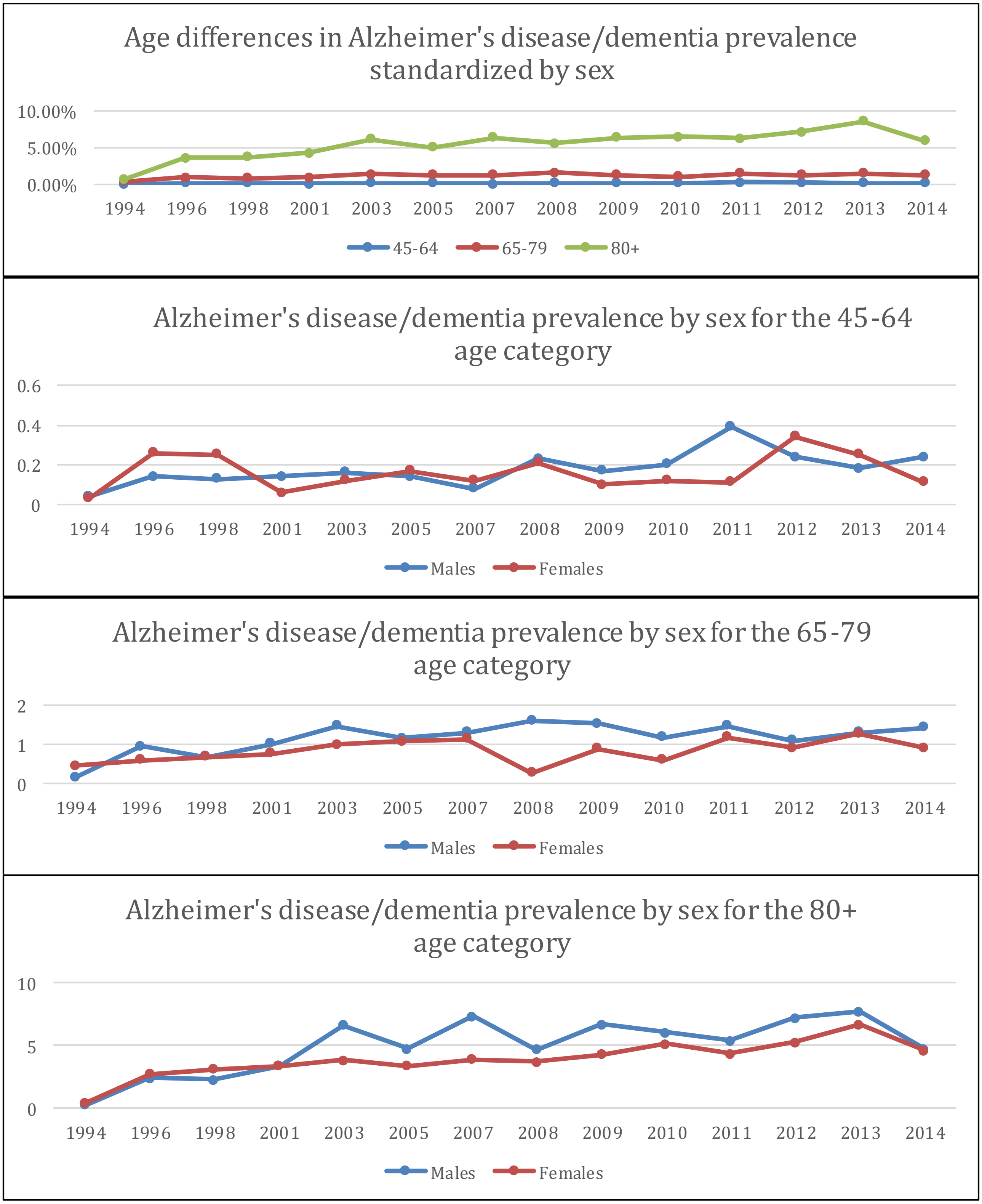


4.4.3 Age differences in the prevalence of Alzheimer's disease/dementia

According to Figure 4-3, AD/dementia prevalence is highest among men and women in the 80+ age category followed by the 65-79 age category and lowest in the 45-64 age category. Increases in AD/dementia prevalence was most evident among men and women in the 80+ age category when compared to the younger age categories, 45-64 and 65-79. While there is a noticeable increase in AD/dementia prevalence among men and women in the 80+ age category for the period, 1994-2014, the trends in AD/dementia prevalence are holding steady for men and women 45-64 and 65-79 age categories (Figure 4-3).

The highest prevalence for each of the sexes was recorded in 2013 and in the 80+ age category. Additionally, in the 65-79 age category, there was a marked increase in AD/dementia prevalence in males (1.27%) compared to females (0.46%), with increases in prevalence from 1994-2014 being higher in males among all age categories (Table 4-2). As shown in Figure 4-3, there was a decline in AD/dementia prevalence in 2005 which was attributable to the decline of AD/dementia in all age categories of men in that year. While there was a marked decline in AD/dementia prevalence among women in the 65-79 age category in 2008, there was a converse incline in AD/dementia prevalence among females in the 45-64 age category with a small decrease in the prevalence of AD/dementia among women in the 80+ age category for that same year.

Figure 4- 3 The prevalence of Alzheimer's disease/dementia among age groups in Canada, 1994–2014.



4.4.4 Geographic differences in the prevalence of Alzheimer's disease/dementia

We did not observe a significant geographic difference in prevalence of AD/dementia. Figure 4-4 shows that AD/dementia prevalence across all ten province and territories increased over time and the derived estimates are a good predictor of the expected prevalence for AD/dementia. On average, there was a 0.44% increase in prevalence across the country over the period 1994-2014 with no change in prevalence for the territories over time and Eastern, Central and Western Canada reporting significant above average increases in prevalence of 0.71% and 0.60% respectively overtime. After 1994, the lowest recorded prevalence among the regions of residence in Canada was recorded in as 0.46% in Central Canada.

There was a sharp increase in prevalence from 0.15% in Eastern Canada to 0.86% in 2005 and 1.20 % in 2007 followed by a sharp decrease to 0.68% in 2008 and a levelled increase from that point to 2012 when there was a marked increase (1.04%) in AD/dementia prevalence, followed by a decline resulting in a prevalence of 0.60% in 2014. This reflected a 0.45% increase in AD/dementia prevalence in Eastern Canada from 1994 to 2014.

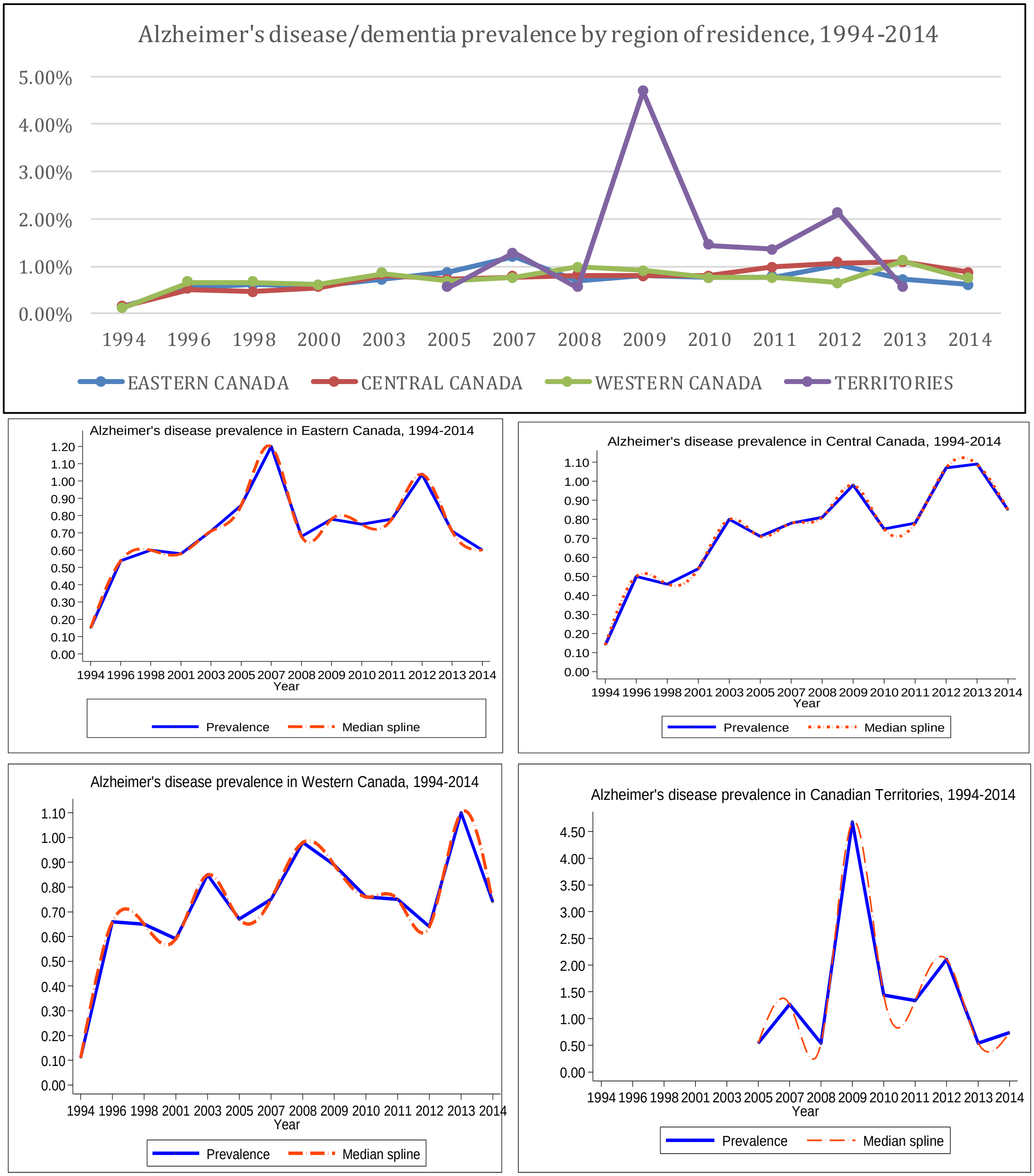
Central Canada recorded a 0.71% increase in prevalence overtime, from 0.14% in 1994 to 0.85% in 2004, reflecting the highest increase in prevalence among the regions of residence in Canada. Central Canada also recorded the steadiest increases in prevalence between 2005 to 2013, reflecting marked inclines in 2008 and 2011 and a sharp decline in 2014.

Western Canada reflected the second highest overall increases in prevalence from 0.11% in 1994 to 0.74% in 2014, accounting for a 0.60% overall increase in prevalence for that region. The highest prevalence recorded in Western Canada was 1.10% in 2013. There were other sharp inclines in 1996, 2003, and 2008. Apart from 1994, the lowest prevalence recorded in Western Canada was 0.59% in 2001.

The trend in AD/dementia prevalence observed in the territories is similar in undulation to that observed in Eastern Canada. The territories had the highest prevalence of AD/dementia due to the fact that the number of people living in that region of Canada is small compared to that of other provinces and regions in Canada. Figure 4-5 demonstrates that though there was a marked increase from 0.54% in 2005 to 4.68% in 2009, this was followed by a steady decline to

0.54% in 2013 resulting in no real change in the overall prevalence of AD/dementia in the territories over the period for which data was available.

Figure 4- 4 The prevalence of Alzheimer’s disease/dementia according to region of residence in Canada, 1994–2014.



4.4.5 Educational differences in the prevalence of Alzheimer's disease/dementia

We observed educational differences in AD/dementia prevalence overtime. The average all time increase in prevalence by education was 0.74%. Figure 4-5 and Table 4-3 show that the highest number of prevalence estimates >1.00% was recorded in those with the lowest level of education, i.e., those who had less than secondary education. Those in the category of less than secondary education also recorded an above average increase in prevalence of 1.22% over the period 1994-2014. Though overall increase in prevalence was higher in those who had completed secondary education (0.70%) than in those with some post-secondary education (0.52%), yearly prevalence increases were higher among those who had some post-secondary education in 1994, 1996, 2001, 2008, 2009, 2010 and 2012.

There was little difference between the overall increase in prevalence between those who graduated post-secondary and those who had some post-secondary education (Table 4-3). Additionally, those who reported post-secondary graduation reported a steadier increase in prevalence compared to those who reported some post-secondary education, who had more significant shifts in prevalence increases overtime, suggesting a more protective relationship between the completion of higher levels of education and AD/dementia than mere exposure to higher education.

Figure 4- 5 The prevalence of Alzheimer's disease/dementia according to level of education in Canada, 1994 –2014.

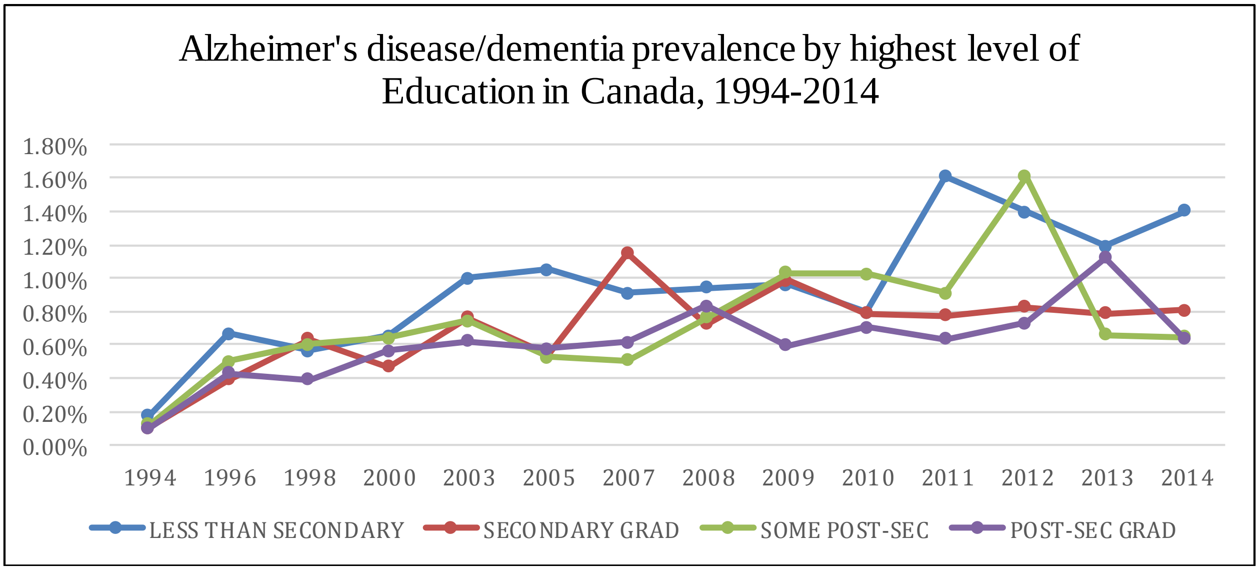


Table 4- 3 Trends in the prevalence of Alzheimer's disease/dementia by level of education in Canadian health surveys over the period 1994-2014

	Adjusted percentage of persons with Alzheimer's disease/dementia and percentage change in trends 1994-2014														
Levels of Education	1994	1996	1998	2001	2003	2005	2007	2008	2009	2010	2011	2012	2013	2014	**Change (% pts[2])**
Less than secondary	0.18	0.67	0.57	0.66	1.00	1.05	0.91	0.94	0.96	0.79	1.61	1.39	1.19	1.40	1.22
Secondary grad	0.11	0.39	0.63	0.47	0.76	0.54	1.15	0.73	0.99	0.79	0.78	0.82	0.79	0.81	0.70
Some post secondary	0.12	0.50	0.60	0.64	0.74	0.52	0.51	0.77	1.03	1.02	0.91	1.60	0.66	0.64	0.52
Post-secondary grad	0.10	0.43	0.39	0.57	0.62	0.58	0.62	0.83	0.60	0.70	0.64	0.73	1.12	0.63	0.53
Total std[1]	0.14	0.55	0.54	0.57	0.81	0.71	0.80	0.85	0.82	0.78	0.90	0.94	1.06	0.80	0.66

[1] Total prevalence for men and women, women, and men, standardized according to the age distribution in 2001

[2] Percentage points

4.5 Discussion

There are not many studies that have examined national trends in AD/dementia prevalence in Canada over time. Other studies focused on a single province, a subgroup in the population, all dementias or predicted overall change in prevalence from a single point in time to some future time period decades later (3, 15, 29-31). While these studies examined prevalence, they did not look at annual trends over time or by strata within the population. More studies focusing on trends in AD/dementia and dementia prevalence were conducted internationally (2, 32-37). It is difficult to compare the results of such studies due to the variation of dementias included, characteristics of the study populations including strata, age and sex standardization and differences in the period or country studied (38,39).

Notwithstanding, previous studies reported findings similar to our study. We found that the prevalence of AD/dementia recorded an overall 0.66-point increase between 1994-2014, and a 5.12-point increase in individuals 65+ years of age, in that same period. One study which also focused on age and sex standardized prevalence estimates for AD/dementia using Ontario data, found that the prevalence over time was increased by 18.2 % in individuals 66+ years of age (29). This finding was corroborated by Sekita et al. (2010), who studied prevalence of AD/dementia in Japan (32). The increase in prevalence of AD/dementia over time may be attributable to the continued increase in size of the older population, growing awareness of the disease (2) and earlier diagnosis of cognitive deficits (40). Our study showed small increases in prevalence year over year, but bigger increases overtime, signifying smaller increases in incidence of AD/dementia, and declining mortality, resulting in more people living longer with the disease (41). Improved mortality among those at risk for AD/dementia may be caused by improved survival rates for strokes and cardiovascular diseases, largely due to more public health promotion activities targeted to nutrition and other life style factors, leading to earlier identification and treatment of lifestyle related diseases (e.g. diabetes and hypertension), greater control of serum lipid levels, and decreases in cigarette smoking (2, 42).

We observed that the prevalence of AD/dementia increased with age in both men and women across all years, but increased significantly after age 80. This is consistent with the findings from previous studies (32, 39, 43), which is in keeping with the expectation that, over time, there will be a greater number of the elderly living in the community and with AD/dementia (5, 40). While the increase in prevalence of AD/dementia was consistent with age in both males and females, our study found that over time, there was a greater increase in prevalence among men than women. This finding is contradictory to some studies which report that AD/dementia prevalence is greater among women than men (32, 43-45). On the other hand, the more recent Canadian study with similar methodology (29) supported our finding that although prevalence rates were highest among women, the increase in the rate over time was greater among men. This higher prevalence in men may be an artifact of survey methodology which excluded those living in institutions (24, 25). Women are more likely to live in long term care facilities after a confirmation of AD/dementia as opposed to men who spend more time living in their communities after AD/dementia diagnosis (47). On the other hand, neurodegeneration and development of clinical symptoms significantly contributing to mortality are more severe and progress faster in women than in men (48-51), resulting in less women with AD/dementia living in the community.

We did not observe a significant geographic difference in the prevalence of AD/dementia throughout the years. However, there was variation in the level of AD/dementia prevalence increase across all provinces, over time. Few trend studies highlighting geographic differences have been published in Canada. It is therefore difficult to make adequate comparisons. Venketasubramanian, Sahadevan, Kua, Chen, & Ng, 2011, suggest that if regional variations in Alzheimer’s disease/dementia exist, they exist for reasons other than lack of standardization of rates or differences in diagnostic protocols across the country (52). Lack of geographic variations in AD/dementia prevalence year over year may be because of population homogeneity in the risks and duration of AD/dementia across the country as well as similarities in preventive approaches and cultural factors influencing the etiology and expected course of AD/dementia. On the other hand, the variations in geographic prevalence increases over time, might be explained by differences in genetic, environmental risk and protective factors that may exist across provinces (53, 54).

Our study found that prevalence increases were less among those who had attained higher levels of education and increased in those with lower levels of education. This is consistent with data in the literature that indicates that low educational assessment is a risk factor for AD/dementia while high educational attainment is protective (18, 55-57). One of the rare analyses of Alzheimer's disease/dementia trends by education, found similar trends in AD/dementia. This study indicated that those with less than secondary education had greater increases in AD/dementia than secondary graduates who in turn had greater increases in AD/dementia than post-secondary graduates (58). Our study found a slightly higher prevalence of AD/dementia among those who completed post-secondary education compared to those with some post-secondary education. This finding could be explained by the protective association between higher education levels and longer life expectancy found in another study (59). In that study, Hubbard, et al., explain that individuals with higher education tend to live longer in general and with AD/dementia; which is consistent with the slightly higher prevalence of AD/dementia observed in those with post-secondary graduation compared to those with some post-secondary exposure. Those with higher levels of education and wealth are more likely to intentionally seek information and improve health behaviors, leading to reduction in risk factors for AD/dementia related to lifestyle factors such as cigarette smoking, nutrition and physical activity (60-62). On the other hand, those in the older age categories may have lower levels of education associated with cognitive decline attendant with AD/dementia (63), accounting for higher increases in prevalence of AD/dementia among the 80+ year groups in our study. This higher prevalence of AD/dementia among individuals 80+ indicate that as persons live longer with AD/dementia, there may be an increased need for long-term care, whether in the community or in facilities, when disease progresses beyond the ability of caregivers (usually spouses of similar age) to provide the relevant care required by AD/dementia patients.

4.5.1 Strengths and limitations of the study

Strengths of this study include consistent definition of AD/dementia cases across years, the use of nationally representative surveys of the Canadian population over a twenty-year time span with relatively high participation rates. Another strength is that our study supports findings of similar studies in other jurisdictions. This study impacts the dearth of trend studies on Canadian data by updating information to AD/dementia prevalence within several strata of the Canadian population, and is a good source of information for the development of targeted public health and community-based approaches to AD/dementia.

A major limitation of our study is that the surveys used did not include respondents living in institutions including health care facilities and nursing homes. In addition, data was lacking for the territories for most years. It is possible that this study may have resulted in an over- or under-estimation of AD/dementia prevalence, due to underdiagnoses of AD/dementia in the community and variation in participants in the surveys over the years as well as the fact that those diagnosed with AD/dementia are more likely to be living in institutions.

4.6 Conclusion

The prevalence of AD/dementia has increased steadily over the past 20 years in the general population of middle aged and older Canadians. The increasing trend seemed to be observed across all strata of the population (age, sex, education and region of residence) and mostly among men aged 65 or older, those with lower levels of educational attainment, and those living in Central Canada, despite a lack of consistent pattern. Future projections of prevalence of AD/dementia in the Canadian population should include data on individuals living in institutions. Focus should also be given to the cultural and behavioral drivers of the etiology of the disease, reflective of the diversity of the Canadian population.

Given, the high life expectancy and projected growth of the elderly population, our study underlines the importance of establishing effective community-based prevention strategies for AD/dementia. It also underscores the need for health system capacity strengthening and preparation for increasing challenges associated with long-term care of AD/dementia including rising costs, caregiver burden and increased demand for neurologists' services. Additionally, public health prevention strategies that focus on minimizing risk and optimizing protection are needed to mitigate against the steady increases in prevalence of AD/dementia in the community.

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CHAPTER 5 – UNMET HEALTH CARE NEEDS: FACTORS PREDICTING SATISFACTION WITH HEALTH CARE SERVICES AMONG COMMUNITY-DWELLING CANADIANS LIVING WITH NEUROLOGICAL CONDITIONS IN ONTARIO USING DATA FROM CANADIAN COMMUNITY HEALTH SURVEY-ANNUAL COMPONENT, 2010

A version of this chapter will be submitted for journal publication review.

The analysis presented in this paper was conducted at the Saskatchewan Research Data Centre (SKY-RDC) which is part of the Canadian Research Data Centre Network (CRDCN). The services and activities provided by the Saskatchewan Research Data Centre (SKY-RDC) are made possible by the financial or in-kind support of the SSHRC, the CIHR, the CFI, Statistics Canada, and the University of Saskatchewan. The views expressed in this paper do not necessarily represent the CRDCN's or that of its partners'.

5.1 Abstract

Background: Neurological conditions can lead to long term challenges with functional impairments and limitations to activity. Not surprisingly, people with neurological conditions report unmet health care needs and experience barriers to care. Earlier studies indicate that unmet health care needs are associated with decreased patient satisfaction with health care services and lowered health-related quality of life. There are few studies that examine patient satisfaction with health care services among Canadians with neurological conditions as a whole. The goals of this study were to (1) explore the factors predicting patient satisfaction with general health care services, hospital and physician services among Canadians with neurological conditions and (2) contrast patient satisfaction between physician care and hospital care among Canadians with neurological conditions.

Methods: The Canadian Community Health Survey - Annual Component, 2010 (CCHS - 2010) was used, in this study, to conduct secondary analyses on a subset of the data, containing a total number of 8848 respondents with neurological conditions, of whom 2902 received health care services, 1222 received hospital services and 2211 received physician services within twelve months leading up to data collection (January-December, 2010). Multivariate logistic regression was used to estimate odds ratios and their corresponding confidence intervals for the relationship between unmet health care needs and other predictors of satisfaction, and patient satisfaction with health care services.

Results: Excellent quality care predicts higher odds of patient satisfaction with general health care services, 237.60 (95% CI 70.43-801.52), hospital services, 166.99 (95% CI 67.91-410.64), physician services, 176.45 (95% CI 63.89-487.30). In contrast, self-perceived unmet health care needs negatively predicts patient satisfaction across all health care services: general services, OR=0.59 (95% CI 0.37-0.93), hospital services, OR=0.41 (95% CI 0.21-0.77), and physician services, OR=0.29 (0.13-0.69). Other negative predictors of patient satisfaction include some post-secondary education, OR= 0.36 (95% CI 0.18-0.72), general health services, and OR=0.26 (95% CI 0.09-0.80), physician services; secondary [OR=0.32 (95% CI 0.13-0.76)] and post-secondary graduation [OR= 0.28 (0.11-0.67)], physician services, and being an ER patient most recently, OR=0.39 (95% CI 0.20-0.77), hospital services.

Conclusions: We conclude that self-perceived unmet health care needs (attributable to availability and quality of care) as a single variable, is a common significant negative predictor of neurological patient satisfaction across health care services. This emphasizes the importance of ensuring coordinated efforts to provide relevant and accessible care of the highest quality for Canadians with neurological conditions.

5.2 Introduction

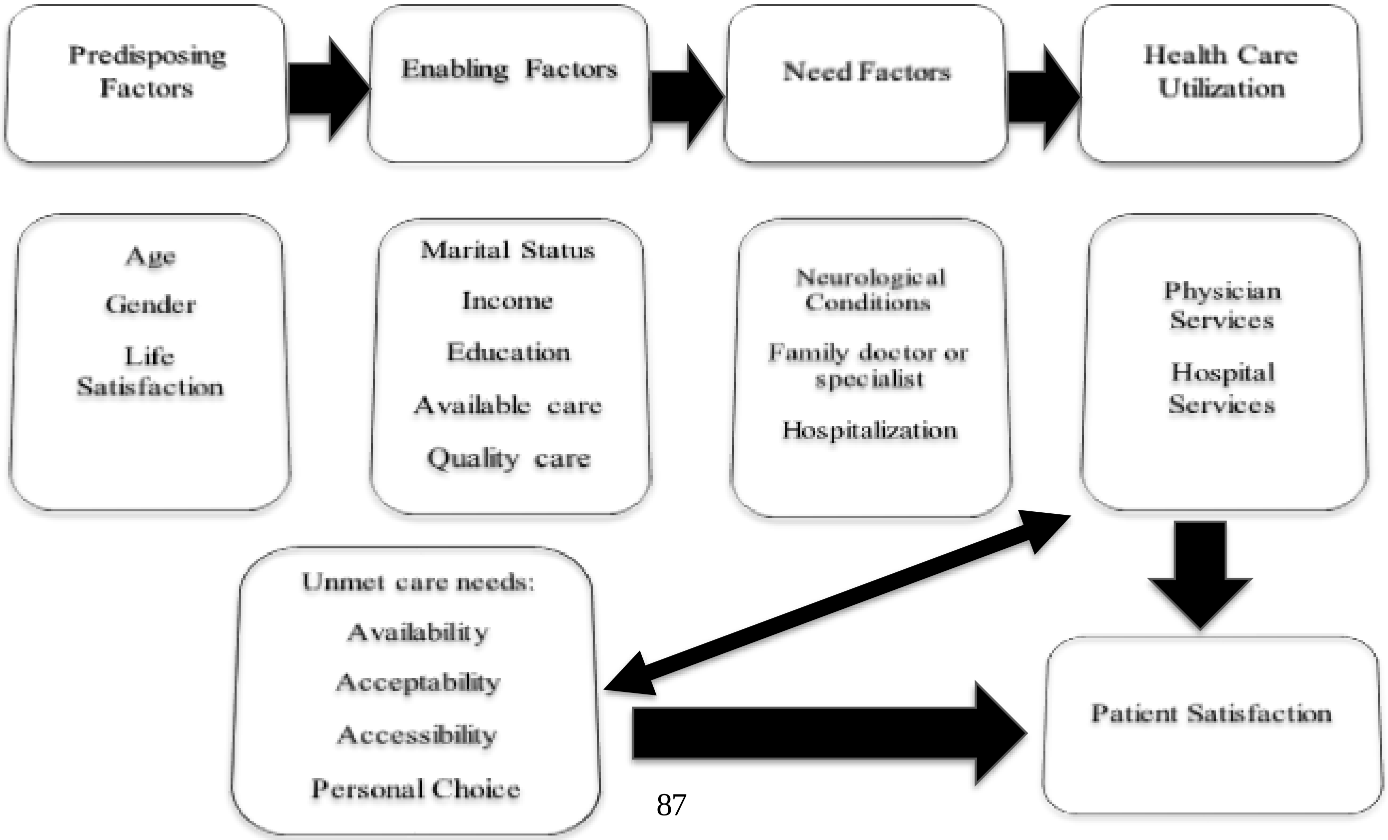
Neurological conditions such as Alzheimer's disease (AD)/dementia, Parkinson's disease (PD), amyotrophic lateral sclerosis (ALS), migraine headaches, multiple sclerosis (MS), epilepsy, cerebral palsy, Huntington's disease, stroke effects, Tourette's syndrome, dystonia, muscular dystrophy, spina bifida, brain and spinal cord injuries, brain and spinal cord tumors, and hydrocephalus, were the focus of a Statistics Canada survey in 2010 (1). Neurological conditions, especially those that grow increasingly debilitating with age, for e.g. PD and AD/dementia, lead to long term challenges with functional impairments and limitations to activity (2, 3). People with neurological conditions not surprisingly report unmet health care needs (4, 5) and experience barriers to care including lack of resources (time and money), lack of services and no local specialists (2, 6, 7).

Self-reported unmet health care need is a commonly used measure of access to care/health care utilization (8-10). Health care utilization is impacted by four factors: availability, acceptability, accessibility, and personal choice not related to the health system (11-13). Perceived unmet health care needs may be categorized according to these health care utilization factors as follows: availability – waiting time too long, care not available when requested, care not available in area; acceptability – dislike doctor/afraid, language problems, didn't know where to go; accessibility –cost and transportation; or personal choice – too busy, didn't get around to it/didn't bother, felt it would be inadequate, decided not to seek care, and personal/family responsibilities (7, 10).

Anderson's health behavior model describes health care utilization as a function of three factors: predisposing, enabling and need. Predisposing factors exist before presentation with a health condition and are socio-demographic characteristics and may be socio-cultural in nature; enabling factors represent the means or logistics for accessing health services; and need factors are the effectual cause of health service use and is a reflection of the perceived health status of the health care user (14, 15). The outcome measure for this study, patient satisfaction, is widely accepted as an assessment of overall healthcare quality (16, 17). In the same vein, patient satisfaction has been found to be positively associated with health related quality of life (an individual's or a group's perceived physical and mental health over time). (18). Some studies indicate that unmet health care needs result in decreased patient satisfaction with health care services (19-21) and thus lowered health care quality and poorer quality of life (22-24).

An understanding of unmet health care needs and patient satisfaction with health services among older Canadians with neurological conditions is crucial in the ongoing evaluation and resulting continuous quality improvement of healthcare services for this vulnerable population (14). Such knowledge will contribute to the Canadian health system's preparation of and strengthening of services to adequately provide for and meet the needs of the constantly increasing aging population. This study examines the impact of unmet health care needs on satisfaction with health care services in Canada among those with neurological conditions from the CCHS-2010. We incorporate life satisfaction as a predisposing factor in predicting patients' satisfaction with health care system. Life satisfaction presents an overarching view of an individual's satisfaction and would therefore influence one's satisfaction with the health system. The research model for this study utilizes Andersen's health behavior model follows in figure 5-1 below:

Figure 5- 1 Research model of health care utilization in current study based on Andersen's health behavior model



The objectives of this study are:

1. To explore the factors predicting patient satisfaction with general health care services, hospital and physician services among Canadians with neurological conditions.
2. To contrast patient satisfaction between physician care and hospital care among Canadians with neurological conditions.

5.3 Methods

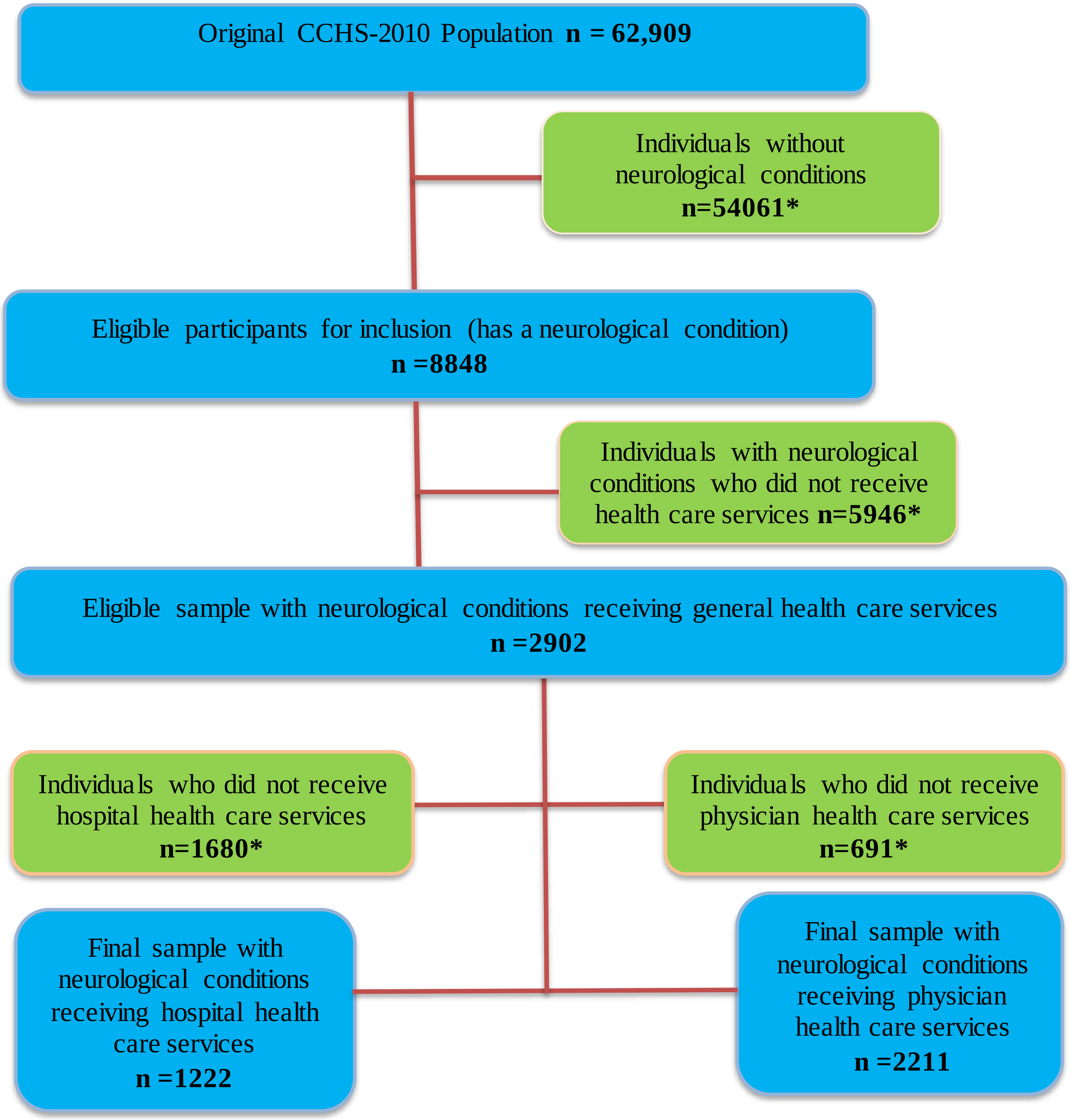
5.3.1 Data Sources

Data were extracted from the Canadian Community Health Survey - Annual Component, 2010 (CCHS - 2010). CCHS-2010 is a cross-sectional survey that collects population-wide information pertaining to health status, health care utilization and health determinants of Canadians (25). The CCHS data is collected from persons aged 12 and over living in private households in the 117 health regions covering all provinces and territories. Persons living on lands designated as Indian Reserves or by the Crown, those dwelling in institutions, or in certain remote regions as well as full-time members of the Canadian Forces are excluded from this survey (25). The survey was conducted between January and December, 2010 using computer assisted interviewing (CAI). Approximately half the interviews were conducted in person using computer assisted personal interviewing (CAPI) and the other half were conducted over the phone using computer assisted telephone interviewing (CATI) (25). The overall person-level response rate for the survey was 88.6% and the combined response rate was 71.5% at the Canada level (26).

In addition to the common content answered by all respondents, the CCHS survey contains optional content selected at the Health Region level. The optional content despite being harmonized across the province, may vary annually and is unique to each region or province (26). The CCHS-2010 was used because the data contained one-year unique common content on health care utilization: unmet health care needs (UCN) and neurological conditions (NEU) and the optional content on patient satisfaction (27), all of interest in this study. Respondents with neurological conditions who received health care services and completed the optional module on patient satisfaction as well as the unique common content on unmet health care needs resided in the province of Ontario. The population of 10,819,146 in Ontario in 2010 represented a little over one-third of the Canadian population in that year. The view of those respondents should provide good insight as to what is the concerns of Canadians with neurological conditions. Therefore, for this particular study, a subset of the data, containing a total of 8848 respondents, living in the province of Ontario with neurological conditions was used. From that number 2902 who received health care services, 1222 who received hospital services and 2211 who received physician services within twelve months leading up to data collection were selected. These individuals also completed the modules on unmet needs and patient satisfaction were included in the analysis for this study.

Respondents in age categories 12-44 years were grouped to protect anonymity, due to the small sample size of the study population, and the fact that there were very few people in the youngest age categories reporting neurological conditions and unmet needs. Proxy responses were not utilized for individuals age 12 and above and especially for more serious chronic conditions. Figure 5-2 below demonstrates the restriction criteria used to obtain the subsample from the CCHS-2010.

Figure 5- 2 Restriction criteria employed to obtain the sub-sample of CCHS-2010 in this study



*** Excluded from the analysis**

5.3.2 Measures

5.3.2.1 Assessment of neurological conditions (subpopulation) and patient satisfaction (outcome of interest) in CCHS-2010

Neurological conditions in the CCHS-2010 sample was derived from a response of yes to having a neurological condition. Neurological conditions included in this module were AD/dementia, PD, MS, epilepsy, cerebral palsy, ALS, Huntington's disease, stroke effects, Tourette's syndrome, dystonia, muscular dystrophy, spina bifida, brain injuries, SCI, brain and spinal cord tumors, hydrocephalus, and migraine headaches. Respondents were included in this study if they responded yes to having a neurological condition.

For this study, the outcome of interest, patient satisfaction, was defined according to satisfaction with general health care services, hospital services and physician services. The following questions were answered by respondents for each type of care received:

"Overall, how satisfied were you with the way health care services were provided?"

"How satisfied were you with the way hospital services were provided?"

"How satisfied were you with the way physician care was provided?"

Responses for the levels of satisfaction with the various types of health care services were ordinal in nature and coded by categories: 1 = very satisfied, 2 = somewhat satisfied, 3 = neither satisfied nor dissatisfied, 4 = somewhat dissatisfied, and 5 = very dissatisfied. For each of the patient satisfaction variable (general health care, hospital and physician), categories 1 and 2 were collapsed and recoded as "satisfied" = 1, while categories 3-5 were collapsed and recoded as "dissatisfied" = 0.

5.3.2.2 Predictors/covariates

We examine the relationship between self-perceived unmet health care needs and patient satisfaction. A self-perceived unmet care need (main predictor variable) was identified in the CCHS-2010 by the question, "During the past 12 months, was there ever a time when you felt that you needed health care but you didn't receive it?" Responses were coded, "yes" = 1 and "no" = 0. For this variable, reasons for indicating unmet care needs included, unavailability of care – waiting time too long, care not available when requested, care not available in area, doctor didn't think care was necessary; unacceptability of care – dislike doctor/afraid, language problems, didn't know where to go; inaccessibility –cost; or personal choice – too busy, didn't get around to it/didn't bother, felt it would be inadequate, decided not to seek care, and personal/family responsibilities.

Other sociodemographic predictors and covariates that were contained within our analyses were:

Age (< 45, 45-64, 65-79, 80+ years),

Sex ("male" = 0 vs "female" =1),

Marital status ("married", "common-law", "widowed/divorced/separated", "single/never married"),

Level of education ("less than secondary", secondary graduation", "some post-secondary education", "post-secondary graduation"),

Total personal income from all sources (less than 20,000, 20,000-39,999, 40,000-69,999, 70,000 or more), and

Satisfaction with life in general ("dissatisfied", "very satisfied", "satisfied", "neither satisfied nor dissatisfied"),

Rating of availability of provincial health care: general health care ("poor", "fair", "good", "excellent"); hospital services ("poor", "fair", "good", "excellent"); and physician services ("poor", "fair", "very good"),

Rating of quality of care received: general health care ("poor", "fair", "good", "excellent"); hospital services ("poor", "good", "excellent"); and physician services ("poor", "good", "excellent"),

Type of patient at most recent visit ("admitted overnight", "outpatient", "ER patient"),
Type of physician seen at most recent visit ("family doctor" = 0 vs "specialist" =1).

Variables that included categories indicated as "do not know", "refusal" and "not stated" were recoded category as (".") and treated as missing values. These variables were of interest due to their relation to health related quality of life; i.e. self-perceived physical and mental health over time. Education, income, gender, influence health status and therefore satisfaction with care. General life satisfaction is a global measure of one's perceived satisfaction as a whole and provides overarching context in which health satisfaction may be a part. The availability and quality of care received also influences satisfaction with health care services.

5.3.3 Statistical Analyses

Data was analyzed using STATA version 14.0. Bootstrapping, which is a statistical technique that allows estimation of the sampling distribution of data would normally be applied to data collected by random sampling methods. However, due to the small sample size of the study population, sampling weights only were applied in order to account for survey design. Descriptive statistics were tabulated for the main exposure variable, outcome variable, and covariates as well as the socio-demographic factors (age, gender, marital status, education, and personal income) of respondents who reported having a neurological condition during the data collection period. To account for missing data identified among all variables, prevent loss of information and selection bias, multiple imputation was conducted using the chained equations technique in STATA. All missing values were retrieved and included in the model building process.

Univariate logistic regression models were utilized to examine the association between self-perceived unmet care needs, other predictors/covariates and satisfaction with health care services (general health care, hospital and physician). The unadjusted odds ratios and 95% confidence intervals (CI) and p-values were reported. Predictors/covariates with unconditional p-values ≤0.2 (5) were retained for use in the multivariate model building phase of analysis.

In the multivariate model building process, variables with p-values >0.05 were individually eliminated in sequence of descending p-values, using a manual backward elimination strategy. Variables with significant p-values ≤0.05 were retained in the final model. All variables of interest which were manually eliminated due to insignificant p-values were checked for confounding and retained when they altered the coefficients for the exposure of interest by >20%. Any variable with an initial significant p-value at unconditional analysis that was eliminated by backward elimination was assessed for interaction with exposure of interest (self-perceived unmet health care needs). All variables were included in the final model. The overall significance of this logistic regression model was checked by performing a likelihood ratio test.

5.4 Results

5.4.1 Characteristics of the study population – individuals with neurological conditions

Analysis for this study was limited to the final subsamples of 2902, 1222, and 2211 individuals with neurological conditions who received general health care services, hospital services and physician services respectively within the 2010 survey year. Table 5-1 below demonstrates the demographic characteristics of the study population for all three study samples. Total number of weighted cases vary due to missing values.

Table 5- 1 Sociodemographic characteristics of CCHS-2010 samples

Characteristics	**General Health Care Services**	**Hospital Services**	**Physician Services**
	n(%)	n(%)	n(%)
Age categories, years			
≤44 years	3,507 (40.2)	1,242 (35.6)	2,553 (39.6)
45 to 64	2,725 (31.3)	1,103 (31.6)	2,086 (32.3)
65 to 79	1,636 (18.8)	758 (21.7)	1,125 (17.4)
80 and above	844 (9.7)	389 (11.1)	687 (10.7)
Sex			
Male	2,804 (32.2)	1,091 (31.2)	1,925 (29.8)
Female	5,908 (67.8)	2,401 (68.8)	4,526 (70.2)
MARITAL STATUS			
single	2,583 (29.7)	954 (27.4)	1,843 (28.6)
married	3,515 (40.4)	1,349 (38.7)	2,583 (40.1)
common-law	413 (4.7)	193 (5.5)	301 (4.7)
wid/sep/div	2,193 (25.2)	992 (28.4)	1,717 (26.6)
EDUCATION			
<secondary	2,517 (29.0)	1,033 (29.7)	1,774 (27.6)
secondary grad	1,569 (18.1)	543 (15.6)	1,116 (17.4)
other post sec	666 (7.7)	326 (9.4)	485 (7.6)

post-sec grad	3,916 (45.2)	1,577 (45.3)	3,046 (47.4)
INCOME			
<=19,999	3,541 (43.1)	1,468 (44.6)	2,634 (43.3)
20,000-39,999	2,376 (29.0)	1,037 (31.5)	1,828 (30.1)
40,000-69,999	1,548 (18.9)	536 (16.3)	1,074 (17.7)
70,000->100,000	735 (9.0)	252 (7.6)	544 (8.9)

In all subsamples, the majority of the respondents were females (57.8%), (68.8%) and (70.2%) respectively. Most of the respondents were 44 years of age or below (40.2%), (35.6%) and (39.6%). Many of the respondents had postsecondary graduation (45.2%), (45.3%) and 47.4%), respectively. Most respondents in all samples were married, (40.4%), (38.7%) and (40.1%) respectively. Most respondents earned $19,999 or less annually (43.1%), (44.6%) and (43.3%). Under 20% of the respondents in each sample reported unmet health care needs. Table 5-2 below describes the variables associated with health care services received by the respondents.

Table 5- 2 Description of variables associated with utilization of health care services: general, hospital and physician.

Variables	**General Health Care Services**	**Hospital Services**	**Physician Services**
Unmet Health Care Needs			
No	7,329 (84.2)	2,797 (80.2)	5,249 (81.4)
Yes	1,375 (15.8)	691 (19.8)	1,197 (18.6)
General Life Satisfaction			
dissatisfied	590 (6.8)	279 (8.0)	434 (6.7)
very satisfied	2,787 (32.2)	1,012 (29.2)	2,007 (31.3)
satisfied	4,396 (50.7)	1,822 (52.5)	3,342 (52.1)
neither satisfied nor dissatisfied	895 (10.3)	359 (10.3)	633 (9.9)
Rating of availability of Provincial care			
poor	1,218 (14.0)	537 (15.5)	845 (13.2)
fair	2,182 (25.2)	923 (26.6)	1,647 (25.6)
good	3,884 (44.8)	1,381 (39.7)	3,928 (61.2)[1]
excellent	1,392 (16.0)	633 (18.2)	
Quality of Care Received			
poor	299 (3.4)	595 (17.0)	694 (10.8)
fair	1,072 (12.3)	1,293 (37.1)[2]	2,233 (34.6)[2]
good	3,993 (45.9)		
excellent	3,336 (38.3)	1,599 (45.9)	3,517 (54.6)
Patient Satisfaction			

dissatisfied	1,396 (16.1)	660 (18.9)	568 (8.8)
satisfied	7,299 (83.9)	2,827 (81.1)	5,875 (91.2)
Most recent patient			
Outpatient	-	1,363 (39.0)	-
Admitted Overnight	-	817 (23.40)	-
ER Patient	-	1,312 (37.6)	-
Physician Type			
Family Doctor	-	-	5,303 (82.3)
Specialist	-	-	1,144 (17.7)

[1] good and excellent categories collapsed to very good

[2] fair and good categories collapsed to good

Most respondents were satisfied with life in general (50.7% -52.5 %) and with health services in general (83.9%), hospital (81.1%) and physician services (91.2%). Majority of respondents (45.9%) felt they received good health care in general and excellent hospital (45.9%) and physician care (54.6%). Most respondents who received hospital services were outpatients (39%) while majority of physician services were had from a family doctor (82.3%) (Table 5-2).

5.4.2 Characteristics associated with patient satisfaction with general health care, hospital, and physician services among individuals with neurological conditions (univariate analysis)

Based on the results of the univariate analysis shown in Table 5-3, all variables (age, sex, marital status, education, income, unmet health care needs, general life satisfaction, availability of health care, and quality of care received), excepting sex were significant predictors of patient satisfaction with general health care services. The odds of patient satisfaction with general health care services increased with age [1.77 (p=0.004), 2.18 (p=0.004), 3.97 (p<0.001)], demonstrating a significant positive association with patient satisfaction with health care services in general, while there was an insignificant negative association with common law unions (OR = 0.71, p=0.297). There was a strong protective association with being married and being satisfied with health care services in general (OR= 1.63, p=0.022), while the odds of being satisfied with general health care services among all categories of education was negative [0.58, (p = 0.053), 0.40, (p = 0.004), and 0.76 (p = 0.163)], with the most highly educated being least likely to be satisfied with health services in general. There was no significant association between varied levels of income and patient satisfaction with general health care services, while unmet health care needs demonstrated a strong negative association with patient satisfaction (Table 5-3). The greater the availability of provincial health care services, the better the quality of care received and the higher the level of satisfaction with life in general, was the greater the satisfaction with general health care services (Table 5-3).

Age, self-perceived unmet health care needs, availability of health care, and quality of care received and patient type at most recent hospital visit significantly predicted patient satisfaction with hospital services. The odds of patient satisfaction with hospital services was highest among the youngest old (45-64 years), demonstrating the only significant protective association among the age categories (2.55, p = 0.001), while those with self-perceived unmet health care needs were significantly less likely to be satisfied with hospital services (OR = 0.35, p<0.001) than those who health care needs were perceived to be met. The odds of patient satisfaction with hospital services significantly increased with the perceived availability of provincial health care (fair =3.22, p = 0.001; good = 3.27, p<0.001; and excellent = 18.27, p<0.001). The same is true for the association between quality of hospital care received and patient satisfaction (fair = OR, 24.34, p<0.001 and very good = OR, 179.11, p<0.001), while being admitted overnight (OR = 0.88, p = 0.778) and visiting the ER (OR = 0.17, p<0.001) were negatively associated with patient satisfaction with hospital services, with being an ER patient demonstrating a strong association with patient dissatisfaction (Table 5-3).

Unmet health care needs, general life satisfaction, availability of health care, and quality of care received were significant predictors of patient satisfaction with physician services. When compared with those without self-perceived unmet health care needs, those with self-perceived unmet health care needs were significantly less likely (OR = 0.18, p<0.001) to be satisfied with physician services, while satisfaction with physician services increased with increasing levels of satisfaction with life in general (neither satisfied nor dissatisfied = OR, 2.10, p = 0.150; satisfied = OR, 2.21, p = 0.041; and very satisfied = OR, 5.73, p = <0.001). The odds of patient satisfaction with physician services significantly increased with the quality of care provided (good = 19.61, p<0.001 and excellent = 167.97, p<0.001) and decreased when health care services were provided by a specialist (0.63, p = 0.352) compared to a family doctor, though this association was not significant.

In summary, quality of care received, and availability of care were protective predictors of patient satisfaction with health care services in general, hospital services and physician services, while self-perceived unmet health care needs was a negative predictor of satisfaction which each type of health care service identified above.

Table 5- 3 Univariate analysis of predictors of patient satisfaction with general health care, hospital, and physician services from CCHS Annual Component 2010

Variables	**General Health Care Services**		**Hospital Services**		**Physician Services**	
	OR, 95% CI	p-Value	OR, 95% CI	p-Value	OR, 95% CI	p-Value
Age categories, years		<0.001		0.009		0.140
≤44 years	Reference		Reference		Reference	
45 to 64	1.77 (1.20-2.62)	0.004	2.55 (1.46-4.46)	0.001	1.36 (0.63-2.96)	0.423
65 to 79	2.18 (1.29-3.70	0.004	1.74 (0.88-3.47)	0.114	2.01 (0.93-4.33)	0.077
80 and above	3.97 (1.87-8.45)	<0.001	2.02 (0.81- (5.08)	0.133	1.99 (0.90-4.37)	0.087
Sex		0.633		0.424		0.094
Male	Reference		Reference		Reference	
Female	1.10 (0.74-1.65)	0.663	1.25 (0.72-2.17)	0.424	0.60 (0.33-1.09)	0.094
Marital Status		0.015		0.104		0.709
single	Reference		Reference		Reference	
married	1.63 (1.07-2.48)	0.022	1.72 (0.96-3.10)	0.068	0.91 (0.47-1.75)	0.775
common-law	0.71 (0.38-1.35)	0.297	0.88 (0.35-2.19)	0.781	0.70 (0.33-1.51)	0.366
widowed/separated/divorced	1.53 (0.98-2.37)	0.061	1.85 (0.99-3.45)	0.054	1.10 (0.61-2.00)	0.612
Education		0.021		0.926		0.085
<secondary	Reference		Reference		Reference	
secondary graduate	0.58 (0.33-1.01)	0.053	1.24 (0.55-2.79)	0.610	0.49 (0.23-1.04)	0.064
other post-secondary	0.40 (0.21-0.75)	0.004	1.07 (0.43-2.68)	0.889	0.39 (0.17-0.91)	0.030
post-secondary graduate	0.76 (0.51-1.12)	0.163	0.97 (0.52-1.83)	0.929	0.59 (0.32-1.11)	0.919
Income		0.146		0.291		0.570
≤ 19,999	Reference		Reference		Reference	
20,000-39,999	0.90 (0.57-1.43)	0.660	1.12 (0.60-2.10)	0.718	1.16 (0.61-2.20)	0.646
40,000-69,999	1.59 (1.01-2.53)	0.047	1.46 (0.71-2.99)	0.303	0.95 (0.37-2.48)	0.923
≥ 70,000	1.28 (0.62-2.62)	0.501	0.55 (0.23-1.30)	0.170	1.94 (0.76-4.97)	0.165
Unmet Care		<0.001		<0.001		<0.001
No	Reference		Reference		Reference	
Yes	0.18 (0.12-0.27)	<0.001	0.35 (0.20-0.61)	<0.001	0.18 (0.10-0.32)	<0.001
General Life Satisfaction		<0.001		0.433		<0.001
dissatisfied	Reference		Reference		Reference	
very satisfied	4.62 (2.41-8.83)	<0.001	1.11 (0.44-2.82)	0.819	5.73 (2.61-12.58)	<0.001
satisfied	2.90 (1.72-4.89)	<0.001	0.72 (0.34-1.49)	0.372	2.21 (1.03-4.73)	0.041
neither sat nor dissatisfied	1.75 (0.84-3.67)	0.137	0.59 (0.23-1.47)	0.253	2.10 (0.76-5.77)0.	0.150
Availability of provincial care		<0.001		<0.001		<0.001
poor	Reference		Reference		Reference	

fair	2.82 (1.69-4.73)	<0.001	3.22 (1.66-6.23)	0.001	1.98 (1.06-3.74)	0.033
good	9.18 (5.42-15.53)	<0.001	3.27 (1.69-6.34)	<0.001		
excellent	27.07 (11.00-66.66)	<0.001	18.27 (7.08-47.16)	<0.001	4.29 (1.95-9.63)	<0.001
Quality of care received		<0.001		<0.001		<0.001
poor	Reference		Reference		Reference	
fair	9.55 (2.96-30.80)	<0.001	24.34 (12.20-48.57)	<0.001		
good	77.98 (25.61-237.43)	<0.001			19.61(8.09-47.56)	<0.001
excellent	642.64 (193.27-2136.79)	<0.001	179.11 (76.28-420.58)	<0.001	167.97 (71.07-396.94)	<0.001
Most recent patient				<0.001		
Outpatient			Reference			
Admitted Overnight			0.88 (0.35-2.18)	0.778		
ER Patient			0.17 (0.09-0.30)	<0.001		
Physician type						0.352
Family Doctor					Reference	
Specialist					0.63 (0.24-1.66)	0.352

5.4.3 Characteristics associated with patient satisfaction with general health care, hospital, and physician services among individuals with neurological conditions (multivariate analysis)

Insignificant variables (p=>0.2) were excluded in the initial multivariate logistic regression model building. However, after checking for confounding, all variables which were originally removed during the initial model building processes were included in the final models after checking for confounding because they altered the coefficients for the exposure of interest by >20%. Table 5-4 demonstrates the results of the final multivariate logistic regression models for patient satisfaction with adjusted predictor and/or covariate variables. Our study generated odds ratio estimates to examine the association between sociodemographic factors and experiences with health care and patient satisfaction with health care services in general, hospital services and physician services among individuals with neurological conditions.

We found self-perceived unmet health care needs to be a strong negative predictor for patient satisfaction across all health care services. For those with self-perceived unmet needs, the greatest dissatisfaction was most likely found with physician services (OR = 0.29, p = 0.005), followed by hospital services (OR = 0.41, p = 0.006) and then general health care services (OR = 0.59, p = 0.024), when compared to those without unmet health care needs. Conversely, quality of care received and availability of care were significantly strong protective predictors of patient satisfaction across all health care services. When compared to those who received poor quality care, the odds of patient satisfaction (general health care services, 237.60, p<0.001; hospital services,166.99, p<0.001; and physician services, 176.4, p<0.001) were highest across all services among those who received excellent quality care; with those receiving general health services most likely to be satisfied in all categories of quality care: fair (OR = 6.15, p = 0.002), good (OR = 36.37, p <0.001) and excellent (OR = 237.60, p<0.001) (Table 5-4). Regarding the association between availability of care and patient satisfaction, the odds of patient satisfaction across all health services were higher with increasing availability of care. When compared to poor availability of care, the odds of patient satisfaction were highest among those who reported excellent availability care across all health care services in general (4.45, p<0.001) and hospital services (6.30, p<0.001), with those receiving hospital services most likely to be satisfied across all categories of care availability: fair (OR = 2.77, p = 0.011), good (OR = 3.90, p<0.001) and excellent (OR = 6.30, p<0.001). On the other hand, those who reported very good availability of physician care were less likely to be satisfied (OR = 1.10, p = 0.833) than those who reported fair availability of physician care (OR = 1.25, p = 0.592), though both categories of availability were more likely to be satisfied with physician than poor availability of physician care. This association between physician care and patient satisfaction was not significant.

When compared to those 44 years of age or lower, there was decreased odds of patient satisfaction with hospital and physician services, respectively, among those with neurological conditions in the 65-79 (0.39, p = 0.092; 0.75, p = 0.585) and 80+ (0.48, p = 0.334; 0.73, p = 0.593) age categories, while those in the 45-64 age category were more likely to be satisfied with hospital (OR = 2.02, p = 0.120) and physician services (OR =1.14, p = 0.747). In contrast to age playing a negative role in patient satisfaction with hospital and physician services for the older age categories, age was associated with an increased likelihood of being satisfied with health care services in general, with those 80+ most likely (OR = 2.57, p =0.059) to be satisfied with those services, compared to those 44 years of age or lower. Women were more likely to be satisfied with general health care services and hospital services and less likely to be satisfied with physician services, compared to men. Marital status was a positive predictor for satisfaction with health care services in general. In comparison to being single, those who were widowed, separated or divorced were most likely (OR = 1.48, p=0.254) to be satisfied followed by those who were married (OR = 1.39, p = 0.264), then those who were in common-law unions (OR = 1.31, p = 0.427).

Education was a negative predictor of patient satisfaction among those who received general health services with higher levels of education being more dissatisfied with care, [(secondary graduate, OR = 0.62, p = 0.126); (other post-secondary, OR = 0.36, p = 0.004); and post-secondary graduate, OR = 0.54, p = 0.050)] and those who received physician services [(secondary graduate, OR = 0.32, p = 0.010); (other post-secondary, OR = 0.26, p = 0.019); and post-secondary graduate, OR = 0.28, p = 0.005)], while there were contrasting directions of association between the categories education [(secondary graduate, OR = 2.00, p = 0.177); (other post-secondary, OR = 2.81, p = 0.065); and post-secondary graduate, OR = 0.98, p = 0.967)] and patient satisfaction with hospital services. Other post-secondary education was associated with the lowest significant odds of patient satisfaction among those receiving general health services and physician services while it was associated with an increased insignificant odds of patient satisfaction with hospital services. In addition, post-secondary graduates provided reduced odds of being satisfied with hospital services compared to those with less than secondary education and registered least likely chance of patient satisfaction with hospital services in the education category. Income on the other hand demonstrated no significant association with patient satisfaction across all health care services (Table 5-4).

Physician type seen and most recent type of patient during last health care services were also predictors of patient satisfaction with physician and hospital services respectively. Respondents who received specialist care were 47% less likely (OR = 0.47, p = 0.106) to be satisfied with physician services than those who saw a family doctor when they last received health care services. Patients who were admitted overnight were more likely (OR = 1.20, p = 0.660) to be satisfied with hospital services than inpatients, while ER patients were significantly less likely (OR = 0.39, p = 0.007) to be satisfied with hospital services than both inpatients and overnight patients.

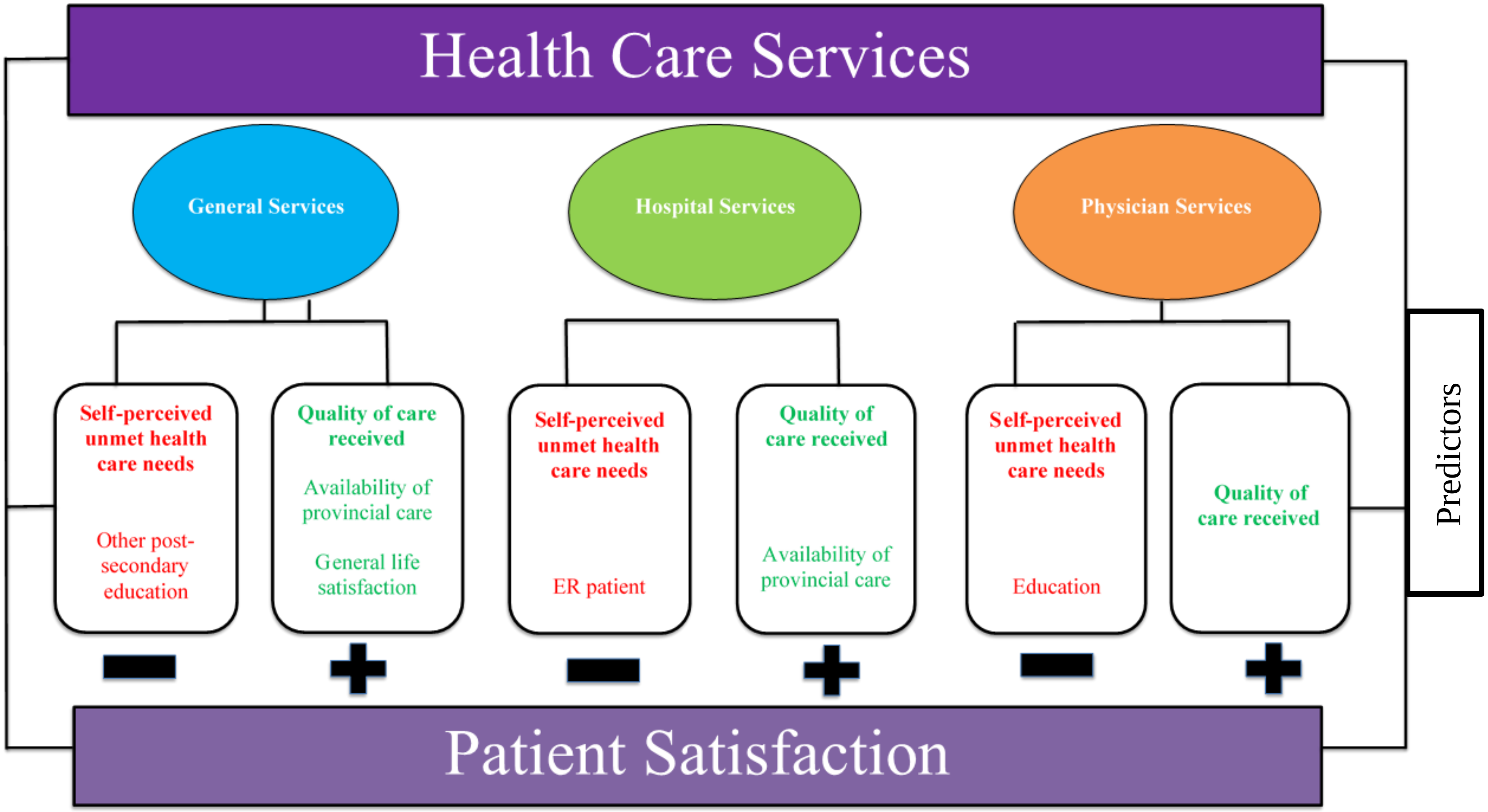
Table 5- 4 Multivariate analysis of predictors of patient satisfaction with general health care, hospital, and physician services from CCHS Annual Component 2010

Variables	**General Health Care Services**		**Hospital Services**		**Physician Services**	
	OR, 95% CI	p-Value	OR, 95% CI	p-Value	OR, 95% CI	p-Value
Age categories, years						
≤44 years	Reference		Reference		Reference	
45 to 64	1.80 (0.98-3.32-)	0.059	2.02 (0.83-4.91)	0.120	1.14 (0.51-2.57)	0.747
65 to 79	1.24 (0.59-2.59	0.576	0.39 (0.13-1.17)	0.092	0.75 (0.27-2.08)	0.585
80 and above	2.57 (0.97-6.86)	0.059	0.48 (0.11-2.13)	0.334	0.73 (0.23-2.29)	0.593
Sex						
Male	Reference		Reference		Reference	
Female	1.32 (0.80-2.17)	0.276	1.12 (0.53-2.37)	0.764	0.62 (0.32-1.19)	0.152
Marital Status						
single	Reference		Reference		Reference	
married	1.39 (0.78-2.50)	0.264	0.55 (0.19-1.61)	0.278	0.62 (0.31-1.21)	0.160
common-law	1.31 (0.67-2.58)	0.427	0.69 (0.23-2.10)	0.514	1.21 (0.42-3.53)	0.727
widowed/separated/divorced	1.48 (0.76-2.89)	0.254	0.68 (2.01-2.27)	0.524	1.06 (0.41-2.71)	0.603
Education						
<secondary	Reference		Reference		Reference	
secondary graduate	0.62 (0.38-1.14)	0.126	2.00 (0.73-5.47)	0.177	0.32 (0.13-0.76)	0.010
other post-secondary	0.36 (0.18-0.72)	0.004	2.81 (0.94-8.40)	0.065	0.26 (0.09-0.80)	0.019
post-secondary graduate	0.54 (0.29-1.00)	0.050	0.98 (0.42-2.28)	0.967	0.28 (0.11-0.67)	0.005
Income						
≤ 19,999	Reference		Reference		Reference	
20,000-39,999	0.73 (0.41-1.30)	0.281	1.49 (0.58-3.80)	0.404	1.57 (0.69-3.54)	0.278
40,000-69,999	1.54 (0.75-3.17)	0.242	1.04 (0.36-3.00)	0.939	1.06 (0.33-3.46)	0.917
≥ 70,000	0.90 (0.39-2.12)	0.817	0.33 (0.11-0.97)	0.045	1.17 (0.38-3.63)	0.783
Unmet Care						
No	Reference		Reference		Reference	
Yes	0.59 (0.37-0.93)	0.024	0.41 (0.21-0.77)	0.006	0.29 (0.13-0.69)	0.005
General Life Satisfaction						
dissatisfied	Reference		Reference		Reference	
very satisfied	2.15 (1.03-4.49)	0.041	1.56 (0.45-5.41)	0.481	2.53 (0.88-7.26)	0.084
satisfied	1.80 (0.92-3.53)	0.085	0.77 (0.25-2.33)	0.642	1.24 (0.46-3.37)	0.668
neither sat nor dissatisfied	1.29 (0.60-2.76)	0.510	0.46 (0.13-1.69)	0.244	1.60 (0.57-4.52)	0.372

Availability of provincial care						
poor	Reference		Reference		Reference	
fair	1.72 (1.03-2.87)	0.039	2.77 (1.27-6.05)	0.011	1.25 (0.54-2.93)	0.592
good	3.18 (1.78-5.68)	<0.001	3.90 (1.92-7.92)	<0.001		
excellent	4.45 (1.76-11.25)	<0.001	6.30 (2.35-16.86)	<0.001	1.10 (0.44-2.75)	0.833
Quality of care received						
poor	Reference		Reference		Reference	
fair	6.15 (2.00-18.94)	0.002				
good	36.37 (12.09-109.44)	<0.001	35.61 (18.71-67.78)	<0.001	26.78 (13.36-53.69)	<0.001
excellent	237.60 (70.43-801.52)	<0.001	166.99 (67.91-410.64)	<0.001	176.45 (63.89-487.30)	<0.001
Most recent patient						
Outpatient			Reference			
Admitted Overnight			1.20 (0.53-2.72)	0.660		
ER Patient			0.39 (0.20-0.77)	0.007		
Physician type						
Family Doctor					Reference	
Specialist					0.47 (0.18-1.18)	0.106

In summary, significant positive predictors of patient satisfaction with health care services in general are quality and availability of provincial and received care, and being very satisfied with life in general. Significant positive predictors of patient satisfaction with hospital services are quality and availability of provincial and received care, while the positive predictor of patient satisfaction with physician services is quality of care received. Quality of care is therefore, strongly and positively associated with patient satisfaction across all health services. In contrast, the common significant negative predictor of patient satisfaction across all health care services is self-perceived unmet health care needs. Other significant negative predictors of patient satisfaction include other post-secondary education (general health services and physician services), secondary and post-secondary graduation (physician services), and being an ER patient most recently (hospital services) (Figure 5-3).

Figure 5- 3 Summary of significant associations between health care services and patient satisfaction among individuals with neurological conditions



5.5 Discussion

The major findings of our study can be summarized by Anderson's health behavior model predicting health care utilization. This model fittingly demonstrates the relationship among predisposing (age, gender, and general life satisfaction), enabling (marital status, income, education, availability of health care and quality of care) and need factors (neurological patients' use of general health care services, hospital and physician services) and patient satisfaction. One enabling factor, quality of received care, demonstrated a strong positive association with patient satisfaction with all health care services received in this study, while another enabling factor, availability of provincial care, was positively associated with patient satisfaction with general health care and hospital services. One predisposing factor, general life satisfaction, was positively associated with patient satisfaction with general health care services. On the other hand, a disabling factor, self-perceived unmet health care needs commonly reduced the odds of patient satisfaction with the need factors, health care services in general, physician and hospital services. Education was deemed a disabling factor, with all levels negatively associated with patient satisfaction with physician care and other post-secondary education negatively associated with general health care services. The need factor, receiving services at the ER at the last encounter with the health system, was negatively associated with patient satisfaction with hospital services.

Of particular interest is the relationship between patient satisfaction and the predisposing factor of health care utilization, General Life Satisfaction (GLS) which represents quality of life in several studies (28-31). Our finding that GLS was positively associated with patient satisfaction with general health care services is consistent with that of other studies which reported quality of life, including satisfaction in life domains as positively associated with patient satisfaction (32-34). While GLS impacting health related quality of life may be positively associated with patient satisfaction with general health care services, significant decreases in health related quality of life among people living with long term neurological conditions have been reported in other studies (35-41). This suggests that increased levels of GLS positively associated with greater odds of patient satisfaction among patients with neurological conditions in our study may be impacted by increased health-related quality of life related to enabling factors, availability and the more common predictor of patient satisfaction among all health services, quality of care.

Our study found that while availability and quality of care were positive predictors of patient satisfaction across all health services, availability of care was not significantly associated with patient satisfaction with physician services. Availability and quality of care are important predictors of health related quality of life as satisfied patients are more likely to comply with treatment, demonstrate positive health behaviours and register improved health outcomes (42-44). Consistent with our study, one other study found that quality of care was associated with high levels of patient satisfaction among neurological patients (45). The quality of care in that study referred to the early connection between patients and neurologists and education and advice on living with neurological conditions (45). In another similar study of patients with neurological conditions, patient satisfaction with coordination of safe, compassionate, and multiple health care services for those with mobility challenges was high (46), supporting our finding that when health care services are available, the odds of neurological patient satisfaction are increased.

The association of unmet health care needs, patient satisfaction with health care services and health related quality of life have been supported in chronic disease patients, oral health, cardiac, and cancer patients (22, 47-54). As patient satisfaction is positively associated with health related quality of life (18, 55-57), it may be deduced from this study that self-perceived unmet health care needs has some association with health-related quality of life among those with neurological conditions, though the direction of that association cannot be predicted from this study. One particular study which examined the relationship between unmet health care needs and health-related quality of life among patients with multimorbidity (58), found that the presence of unmet health care needs was associated with lowered health-related quality of life. This is consistent with our findings on the negative association between unmet health care needs and patient satisfaction among patients with neurological conditions.

Higher education levels and hospital admission through the ER were associated with decreased patient satisfaction in our study. This is consistent with findings of other studies (59, 60), one of which suggests that health care providers may create a better patient experience through increased communication or more active referral to patient representatives for ER patients (59). One other study found that the highest level of education strongly predicted favourable satisfaction with communication with doctors (61). This suggests that the negative association between highest levels of education and patient satisfaction among individuals with neurological conditions in our study may be due to the expectation of communication not being met, among neurological patients with higher levels of education.

The association between ER care in hospitals and lowered patient satisfaction in our study may be explained by a reduction in one or more of the components of patient satisfaction proposed by Mollaoğlu and Çelik, 2016: guidance, debriefing, paying attention and being kind, having empathy, providing psychosocial support, speed of service, timing, proficiency and overall quality (62). In addition, severity of patient condition (63) and the stress of a neurological patient being in the ER (62) may negatively influence patient's level of satisfaction with emergency services. Given the protective association between high availability of care and positive patient satisfaction, lowered odds of patient satisfaction among those who received hospital services, particular ER neurological patients, demonstrated in this study, may be indicative of decreased availability of care– waiting time too long, care not available when requested, care not available in area (few of the elements of unmet health care needs reported in the CCHS-2010) (26).

5.5.1 Strengths and limitations of the study

One strength of this study is that it supports the finding that unmet health care needs is a risk factor for decreased patient satisfaction among those with neurological conditions and that availability and quality of care are positive predictors of patient satisfaction across health services. Other strengths include the use of a nationally representative survey of the Canadian population with relatively high participation rates which allows for generalization in the interpretation of the findings; and the provision of information on specific health care services, i.e., general health care services, hospital and physician services that may vary in their impact on patients with neurological conditions.

There are a number of limitations: (1) Persons living on lands designated as Indian Reserves or by the Crown, those dwelling in institutions, or in certain remote regions as well as full-time members of the Canadian Forces are excluded from this survey Therefore, the data is not representative of these groups, especially those residing in institutions, whose information would add substantial value to this study. (2) Types of unmet health care needs and neurological conditions were not specified, and severity of disease conditions was not measured making it difficult to address patient satisfaction within groups of neurological conditions and identify specific unmet health care needs for targeted interventions. (3) The use of data from optional modules in the survey results in a reduction in the sample size, due to only one province, Ontario opting in for modules of interest for this study, decreasing the generalizability of the findings to the entire population.

5.6 Conclusion

Self-perceived unmet health care needs, as a single variable is a common significant negative predictor of neurological patient satisfaction across health care services, while availability and quality of care are strong predictors of positive patient satisfaction among the same group. Future studies on predictors of neurological patient satisfaction with health care services should focus on specific unmet health care needs impacting the different neurological conditions and their associations with patient satisfaction.

People with neurological conditions are known to report unmet health care needs and experience barriers to care, limiting their quality of life. Therefore, our study emphasizes the importance of ensuring relevant care of the highest quality is available and accessible, especially for older Canadians with neurological conditions. This demands a care model that employs a coordinated approach assuring access to various types of care needed by Canadians with neurological conditions.

5.7 References

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CHAPTER 6 – AN EXPLORATION OF THE SOCIODEMOGRAPHIC FACTORS AND SELECT MEASURES OF SPIRITUALITY/RELIGIOSITY THAT PREDICT GENERAL LIFE SATISFACTION AMONG CANADIANS WITH NEUROLOGICAL CONDITIONS LIVING IN THE PROVINCES OF NEW BRUNSWICK AND MANITOBA

A version of this chapter will be submitted for journal publication review.

The analysis presented in this paper was conducted at the Saskatchewan Research Data Centre (SKY-RDC) which is part of the Canadian Research Data Centre Network (CRDCN). The services and activities provided by the Saskatchewan Research Data Centre (SKY-RDC) are made possible by the financial or in-kind support of the SSHRC, the CIHR, the CFI, Statistics Canada, and the University of Saskatchewan. The views expressed in this paper do not necessarily represent the CRDCN's or that of its partners'.

6.1 Abstract

Background: The symptoms of neurological conditions may affect both patients and caregivers leading to substantial reductions in quality of life. Life satisfaction (representing quality of life) has been found to be associated with good general and mental health in earlier studies. Religion/spirituality have been reported as a source of coping with life difficulties and has been associated with improved health outcomes and quality of life domains. Few studies examine the effect of religion and spirituality on general life satisfaction among those with neurological conditions. Our study aims to examine the sociodemographic factors and select measures of spirituality/religiosity that predict general life satisfaction among Canadians with neurological conditions.

Methods: In this study, the Canadian Community Health Survey - Annual Component, 2011 (CCHS - 2011) was used to perform secondary analyses on a subset of the data, containing 802 respondents with neurological conditions. Multivariate logistic regression was used to generate odds ratios (ORs) and their corresponding confidence intervals for the relationship between spiritual and religious factors and other predictors and general life satisfaction.

Results: The OR for reporting general life satisfaction was lowest among those with: post-secondary education, 0.83 (95%CI = 0.30-2.30); an annual income of $40,000-$49,000, 0.88 (95%CI = 0.19-4.07); and spiritual values playing important role in life, 0.53 (95%CI = 0.18-1.58). The OR for general life satisfaction was highest among those with: an annual income > $50,000, 3.44 (95%CI = 0.48-24.61); spiritual strength to face everyday difficulties, 4.65 (95%CI = 1.13-19.18); regular attendance at religious services, 3.00 (95%CI = 1.07-8.42); very good self-perceived mental health, 12.02 (95%CI = 4.40-32.85); and excellent self-perceived general health, 17.30 (95%CI = 5.17-57.93).

Conclusions: We conclude that our findings are consistent with those of previous studies indicating that spiritual coping, self-perceived general and mental health are protective predictors of life satisfaction and improved quality of life. It may be beneficial to incorporate spiritual/religious needs in the circle of care for those living with neurological conditions in Canada.

6.2 Introduction

People with neurological conditions are living longer due to many factors (1), which have led to increasing focus on quality of life for this population. The progression of some neurological conditions may lead to symptoms such as pain, sensory motor symptoms, symptoms of movement disturbances, seizures and sensory symptoms (2). These symptoms may affect both patients and caregivers leading to substantial reductions in quality of life (2- 4). Life Satisfaction has been defined as the "subjective cognitive judgment of one's quality of life as a whole" (5, 6). Life satisfaction (representing quality of life) has been found to be associated with good general and mental health (7-10). Several studies examining predictors of mental health have been identified in the literature (11-16). Religion/Spirituality is prominently identified as positively impacting mental health (17), and life satisfaction (18-21) as it has been used as a resource for coping with stress (18, 22). Some studies explain the link between religion/spirituality and physical and mental health (23-25). Other studies suggest that embracing religious/spiritual values leads to improved general health and quality of life (26-29). Potential explanatory features of religiosity/spirituality include "better health practices prescribed by particular religions, lower levels of substance use that contribute to negative affect, positive reappraisal of stressful life events, more hopeful and positive expectancies and better social support" (30).

Notwithstanding the many studies that examine the link between religion/spirituality and physical health, there are few studies that look at the relationship between elements of spirituality and quality of life domains such as general life satisfaction (GLS) among those living with neurological conditions, in the Canadian context. Yet, Canada has an increasingly diverse population, with a wide cross-section of people who espouse spiritual values (31), with approximately three-quarters of Canadians identifying with a religion of some sort or think of themselves as members of a specific religious sect or denomination (32). In the same vein, many Canadians believe in crucial religious principles such as the existence of God, and divine intervention (33). Tate and Forchheimer, 2002, argue that, while spirituality is a construct separate from religion, it is related to religion and religiosity, in the sense that religiosity describes affiliation with a group that holds specific doctrine and spirituality describes one's relationship to a Supreme Being. Thus an individual may be religious without being spiritual and vice versa (34). It is therefore, prudent to examine both related concepts and their associations with quality of life. One Canadian quality of life study which focused on a range of neurological conditions found that having a neurological condition affects many areas of life such as general and mental health and causes functional impairments that represent a significant reduction in quality of life (35). The same study identified that important aspects of spirituality were used as a means of coping with neurological conditions. These include a positive attitude and traditional spiritual teachings as in the case of First Nations and Métis peoples (35).

One Italian study explained that different spirituality components, i.e., hope/optimism and beliefs, have diverse associations with quality of life, among neurological patients (36), while another similar study found that spiritual, religious and personal beliefs (SRPB) factors that predicted quality of life were similar in patients with different neurological conditions (37). Facets of SRPB (spiritual connectedness, inner peace, awe and openness, inner independence, and hope and optimism) jointly predict quality of life, through improved ability to face life challenges and difficulties and the capacity to rise above health problems (37).

Given that many Canadians believe in religious principles, and there is an increasing number of Canadians with myriad neurological conditions, it is fitting to examine the impact of spiritual values and religiosity on general life satisfaction with a focus on neurological conditions. An understanding of the relationship between spiritual values and religiosity on general life satisfaction among Canadians with neurological conditions may contribute to the Canadian health system's task of adequately planning, providing for, and meeting the health and quality of life needs of this diverse population.

This study examines the association between spirituality/religiosity and general life satisfaction among Canadians with neurological conditions from the 2011 Canadian Community Health Survey (CCHS). The objective of this study is to explore the sociodemographic factors and select measures of spirituality/religiosity (spiritual values-playing important role in life; spiritual values –strength everyday difficulties; and frequency of attendance at religious services) as predictors of general life satisfaction (subjective self-judgment of quality of life) among Canadians with neurological conditions.

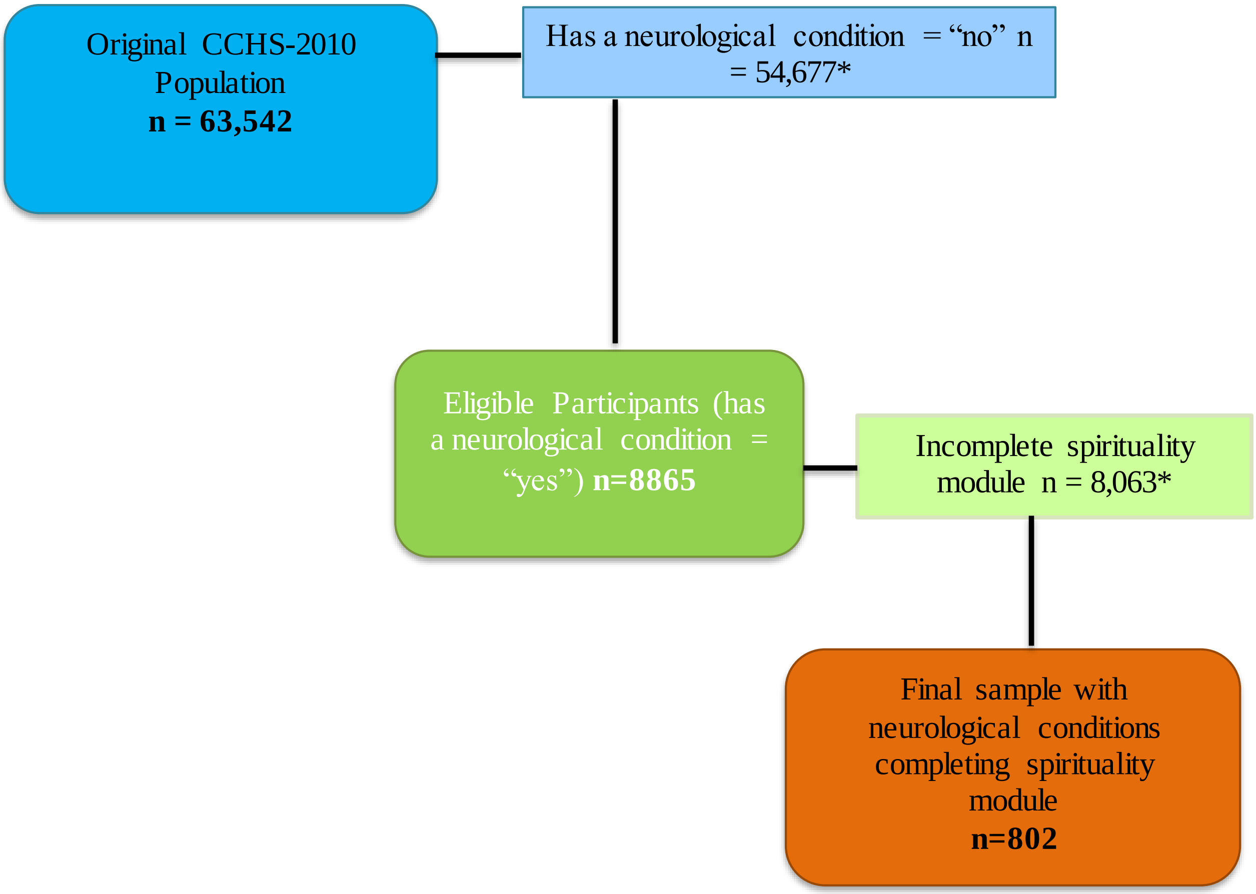
6.3 Methods

6.3.1 Data Sources

Data were extracted from the Canadian Community Health Survey-Annual Component, 2011 (CCHS-2011). The target population for this survey includes persons aged 12 and over living in private dwellings in all provinces and territories. The survey, excluding participants residing in institutions, on Indian Reserves and certain remote regions, and full-time members of the Canadian Forces, was conducted between January and December, 2011 using computer assisted interviewing (CAI) (38). In addition to the common content answered by all respondents, the CCHS-2011 contains optional content which meets the need for information at the level of the health regions and is unique to each region or province, varying annually, despite being harmonized across the province (38).

The CCHS-2011 anonymized Master Files were used for this study because it is the latest survey containing responses on all major variables of interest in this study: common content on general life satisfaction, the one-year unique common content on neurological conditions and the optional content on spiritual values (39). Respondents with neurological conditions who reported on general life satisfaction and completed the optional module on spiritual values resided in the provinces of New Brunswick (NB) and Manitoba (MB), which had a combined population of 1, 959,439 in 2011. Therefore, for this particular study, a subset of the data, containing 802 Canadians who reported neurological conditions in the provinces of NB and MB and reported spirituality was included in the analysis for this study (see Figure 6-1). Respondents in age categories 12-44 years were grouped to protect anonymity, due to the small sample size of the study population, and the fact that there were very few people in the youngest age categories reporting neurological conditions and spiritual values.

Figure 6- 1 Restriction criteria for obtaining sub-sample of CCHS-2011 in this study



*Excluded from analysis

6.3.2 Measures

6.3.2.1 Assessment of neurological conditions (subpopulation) and general life satisfaction (outcome of interest) in CCHS-2011

Neurological conditions in the CCHS-2010 sample was a derived variable indicating whether selected respondents had a neurological condition. The study population for this study was selected from selected respondents who stated yes to having a neurological condition from among the following list of conditions: AD/dementia, PD, Huntington's disease, Tourette’s syndrome, spina bifida, MS, stroke effects, dystonia, epilepsy, cerebral palsy, ALS, muscular dystrophy, brain injuries, SCI, brain and spinal cord tumors, hydrocephalus, and migraine headaches (40).

The outcome of interest used in this study, General Life Satisfaction (GLS), was derived from responses to the question: “Using a scale of 0 to 10, where 0 means "Very dissatisfied" and 10 means "Very satisfied", how do you feel about your life as a whole right now?” This variable groups the 11-point scale to rate respondents’ satisfaction with life into five categories, very satisfied, satisfied, neither satisfied nor dissatisfied, dissatisfied and very dissatisfied (40).

6.3.2.2 Predictors

We assess the relationship between predictor variables and general life satisfaction. Our primary predictor of interest was spiritual values. We selected three variables from the spirituality component of the CCHS-2011 survey based upon our objective of identifying if GLS is influenced by the importance of spirituality in one’s life, spiritual coping and social religious interaction. These elements were identified by the following questions:

(1) Importance of spirituality: Do spiritual values play an important role in your life? Responses were coded, “yes” = 1 and “no” = 0.
(2) Spiritual coping: To what extent do your spiritual values give you the strength to face everyday difficulties? For the purpose of this study, the question was interpreted as “do spiritual values give you strength to face everyday difficulties”? Response categories were collapsed and recoded as follows: “yes” = 1, a combination of the responses “a lot” and “some” and “no” = 2, a combination of “a little” and “not at all”.
(3) Social religious interaction: “Not counting events such as weddings or funerals, during the past 12 months, how often did you participate in religious activities or attend religious services or meetings?” Response categories were collapsed and coded as follows: “not at all” = 0; “regular” (at least once a week/at least once a month) = 1; and “irregular” (at least three times a year/once or twice a year) = 2

The following represent other predictors and covariates of GLS that were included in our analyses:

Age (< 45, 45-64, 65-79, 80+ years),

Sex (“male” = 0 vs “female” =1),

Marital status (“married/common-law”, “widowed/divorced/separated”, “single/never married”),

Level of education (“less than secondary”, secondary graduation”, “post-secondary graduation”),

Total personal income from all sources in Canadian dollars (less than 19,999, 20,000-39,999, 40,000-49,999, 50,000 or more),

Self-perceived health (“poor”, “good”, “very good”),

Self-perceived mental health (“poor”, “good”, “very good”).

Variables that included categories indicated as “do not know”, “refusal” and “not stated” were recoded as (“.”) and treated as missing values.

6.3.3 Statistical Analyses

Analysis of the data found in the CCHS-2011 was completed using STATA version 14 on restricted confidential master data files accessed through the Saskatchewan Research Data Center at the University of Saskatchewan (https://crdcn.org). Due to this restricted access, there are limitations on the release of data. To account for survey design, weighted analysis was completed by applying sampling weights to our data set. We did not apply bootstrapping due to the very small sample size of our study population. We generated descriptive frequencies for the socio-demographic characteristics (age, gender, marital status, education, and personal income), spiritual values variables, self-perceived health, and self-perceived mental health. Due to the many missing variables across all variables, we performed multiple imputation to prevent selection bias and loss of information. Imputed values were included in the analysis.

Logistic regression was used to estimate the association between predictor variables and general life satisfaction because the assumptions for ordered logistic regression are violated. The outcome variable categories 1 and 2 were collapsed and recoded as “satisfied” = 1, while categories 3-5 were collapsed and recoded as “dissatisfied” = 0 (39) and logistic regression conducted because generalized ordered logistic regression models would not converge in the model building process.

Screening of selected variables was done by examining unconditional associations between each predictor and the outcome of interest (GLS), with liberal p-values set at $p<0.20$. Unadjusted odds ratios (UOR) and 95% confidence intervals (CI) were reported. All variables with a p-value <0.20 in the univariate analyses were retained for further use in multivariate analysis.

A manual backward elimination strategy was used to remove variables with p-values >0.05 in the multivariate model building process. All variables with significant p-values ≤ 0.05 were retained in the final model. Eliminated variables that had an initial significant p-value at unconditional analysis were checked for confounding and interaction and retained in the final model if they demonstrated interaction with or altered the coefficients for any exposure of interest by >20%. The final model was analyzed using multivariate logistic regression. Adjusted odds ratios (AORs) and 95% confidence intervals (CI) were generated and interpreted to demonstrate the association between spiritual values and other predictors and general life satisfaction. A likelihood ratio test was performed to check the overall significance of this multivariate logistic regression model.

6.4 Results

6.4.1 Characteristics of the study population – individuals with neurological conditions

Participants who did not report neurological conditions or complete the optional module on spiritual values were excluded from our analysis. Therefore, the final weighted subsample contained a total number of 4, 562 individuals with neurological conditions who responded to the spiritual values component of the restricted access CCHS-2011. Majority of respondents were females (60.4%), while approximately half were 44 years of age or younger (50.4%), married or in common-law unions (46.5%) and earned less than $20, 000 annually (46.1%). Most people were satisfied with life in general (84.5%), while a little more than one-third had less than secondary education (38.5%). A smaller number of respondents reported spirituality playing an important role is life (38.9) than those for whom it did not play an important role (61.1%). Almost 75% depended on spiritual values for strengths to face everyday difficulties (74.8%), while half of the respondents did not attend religious services ((50.5%). Table 6-1 below shows the demographic features of the study population, including perceived health status and spirituality characteristics. Total number of cases vary due to missing values which were imputed for further analysis.

Table 6- 1 Sociodemographic and other characteristics of study population

Characteristics	Frequency (n)	Percentage (%)
Age categories, years		
≤44 years	2301	50.4
45 to 64	1262	27.7
65 to 79	612	13.4
80 and above	387	8.5
Sex		
Male	1809	39.6
Female	2753	60.4
Marital Status		
single	1555	34.1
Married/common-law	2121	46.5
widowed/separated/divorced	884	19.4
Level of Education		
<secondary	1752	38.5
secondary grad	1051	23.1

post-sec grad	1746	38.4
Personal income		
<=19,999	2055	46.1
20,000-39,999	1278	28.7
40,000-49,999	385	8.6
>=50,000	738	16.6
General Life Satisfaction		
Dissatisfied	689	15.2
Satisfied	3828	84.8
Spiritual values –playing imp role in life		
No	2761	61.1
Yes	1756	38.9
Spiritual values –strength everyday difficulties		
No	1076	25.2
Yes	3196	74.8
Frequency of attendance at religious services		
Not at all	1914	50.5
Regular	980	25.8
irregular	897	23.7
Self-perceived health		
Poor	1281	28.1
Good	1485	32.5
Very good	1796	39.4
Self-perceived mental health		
Poor	569	12.6
good	1417	31.3
Very good	1595	35.2
excellent	949	20.9

6.4.2 Characteristics associated with general life satisfaction among individuals with neurological conditions (univariate analysis)

Table 6-2 reports the unadjusted Odds Ratio (OR) of general life satisfaction by each predictor in our study. Age, sex and marital status were insignificant negative predictors (p = 0.157; 0.078; and 0.112, respectively) of GLS. The unadjusted odds of reporting general life satisfaction decreased with age, with individuals 45-64 being, 0.54 (95%CI = 0.24-1.27) times less likely to report satisfaction with life in general, than those 44 years of age or younger and were 0.42 (95%CI = 0.16-1.10) times lower in the 65-79 age category and 0.44 (95%CI = 0.16-1.21) times lower in the 80+ age category. Females were less likely (OR = 0.82, 95%CI 0.39-

1.74) than males to be satisfied with life in general, while those who were widowed, separated or divorced had the lowest chance (OR = 0.56, 95%CI 0.19-1.64) of reporting satisfaction with life in general while those who were married and in common law relationships were 0.99 (95%CI = 0.39-2.50) times less likely to be satisfied with life in general than those who were single.

Protective predictors of general life satisfaction were education, income, spiritual values-playing an important role is life, spiritual values-strength to face everyday difficulties, frequency of attendance at religious services, self-perceived health and self-perceived mental health. The odds of general life satisfaction increased with levels of education, with the unadjusted odds of satisfaction 1.23 (95%CI = 0.50-3.05) times higher in secondary graduates and 2.50 (95%CI = 1.18-5.32) times higher in post-secondary graduates when compared to those with less than secondary education. Similarly, unadjusted odds of GLS increased with income, with the unadjusted odds of GLS being 9.29 (95%CI = 1.60-53.83) times significantly higher among those with an annual personal income of $50,000 or more.

Those who reported spiritual values-playing an important role in life were 1.05 (95%CI = 0.50-2.20) times more likely to be satisfied with life in general compared to those to whom it was not important, while those who reported spiritual values providing strength for everyday difficulties were 2.18 times more likely to be satisfied with life in general compared to those who did not report spiritual values providing strength for everyday difficulties. The unadjusted odds of general life satisfaction increased with frequency of attendance at religious services, with the unadjusted odds of GLS being 1.65 (95%CI = 0.63-4.28) times higher among those reporting irregular attendance and 2.78 (95%CI = 1.28-6.03) times significantly higher among those attending regularly compared to those who did not attend at all.

In a similar thread, the unadjusted odds of being satisfied with life in general significantly increased with increasing self-perceived health. Those reporting good self-perceived health were 4.02 (95%CI = 1.59-10.17) times more likely to be satisfied than those who reported poor self-perceived health, and those with very good health 22.10 (95%CI = 9.33-52.31) times more likely to be satisfied than those with poor self-perceived health. On the other hand, self-perceived mental health was the strongest significant protective predictor of general life satisfaction, with increasing unadjusted odds of GLS with increased self-perceived mental health. Compared to those who reported poor self-perceived mental health, unadjusted odds of GLS were 7.75 (95%CI = 2.82-21.40) times higher among those reporting good self-perceived health, 16.14(95%CI = 6.28-41.52) times higher among those reporting very good self-perceived health and 21.88 (95%CI = 6.64-72.05) times higher among those reporting excellent self-perceived health.

Table 6- 2 Univariate analysis of predictors of general life satisfaction among individuals with neurological conditions

Characteristics	**OR**	**95% CI**	**p-Value**
Age categories, years			
≤44 years	Reference		
45 to 64	0.54	0.24-1.27	0.157
65 to 79	0.42	0.16-1.10	0.078
80 and above	0.44	0.16-1.21	0.112
Sex			
Male	Reference		
Female	0.82	0.39-1.74	0.605
Marital Status			
Single	Reference		
Married/common-law	0.99	0.39-2.50	0.981
widowed/separated/divorced	0.56	0.19-1.64	0.286
Level of education			
<secondary	Reference		
secondary grad	1.23	0.50-3.05	0.646
post-sec grad	2.50	1.18-5.32	0.018
Personal income			
<=19,999	Reference		
20,000-39,999	1.58	0.73-3.42	0.246
40,000-49,999	3.17	0.97-10.33	0.055
>=50,000	9.29	1.60-53.83	0.015
Spiritual values –playing imp role in life			
No	Reference		Reference
Yes	1.05	0.50-2.20	0.893
Spiritual values –strength everyday difficulties			
No	Reference		Reference
Yes	2.18	0.76-6.29	0.142
Frequency of attendance at religious services			
Not at all	Reference		Reference
Regular	2.78	1.28-6.03	0.010
irregular	1.65	0.63-4.28	0.305
Self-perceived health			
Poor	Reference		Reference
good	4.02	1.59-10.17	0.003
Very good	22.10	9.33-52.31	<0.001

Self-perceived mental health			
poor	Reference		Reference
good	7.75	2.82-21.40	<0.001
Very good	16.14	6.28-41.52	<0.001
excellent	21.88	6.64-72.05	<0.001

6.4.3 Characteristics associated with general life satisfaction among individuals with neurological conditions (multivariate analysis)

All the variables with a (p >0 .20) that were excluded in the initial multivariate logistics regression model building process were included in the final multivariate due to presence of confounding and/or interaction with the primary predictor variables of interest. Our study produced the adjusted odds ratios (AORs), estimates of the relationship between sociodemographic characteristics, self-perceived health (mental and physical), spiritual values and general life satisfaction, among individuals with neurological conditions. Table 6-3 below presents the results of the final multivariate logistic regression model for GLS with adjusted predictor variables.

Table 6- 3 Multivariate analysis of predictors of general life satisfaction among individuals with neurological conditions

Characteristics	AOR	95% CI	p-Value
Age categories, years			
≤44 years	Reference		
45 to 64	0.65	0.22-1.92	0.434
65 to 79	0.37	0.11-1.31	0.122
80 and above	0.39	0.09-1.75	0.217
Sex			
Male	Reference		
Female	0.54	0.22-1.34	0.182
Marital Status			
single	Reference		
Married/common-law	1.94	0.57-6.59	0.287
widowed/separated/divorced	1.29	0.37-4.47	0.687
Level of education			
<secondary	Reference		
secondary grad	0.65	0.22-1.96	0.445
post-sec grad	0.83	0.30-2.30	0.723
Personal income			
<=19,999	Reference		
20,000-39,999	1.07	0.40-2.90	0.883
40,000-49,999	0.88	0.19-4.07	0.875
>=50,000	3.44	0.48-24.61	0.210

Spiritual values –playing imp role in life			
No	Reference		
Yes	0.53	0.18-1.58	0.252
Spiritual values –strength everyday difficulties			
No	Reference		
Yes	4.65	1.13-19.18	0.035
Frequency of attendance at religious services			
Not at all	Reference		
Regular	3.00	1.07-8.42	0.037
irregular	1.42	0.48-4.17	0.528
Self-perceived health			
Poor	Reference		
good	2.62	1.06-6.49	0.037
Very good	8.81	2.65-29.34	<0.001
Self-perceived mental health			
Poor	Reference		
Good	12.02	4.40-32.85	<0.001
Very good	9.82	3.87-24.89	<0.001
excellent	17.30	5.17-57.93	<0.001

Our study found that there were negative insignificant associations between GLS and age, sex, education, annual personal income of $40,000-$49,000, and spiritual values playing important role in life. The association between age and GLS was decreased in those aged 45+, compared to those 44years of age or below, with the 65-79 age category demonstrating 0.37 (95%CI = 0.11-1.31) times less adjusted odds of reporting GLS, while the 80+ age category was 0.39 (95%CI = 0.09-1.75) times less likely to report GLS, and those 45-64, 0.65 (95%CI = 0.22-1.92) times less likely to report GLS. Females reported 0.54 (95%CI = 0.22-1.34) times lower odds of GLS compared to males.

The adjusted odds of reporting satisfaction with life in general was 0.83 (95%CI = 0.30-2.30) times lower with the highest level of education, post-secondary education and 0.65 (95%CI = 0.22-1.96) times lower with secondary education when compared to less than secondary education. Earning an annual income of $40,000-$49,000 was associated with 0.88 (95%CI = 0.19-4.07) times lower adjusted odds of GLS when compared to those who earned less than $19,999 personal income annually. On the other hand, earning $20,000-$39,000 was associated with 1.07 (95%CI = 0.40-2.90) times higher adjusted odds of GLS, while earning $50,000 or more in personal income annually was associated with 3.44 (95%CI = 0.48-24.61) higher adjusted odds of GLS. When contrasted with the opposite group, those who found spiritual values playing important role in life reported a 0.53 (95%CI = 0.18-1.58) times lower adjusted odds of GLS.

We found spiritual values providing strength to face everyday difficulties, regular attendance at religious services and self-perceived physical and mental health to be significant protective predictors of GLS. Those who used spiritual strength to face everyday difficulties reported a 4.65 (95%CI = 1.13-19.18) times significantly higher adjusted odds of GLS, when compared to those who did not. When compared to those who did not attend religious services at all, the adjusted odds of GLS were 1.42 (95%CI = 0.48-4.17) times higher in those who attended irregularly and 3.00 (95%CI = 1.07-8.42) times significantly higher in those who attended religious services regularly.

The adjusted odds of GLS were significantly higher with increased ratings of self-perceived health. When compared to poor self-perceived health, the adjusted odds of GLS were 2.62 (95%CI = 1.06-6.49) times higher with good health and 8.81 (95%CI = 2.65-29.34) times higher with very good health. At the same time, when compared to poor self-perceived mental health, the adjusted odds of GLS were 9.82 (95%CI = 3.87-24.89) times higher with very good self-perceived mental health, 12.02 (95%CI = 4.40-32.85) times higher with good self-perceived health and 17.30 (95%CI = 5.17-57.93) times higher with excellent self-perceived health.

6.5 Discussion

Our study demonstrates that spirituality and religiosity, as well as self-perceived health and self-perceived mental health were significantly associated with GLS while spiritual values playing important role in life was associated with lower odds of GLS. Additionally, marital status and incomes greater than $50,000 and between $20,000 - $39,999 demonstrated insignificant positive associations with satisfaction with life in general. On the other hand, age, sex (female), income levels between $40,000-$49,000 and education also demonstrated negative associations with GLS, although these associations were not significant.

Our findings on the protective associations between elements of spirituality and GLS, support that of an earlier study which examined the impact of spirituality on life satisfaction among patients with cancer and spinal cord injury (34). That study found that life satisfaction was influenced by one's spiritual well-being and was more closely related to inner experiences than physical restrictions (34). In another study that sought to determine if spirituality facilitates resilience and adjustments of individuals after spinal cord injury, the authors describe spirituality as not necessarily related to religiosity and encompasses the ability to rise above life's circumstances (41). Our study supports this concept, providing evidence that spiritual values-strength to face everyday difficulties was strongly correlated with GLS in those with neurological conditions. Furthermore, similar to the findings of another Canadian study (37), spiritual values as important to everyday life on its own was not a protective predictor of GLS, suggesting that it is the meaning to life and the coping mechanism and resilience (42-44) provided through the spiritual source of strength (45) that makes the difference in GLS for those with chronic illnesses, including neurological conditions.

Despite not examining support networks, social contacts and social studies in relation to spirituality in this study, we discuss our findings according to that found in other studies. We theorize that the strong positive association between regular attendance at religious services and GLS in our study is similar to the positive association between life satisfaction and the amount and quality of social interactions found in quality of life studies on cancer patients (46-48). This association between GLS and regular attendance at religious services may be explained by regular positive social interactions with individuals who share similar beliefs. One study focusing on older adults found positive associations between the employment of religious coping skills and religious support and greater life satisfaction (49). Other much earlier studies on impairments, disability and spinal cord injury support our theory; reporting greater life satisfaction in those who make deliberate attempts at maintaining customary social connections, have more involvement in general life activities and greater capacity to navigate their surroundings (50-52). On the other hand, regular church attendance, an element of religiosity (53) may be an outward expression of the depth of one's spirituality (54) or relationship with a Supreme being (55), further supporting our finding that frequency of religious attendance, as an element of spirituality in itself, is positively correlated with GLS. Overall, spiritual coping, i.e., spiritual values-strength for everyday difficulties, has a distinctive role in promoting GLS among those with neurological conditions (18).

Our finding that self-perceived physical and mental health are protective predictors of GLS is well established in several studies (56- 59). Increasing ratings of self-reported general and mental health being strongly correlated with life satisfaction in patients with neurological conditions is supported in other studies of patients with chronic musculoskeletal pain (58) and other chronic conditions (60, 61). These associations can be explained by the impact of physical and mental problems connected to neurological conditions on self-perceived ratings of general and mental health (62). Those with neurological conditions may have lower self-perceived general and mental health, when their conditions compromise their physical and mental functionality, leading to decreased life satisfaction (63). The converse may be true, that when they feel better about their physical and mental health, those with neurological conditions are more satisfied with life in general.

Social integration, social roles and their importance to health status and quality of life have been emphasized in different studies and point to the need for consistent social ties, companionship, intimacy and support for well-being and life functioning (64, 65). Respondents with neurological conditions, who were in marriage and common-law relationships, were found in our study to be more likely to be satisfied with life in general than those who had never been married and those who were single due to being widowed, divorced or separated. This finding reported in other studies (34 & 58), is likely explained by the benefits of social integration, one of which is having a proximate adult to depend on when coping with chronic conditions (66).

We found that highest levels of income ($50,000 or more) demonstrated a positive correlation with GLS, providing supportive evidence for previous studies (57, 67-70). To the contrary, lower levels of income ($40,000 to $49,000) demonstrating a negative association with GLS is possibly due to decreased ability to afford medications (71). On the other hand, increasing age for the participants in our study, could mean greater disability associated with neurological conditions and may be synonymous to the disintegration of life, including loss of independence and participation in social activities (72, 73), explaining the negative association between older age categories and GLS.

Higher levels of education negatively associated with GLS adds to the conflicting literature on this matter (58, 74, 75). The subjectivity of life satisfaction as a measure of one's own quality of life as well as the different measures of life satisfaction employed in other studies may explain the contradictory relationship between education and GLS. Additionally, education is known to improve one's chances of better health, earning potential and career possibilities (76). The loss of these abilities due to the debilitating effects of neurological conditions may lead to a lowered estimation of GLS among those with higher levels of education in this study. We propose that higher levels of education associated with decreasing GLS found in our study may be linked to the ability to hold a job which is a common psychosocial difficulty among individuals with neurological conditions (77, 78). Nonetheless, the role of education in life satisfaction is not broadly investigated and not well understood (79, 80).

6.5.1 Strengths and limitations of the current study

The major strength of our study is that it adds to the literature on life satisfaction and neurological conditions, reporting positive findings consistent with spirituality, self-perceived general and mental health and other predictors of life satisfaction. There are several limitations: the small sample size from this cross-sectional study hinders the representativeness of our sample and limits causality and determination of the directionality of the predictors and life satisfaction; exclusion of participants living in institutions, and the inability to rule out a possible selection bias of individuals who were functionally capable of responding the questionnaires (81) may reduce the generalizability of our study.

6.6 Conclusion

Our findings provide added evidence that spiritual coping (spiritual values-strength for everyday difficulties) and regular attendance at religious services, self-perceived health and self-perceived mental health are protective predictors of general life satisfaction, a subjective measure of one's quality of life. Individuals with neurological conditions to whom it may be relevant, would benefit, in alignment with their personal beliefs, from the employment of spiritual and religious resources that have been linked with better management of chronic conditions, for improved quality of life. More research is needed on the severity of disease of specific neurological conditions and specific psychosocial factors of general life satisfaction (e.g., social support and social interaction) among the highly educated within older age categories and accounting for sex difference.

6.7 References

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CHAPTER 7: CONCLUSION, PRACTICAL IMPLICATIONS AND FUTURE RESEARCH

The Canadian National Population Health Study of Neurological Conditions present a grave picture of the burden of the neurological conditions examined in this study, indicating that the burden is indeed high and will get higher as the Canadian population ages (1). Most neurological conditions are accompanied by severe symptoms that affect the quality of life of patients especially as diseases progress and with age (2). Some of the neurological conditions in this study (PD, MS, epilepsy, stroke effects, migraine) are associated with higher prevalence and huge costs in developed countries (3). This along with the fact that the global DALYs associated with neurological conditions is on the increase and is attributable to the aging population (4-6), presents a significant economic burden to a country like Canada whose older population is rapidly growing and whose health system is supported by the public purse. To ensure equities in service across the continuum of care, major investments are required to equip the health system to meet the needs of the increasing population of people with neurological conditions.

There is a dire shortage of health care workers in general, with gaps in training for care of the elderly (7, 8). Furthermore, high-income countries including Canada, report shortages of neurologists. As the population ages and people live longer with PD, AD/dementia and other neurological conditions, the challenge of access to relevant and quality care will likely worsen (9). The increasing prevalence of neurological conditions with reduced incidence year over year as is reported in some high-income countries, will be hard to navigate with a shortage of neurologists who may not have experience in diagnosing common conditions such as PD and AD/dementia (10). The long wait times for initial diagnostic consultations compounds the problem of misdiagnosis before the more progressive states of disease (11). In light of the increasing prevalence, larger numbers of people 65+ living in the population at risk of the debilitating effects of neurological conditions, a major consideration in health systems planning in Canada is equitable access to care. In fact, common care inequalities that have been reported among those with neurological conditions in high-income countries include: poor access to and long waits to see neurologists and other specialists including therapists, and mental health and social care support workers (12).

The Canadian's health care system is designed to provide acute care in a rapidly changing clinical environment (13). These acute health care settings can be difficult for people with NC to navigate as the pace of care can aggravate symptoms associated with NC. For example, in AD/dementia, increasing disorientation and confusion (14), may lead to health care providers overlooking and exacerbating psychosocial needs. (15). The multiple psychosocial difficulties and unmet needs associated with NC impact health care utilization, and quality of life including self-reported health. As the impacts of NC is not confined to patients and their families, but extend to the broader communities and the health system, managing NC amidst the aging population is a public health concern. The common function of public health systems is to prevent disease and promote health (16). The Canadian health system operates on the universal health care model, 70% of which is funded by tax-payers' resources (17). These resources are limited in view of the responsibilities to the population in fulfilling the core functions of public health: policy development and program evaluation, health human resource planning, public education and awareness, exploring health risks and conducting research, tracking health status, community engagement, linking patients to health services and operating within laws and regulations (16). Given that almost ¾ of health spending comes from the public purse, the rising prevalence of NC and attendant psychosocial difficulties, in the midst of a growing older population, will result in a greater strain on the government's budget (18) as well as higher out of pocket expenses for neurological patients.

Population-based research on neurological conditions is vital to ensure that public health policy and planning of programs are informed by current information on risk factors, trends, and quality of life indicators of positive patient outcomes. These principles are embedded in this thesis which examines several areas of neurological conditions research, with studies focusing on select conditions, either independently or collectively. The first objective was to understand the relationship between an established risk factor, toxic occupational exposures (electromagnetic fields, metals and pesticides), and the development of Parkinson's disease. The second identified trends in Alzheimer's disease/dementia prevalence by age, gender, education and geographic regions while the third assessed the relationship between self-reported unmet care needs and other predictors of satisfaction with general health care, physician, and hospital services among Canadians with an assortment of neurological conditions. Finally, the effects of sociodemographic factors, physical and mental health and spirituality on general life satisfaction were examined among Canadians with a mixture of neurological conditions. The relevance of the findings to public health policy, planning and decision-making for the improved quality of life of this vulnerable population within Canada is discussed in this chapter.

7.1 Summary of Major Findings

In chapter 3 of this thesis, we performed a review and meta-analysis of the existing literature to examine the relationship between specific toxic occupational exposures (which have been previously identified as environmental risk factors) and the development of PD. Earlier studies present evidence of a definite association between pesticide exposure and PD and conflicting associations between exposure to electromagnetic fields and metals and PD development. However, most of those studies employed cross-sectional designs or did not discriminate between those designs and longitudinal cohort designs. The interpretation of causality for those studies is therefore, limited. In this study, our main goals were to ascertain the risk of PD attributable to overall toxic occupational exposures, and electromagnetic, metal and pesticide exposures and understand the relationship between toxic occupational exposures and PD by diagnostic methods. The study focused on longitudinal cohort designs which are more advantageous in determining relative risk.

Twenty-four articles met our inclusion criteria. However, as some studies identified more than one exposure of interest included in our study, a total of 35 studies were included in our analysis. The pooled RR between any type of toxic occupational exposure and PD was 1.15 (95% CI 1.06-1.24). For the individual types of toxic occupational exposures and their associations with PD, the RRs were: electromagnetic exposure, 1.03 (95% CI 0.91-1.16); metal exposure, 1.07 (95% CI 0.92-1.24); and pesticide exposure,1.41 (95% CI 1.06-1.65). The pooled RRs for the relationship between toxic occupational exposures and PD by method of diagnoses were: confirmation by neurologist or nurse, 2.17 (95% CI 1.32-3.54); medical records, 1.06 (95% CI 0.92-1.21), and ICD codes, 1.14 (95% CI 1.03-1.26).

Our systematic review and meta-analysis provide solid evidence to support the hypothesis that toxic occupational exposures as a whole is a major environmental risk factor for

PD. This is the first study to our knowledge that demonstrates associations between toxic occupational exposures by method of PD diagnosis. It demonstrates that the strongest association between any toxic occupational exposure and PD was that confirmed by a neurologist or nurse. It is clear that using a reliable standardized approach by a specialist is important for the accurate confirmation of PD and establishing accurate estimates of risk of PD through toxic occupational exposures. The evidence provided by this review supports the need for public health strategies and prevention programs aimed at reducing the risk of PD and a targeted approach to ensuring protection against environmental exposure to occupational toxins.

Chapter 4 of this thesis provides nationally representative community-based prevalence estimates of Alzheimer's disease/dementia by sociodemographic factors (age, sex, education and region of residence) of Canadians over a twenty-year period (1994-2014). Given the projected impacts of an aging Canadian population and the economic and psychosocial burden on AD/dementia patients, their caregivers, and the health system in general, increasing prevalence of AD/dementia is a major concern worldwide. Accurate and updated estimates of these progressively severe conditions are required for effective health care systems planning, and policy decisions. There is a dearth of research on Alzheimer's/dementia trends using Canadian data. We used the NPHS biannual components and the CCHS annual components to identify changes in overall AD/dementia prevalence over a period of twenty years, and to examine differences in prevalence estimates among individuals age 45+, according to their sex, levels of education and regions of residence on Canada.

The prevalence of AD/dementia, standardized by age and sex to the 2001 Canadian population census, increased with age in both men and women across all age categories but increased significantly after age 80 and over time. There was a greater increase in prevalence among men than women. The standardized (2001 Canadian population census) prevalence of AD/dementia among Canadians 45 years or older was 0.14% in 1994 and 0.80% in 2014, an overall 0.66 percentage point increase in AD/dementia between 1994-2014. There was a 0.83% increase in prevalence of AD/dementia among the 65-79 age groups and a 4.29 % increase among those 80+ years of age. We did not observe a significant geographic difference in prevalence of AD/dementia over the years, while lower increases in prevalence were recorded among Canadians with higher levels of educational attainment.

Consistent with other prevalence studies on Alzheimer's disease/dementia conducted in developed countries, this study provides evidence of an increase in prevalence of AD/dementia. This increase appeared to be across all strata in the community in Canada, and mostly among men aged 65 or older, and those with lower levels of educational attainment. Our findings underscore the need for health system capacity strengthening and preparation for increasing challenges associated with long-term care of AD/dementia including rising costs, caregiver burden and increased demand for neurologists' services. As well, prevention strategies that focus on minimizing risk (behavior modification programs, reduced exposure to environmental factors) and enhancing protection (higher levels of education, positive social interaction) are required.

In chapter 5, we conducted multivariate logistic regression modelling to explore unmet health care needs and other predictors of patient satisfaction with general health care services, hospital and physician services among Canadians with neurological conditions. A serious concern of patients with neurological conditions is the psychosocial difficulties that they navigate especially for those with progressive long term conditions. They may not always have equal or easy access to the care that they need. Patient satisfaction has been used as a measure of health care utilization and has been associated with health-related quality of life. An understanding of the relationship between unmet health care needs and patient satisfaction with health services among older Canadians with neurological conditions is crucial in the ongoing evaluation and resulting continuous quality improvement of healthcare services available for this portion of the population dealing with debilitating effects of their conditions. We developed a research model of health care utilization based on Andersen's health behavior model to predict patient satisfaction with the three types of health services.

We found that significant protective predictors of patient satisfaction with health care services in general are quality and availability of provincial and received care, and being very satisfied with life in general. Quality of care was strongly and positively associated with patient satisfaction across all health services. In contrast, the common significant negative predictor of patient satisfaction across all health care services was self-perceived unmet health care needs in this study. People with neurological conditions, because of their attendant disabilities, are known to report unmet health care needs and experience barriers to care, limiting their quality of life. Our study emphasizes the importance of ensuring available and accessible quality care and the increased need for coordinated services that improve patient satisfaction, better health outcomes, and the health-related quality of life for Canadians with neurological conditions.

Finally, chapter 6 of this thesis examined the association between spirituality/religiosity and general life satisfaction among Canadians with neurological conditions from the 2011 Canadian Community Health Survey (CCHS). Spirituality has been reported in multiple studies to be associated with better physical health outcomes, but not many studies have examined the link between spirituality and quality of life domains such as satisfaction with life in general among a group of people living with select neurological conditions. Our objective in this study was to explore the sociodemographic factors and select measures of spirituality/religiosity (spiritual values-playing important role in life; spiritual values –strength everyday difficulties; and frequency of attendance at religious services) as predictors of general life satisfaction (subjective self-judgment of quality of life) among Canadians with neurological conditions.

We found spiritual values providing strength to face everyday difficulties, regular attendance at religious services and self-perceived physical and mental health to be significant protective predictors of satisfaction with life in general. Of particular interest, was the finding that, when compared to those who did not, those who used spiritual strength to face everyday difficulties were 4.65 (95%CI = 1.13-19.18) times more likely to be satisfied with life in general, while those who attended religious services regularly were 3.00 (95%CI = 1.07-8.42) times more likely to be satisfied with life in general than those who did not attend religious services at all. In terms of health status, the odds of satisfaction with life in general were significantly higher with increased ratings of self-perceived health and mental health. Socio-demographic variables were not significant predictors of general life satisfaction, though being married was associated with greater odd of satisfaction with life in general, and surprisingly higher levels of education were associated with lowered odds of general life satisfaction among those with neurological conditions in the community in Canada.

Our findings provide additional evidence that spiritual coping (spiritual values-strength for everyday difficulties) and regular attendance at religious services, self-perceived health and self-perceived mental health are associated with general life satisfaction, a subjective measure of one’s quality of life. Given Canada’s diverse population with multiple religious’ persuasions and concepts of spirituality, it is fitting, where relevant to patients' personal beliefs, to incorporate spiritual and religious resources that have been linked to positive health outcomes in managing the care of those with neurological conditions.

7.2 Practical Implications and Future Research

The findings of our study have important implications for public health prevention strategies and health services planning. The risk factors, trends, and predictors of domains of quality of life among those with neurological conditions confirmed in our study indicate the need for continued dialogue and research in preparation for the projected growth and shift in the age structure to more people in the 65+ age category in the Canadian population by 2031. The significant associations between toxic occupational exposures and Parkinson's disease, found in our systematic review indicate the necessity for public campaigns regarding protection against occupational environmental risk factors such as electromagnetic fields, metals and more importantly, exposures to pesticides. Also, the significant association between diagnosis of PD using standardized methods by a neurologist or nurse and toxic occupational exposures underscores the need for standard education of neurologists and other specialists on the diagnostic methods of the condition.

Rising prevalence of AD/dementia in the community suggests the need for targeted population-based public health prevention and promotion programs as well as health systems planning for long-term care due to the progressive nature of the disease. As more males are living with AD/dementia than females in the community, it's important that while population-based secondary prevention programs, that focus on their psychosocial needs and providing adequate access to resources, are being developed, some attention is paid to the needs of men that may differ from those of women.

Though this thesis does not itemize specific unmet health care needs reported by those with NC, its strong negative association with patient satisfaction is cause for concern. There is some indication from our study findings that receiving services at the ER reduces patient satisfaction. As the availability and quality care are predictors of patient satisfaction, which is correlated with positive health outcomes, the design of health services that promote the concept of a circle of care, that ensures relevant services that meet patients' needs, becomes a necessary addition to the continuum of care for improved quality of life for patients with neurological conditions.

Life satisfaction as a subjective indicator of quality of life is predicted by higher levels of self-perceived physical and mental health and spiritual values, demonstrated in strength to cope with difficulties and regular attendance at religious services in our study. These findings highlight the need for public health interventions that assume a multipronged approach that focuses on alleviating psychosocial difficulties and helping to create a positive outlook in those struggling with neurological conditions. This means that policies are needed to govern accommodation of religious practices and the incorporation of spiritual needs in aspects of care provided to neurological patients.

The increase in the number of people affected by neurological conditions signifies the need for increased resources targeted to effective management that promotes quality of life. Understanding the prevalence of neurological conditions allows for prioritizing financial resources to support health services and also facilitates human resource planning. For, e.g. knowing the challenges to and the predictors of domains of quality of life among those with neurological conditions allows for planning and coordinating health and social services that are common to neurological conditions that are easily accessible. Apart from the viewpoints on public health interventions outlined throughout this thesis, we propose the following approaches to combat challenges associated with neurological conditions and to facilitate improved quality of life among those living with the conditions:

(1) General prevention efforts targeted to those in occupations that expose them to occupational chemicals or toxins. The promotion and regulation of safe use of toxic substances may include: substitution of toxic materials with less hazardous substances, educating professionals on wearing personal protective equipment and safe handling and disposal of toxins, ensuring proper ventilation and respiratory protection when working with harmful environmental toxins.
(2) Population health promotion efforts that encourage healthy lifestyles and social habits and prevention of risky recreational activities. Public awareness campaigns and

educational programs aimed at reducing diabetes mellitus, obesity, cardiovascular disease, hypertension, hypercholesterolemia, depression, alcohol abuse and smoking need to be strengthened. Health promotion programs that focus on building cognitive reserve and mental capacity, increasing physical activity and exercise, encouraging mindfulness and optimism, spiritual and wellness activities, social engagement including attendance at religious services where applicable and healthy nutritional choices, are recommended.

(3) Secondary prevention and health system design that ensure adequate access and quality of care that meet the holistic needs of people living with neurological conditions. This includes building capacity by deploying human resources to increase access to specialist services especially in rural areas. This may involve a wider study of the geographical pockets impacted by long wait times for initial diagnosis. Strengthening the capacity of the health system to adopt a coordinated approach to care that ensures psychosocial difficulties and caregiver burden are addressed and that sustainable long-term care is in place for those individuals whose conditions have so far progressed that they are unable to continue to live in the community. Given the shortage of neurologists and movement disorder specialists, an integrated model of care is necessary for managing neurological conditions. This involves improving self-management by intentional education and facilitation of patient and caregiver involvement in management of their condition; the coordinated provision of care including timely referrals to specialists, therapists and social care workers.

In order to ensure that these recommendations are informed by best practices and will meet the needs of the population, future neurological conditions research is important. There is limited epidemiological research on neurological conditions as a group in Canada. More research is needed on the common modifiable risk factors for varying neurological conditions, so that effective population-based prevention efforts can be established. Trend studies that utilize a longitudinal design to estimate incidence and prevalence of neurological conditions in the Canadian population and within health regions are also needed to help with human health resource planning and designing health services that are accessible along the continuum/circle of care for those with NC.

Including individuals in institutions and identifying specific unmet health care needs and their associations with specific elements of care provided throughout disease progression will be helpful to the further strengthening of the health system's capacity to adequately care for the NC population. As well, understanding the role that severity of disease plays in quality of life is key to understanding unmet health care needs of patients with NC. Performing studies with larger sample sizes and that include a comparison between patients with neurological conditions and those without are important for enhancing generalizability of findings on quality of life domains.

7.3 Conclusion

The key messages from this research are summarized as follows:

(1) Toxic occupational exposures, particularly, pesticide exposures are strongly associated with the development of PD. Standardized methods of PD diagnosis by a neurologist or nurse is important in establishing the relationship between exposures and PD outcomes.

(2) Community-based prevalence of AD/dementia is on the increase across all strata of the society, with more men than women living with the condition in the community.

(3) Unmet health care needs significantly reduce patient satisfaction with general health care services, hospital and physician services. While emergency care received at the hospital decreased the odds of patient satisfaction, there was no significant difference in patient satisfaction between primary care physician and specialist care among those with neurological conditions. Availability of provincial care is important to patient satisfaction with hospital services but not with physician services. Not surprisingly, the quality of care received across health services predicts the level of neurological patients' satisfaction with health care.

(4) General life satisfaction, a subjective measure of one's quality of life is positively predicted by spiritual coping (spiritual values-strength for everyday difficulties) and regular attendance at religious services, self-perceived health and self-perceived mental health.

In light of these findings, the final take-away messages for the Canadian public health system are (1) a population-based approach is needed in strengthening health promotion and primary prevention of neurological conditions, and (2) a coordinated holistic system of care is needed to ensure enhanced quality of life among patients with neurological conditions.

The completion of this thesis was made possible by the services of the SKY-RDC provided through the Canadian Data Research Network Centres of Statistics Canada. We appreciate this service and the data that it allows researchers to access to contribute to knowledge translation. However, we have included recommendations for improvement of the content of the annual surveys and access of the data to researchers.

One limitation of the CCHS data was that it did not include information on the institutional population and people living in certain remote areas. We were not able to generalize our findings to the entire Canadian population. As a result, we recommend to Statistics Canada that surveys that include rural, remote and institutional populations be conducted on occasion. This is important to further the knowledge acquired through studies similar to this thesis, that examines quality of life measures for older Canadians with neurodegenerative chronic conditions.

In addition, researchers' access to data and progression of their work may be hindered by the need to be physically present to utilize the services of a Data Research Network Centre. As such, we recommend utilization of existing technology to augment the security of remote access to data as a more flexible approach to researchers.

7.4 References

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