NeuroToxicology 61 (2017) 2–10

Contents lists available at ScienceDirect

NeuroToxicology

Full length article

Burden of neurological conditions in Canada

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ARTICLE INFO

Article history:
Received 2 May 2016
Accepted 2 May 2016
Available online 3 May 2016

Keywords:
Neurological conditions
Disease burden
Prevalence
Incidence
Systematic review
Onset
Progression
Risk factors

ABSTRACT

Neurological conditions are among the leading causes of disability in the Canadian population and are associated with a large public health burden. An increase in life expectancy and a declining birth rate has resulted in an aging Canadian population, and the proportion of age-adjusted mortality due to non-communicable diseases has been steadily increasing. These conditions are frequently associated with chronic disability and an increasing burden of care for patients, their families and caregivers. The National Population Health Study of Neurological Conditions (NPHSNC) aims to improve knowledge about neurological conditions and their impacts on individuals, their families, caregivers and health care system. The Systematic Review of Determinants of Neurological Conditions, a specific objective within the NPHSNC, is a compendium of systematic reviews on risk factors affecting onset and progression of the following 14 priority neurological conditions: Alzheimer's disease (AD), amyotrophic lateral sclerosis (ALS), brain tumours (BT), cerebral palsy (CP), dystonia, epilepsy, Huntington's disease (HD), hydrocephalus, multiple sclerosis (MS), muscular dystrophies (MD), neurotrauma, Parkinson's disease (PD), spina bifida (SB), and Tourette's syndrome (TS). The burden of neurological disease is expected to increase as the population ages, and this trend is presented in greater detail for Alzheimer's and Parkinson's disease because the incidence of these two common neurological diseases increases significantly with age over 65 years. This article provides an overview of burden of neurological diseases in Canada to set the stage for the in-depth systematic reviews of the 14 priority neurological conditions presented in subsequent articles in this issue.

1. Introduction

Aging of the Canadian population has resulted from an increase in life expectancy and fertility rates below replacement level for the last forty years (Statistics Canada, 2016). The majority of deaths are due to non-communicable diseases and are frequently preceded by a period of chronic disability and an increasing burden of care for patients, their families and caregivers. Neurological conditions are among the leading causes of disability in the Canadian population, and are associated with a large public health burden because many have no cure and worsen over time (Tator et al., 2007). The burden of neurological disease is expected to increase as the population ages because the incidence of two common neurological diseases – Alzheimer's and Parkinson's – increases significantly with age (PHAC, 2014b). Symptoms such as weakened muscles, low coordination and altered cognitive functions can result in reduced physical function and activity limitations. This population health burden, as well as the need for increased informal caregiving, will have significant economic consequences for individuals, caregivers, and the health care system. It was estimated that eleven common neurological disorders cost close to $9 billion a year in Canada in 2007 (Tator et al., 2007), with a subset of six conditions accounting for over 500,000 lost years of healthy life (10.6% of total disability adjusted life-years, or DALYs, for illness in Canada). Cognizant of this growing concern, the National Population Health Study of Neurological Conditions (NPHSNC), representing a $15 million investment over four years by the Government of Canada was initiated (PHAC, 2012).

The NPHSNC constitutes the first comprehensive assessment of neurological disorders in Canada, funded through the Public Health Agency of Canada (PHAC) in collaboration with

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http://dx.doi.org/10.1016/j.neuro.2016.05.001
0161-813X/

Neurological Health Charities Canada and the Canadian Institutes of Health Research (CIHR). The study NPHSNC aims to improve knowledge about neurological conditions and their impacts on individuals, their families, caregivers and health care system. Specific objectives of the study of neurological disorders include: characterizing the scope of these neurological conditions, in terms of incidence, prevalence, and co-morbidities); identifying risk factors for development and progression of these conditions; documenting the use of health services related to these conditions and recommended improvements; evaluating the current burden and projected burden of these neurological conditions over the next 20 years using economic and health-related quality of life measures.

The Systematic Review of Determinants of Neurological Conditions, a specific objective within the NPHSNC, is a compendium of systematic reviews on risk factors affecting onset and progression of the following 14 priority neurological conditions: Alzheimer's disease (AD), amyotrophic lateral sclerosis (ALS), brain tumours (BT), cerebral palsy (CP), dystonia, epilepsy, Huntington's disease (HD), hydrocephalus, multiple sclerosis (MS), muscular dystrophies (MD), neurotrauma, Parkinson's disease (PD), spina bifida (SB), and Tourette's syndrome (TS). The results of this systematic review will be of interest to a broad audience, ranging from caregivers to those shaping public health policy to mitigate the burden of neurological disease in Canada.

The general methodology employed in this study is described by Hersi and colleagues (Hersi et al., 2017). The systematic reviews serve to summarize the current state of knowledge regarding the determinants associated with the onset and progression for the priority neurological conditions. The article by Little and colleagues (Little et al., 2017) synthesizes currently available information on genetic variations associated with the onset and progression of the 14 conditions, which are heterogeneous in terms of their frequency, age of onset, etiology and progression. The final article by Krewski and colleagues (Krewski et al., 2017), summarizes the results of the 14 systematic reviews and strength of evidence for the risk factors associated with the onset and progression of neurological disease.

As depicted in Fig. 1, systematic reviews of the factors affecting onset and progression of above mentioned neurological conditions (NCs) were completed by relying first on existing systematic review judged to be of adequate quality. In the absence of any existing review (such as for ALS), *de novo* systematic reviews were conducted following the systematic review protocol developed at the initiation of the project. For some conditions such as Alzheimer's disease, where the scientific literature was particularly voluminous, the original systematic reviews protocols were streamlined through team discussions involving the five participating centres. For further details on methodology please refer to Hersi et al. (2017).

The working group (WG) on systematic reviews of NCs comprised of the following individuals from the five centers:

- University of Ottawa (lead centre): Daniel Krewski (PI), Julian Little (Co-PI), James Gomes (Co-PI), Neil Cashman (Co-PI), Nicholas J. Birkett (Co-PI), Shalu Darshan, Janet Gaskin, Mona Hersi, Pauline Quach, Ming-Dong Wang, Lindsey Sikora, Brittany Irvine, Reem El Sheriff, Pallavi Gupta, Mohamed K. Taher and Nawal Farhat.
- University of Toronto: Caroline Barakat-Haddad (Co-PI), Rosemary Martino (Co-PI), Pascal van Leishout (Co-PI), Sabina Chin, Hamilton Candundo, James Crispo, Samantha Lewis.
- University of Calgary: Tamara Pringsheim (Co-PI), Jin Hu, Ting-Kuang Chao, Ruksana Rashid, Wing Hoi Poon.
- University of British Columbia: Helen Tremlett (Co-PI), Kyla McKay, Tom Duggan, Shayesteh Jahanfar, Stacey Tkachuk.
- Newfoundland and Labrador Centre for Health Information: Don MacDonald (Co-PI), Jennifer Donnan, Stephanie Walsh, Yannick

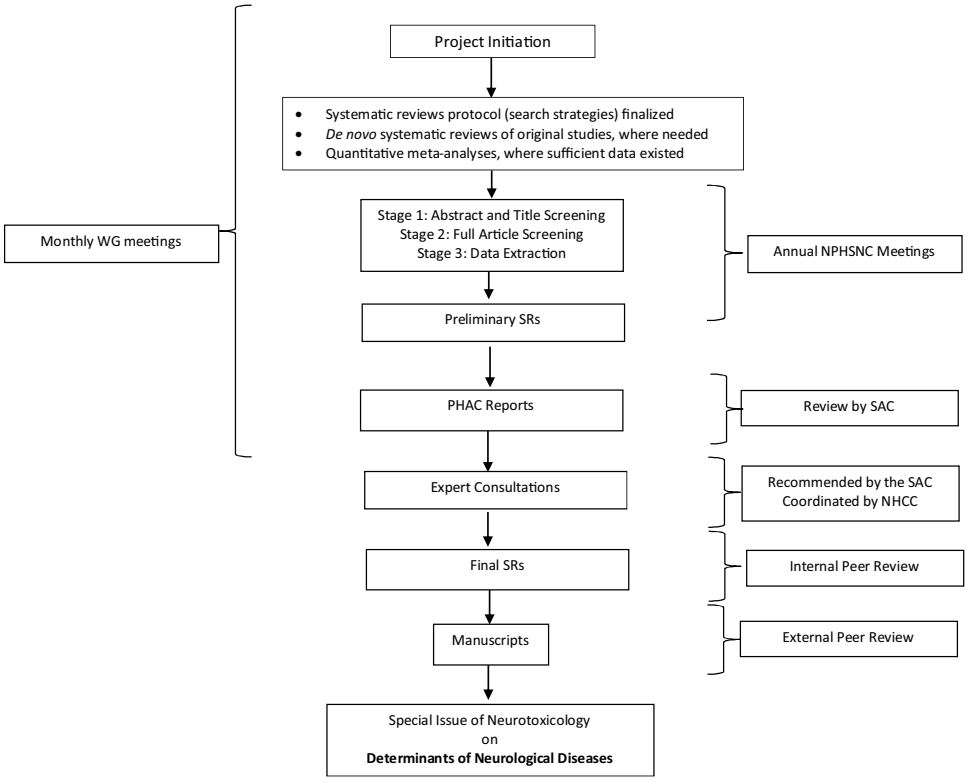

Fig. 1. Work flow diagram for the conduct of systematic reviews of factors affecting the onset and progression of neurological conditions in Canada.