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The financial burden of prescription drugs for neurological conditions in Canada: Results from the National Population Health Study of Neurological Conditions

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ABSTRACT

This paper describes the current situation in Canada concerning the availability and use of prescription drugs for neurological conditions. We conducted semi-structured qualitative interviews with health care providers, administrators, community organization representatives, opinion leaders and policy makers. The analysis revealed three primary themes related to the availability of and access to prescription drugs to treat neurological conditions. First, we learned that across Canada there is significant vulnerability and a need for advocacy on behalf of people living with these conditions. Second, we learned that the heightened level of vulnerability and need for advocacy stems in part from the significant differences in the drug coverage available in the different provinces and territories. As a result, there are significant inequities across Canada. Third, we determined that the existing situation is also due to the current approach to health governance (i.e., accountability, transparency). Our study provides evidence for the urgent need for a formal discourse on national pharmacare in Canada, with representatives of neurological conditions having a voice at the table.

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1. Introduction

Across the globe, neurological conditions are an increasingly growing public health concern. As of 2006, an estimated one billion people were affected worldwide with neurological conditions [1]. In Canada, it is estimated that 3.6 million persons living in the community and 170,000 persons in long-term care facilities are affected by neurological conditions [2]. As non-communicable diseases, neurological conditions encompass a wide array of conditions and disorders with onset at any stage of life. The effects may be physical, mental/cognitive and/or behavioural, often resulting in significant disability, morbidity and mortality [1]. According to the World Health Organization, neurological conditions contributed 6.3% to the global burden of disease as measured by disability-adjusted life years in 2005; higher than HIV/AIDS, cancer, ischemic heart disease and respiratory conditions [1]. Given the shift with an aging population, the incidence of neurological conditions associated with aging (e.g., Alzheimer's disease and other dementias, Parkinson's disease) is expected to increase [3]. Furthermore, the direct and indirect costs to society as a result of neurological conditions are substantial and projected to increase [1,4].

The direct costs for prescription drugs are significant and rising [5], especially for neurological conditions such as multiple sclerosis and epilepsy [6]. Over the past decade, prescription drug costs have grown at a faster rate than hospital or physician-related expenditures [7]. Globally, the trend for higher prescription drug costs are concerning [5], particularly for countries that pay higher per capita spending on prescription drugs such as the United States, Canada, Japan and Germany [8]. In the United States, per capita spending has increased by 20% from 2013 to 2015 [9], resulting in higher payments among patients despite coverage through public or private plans (employer-sponsored or individual-based) [10]. Importantly, these higher payments may negatively impact access to prescription drugs necessary for treating the conditions, and result in sub-optimal health outcomes [9,11].

Given the global health burden for neurological conditions and increasing costs for prescription drugs [5,6], it is important to understand the impact of drug coverage such as the availability and use of prescription drugs for persons living with neurological conditions. Several neurological conditions present symptoms during young to mid adulthood (e.g., epilepsy, multiple sclerosis), and may negatively impact employment opportunities [1]. Private plans are often employment-sponsored [5] thus posing challenges for persons to obtain insurance coverage who are not employed in the absence of public drug coverage. While there is an ongoing debate in Canada on the need for universal drug coverage [7,12–16], there has been minimal data published on implications for persons with neurological conditions. The present study was part of the larger National Population Health Study of Neurological Conditions (NPHSNC) [2,3,17], which involved unique partnerships between the Neurological Health Charities Canada (NHCC), the Public Health Agency of Canada (PHAC), Health Canada and the Canadian Institutes for Health Research [12]. The specific objective for this study was to explore the perspectives of key stakeholders on the availability of and access to prescription drugs for neurological conditions in Canada.

2. Material and methods

2.1. Study design

This paper is one of a series of papers from the health services NPHSNC funded study "Use and Gaps in Health and Community-Based Services for Neurological Populations: A Systems Analysis" [2,18]. A detailed description of the methods has been previously published [18]. In brief, we conducted semi-structured qualitative interviews with health care providers, administrators, community organization representatives, opinion leaders and policy-makers to understand the existing health and community service needs for individuals with neurological conditions and their family members/caregivers; and the perceived health system level facilitators and barriers in the management of these conditions [18]. Based on the NPHSNC, the priority neurological conditions were amyotrophic lateral sclerosis, Alzheimer's disease and related dementia, brain tumours, cerebral palsy, dystonia, epilepsy, Huntington's disease, hydrocephalus, neurotrauma (including brain and spinal cord injuries), multiple sclerosis, muscular dystrophy, Parkinson's disease, Rett syndrome, spina bifida and Tourette syndrome [12]. Ethics approval was obtained from the University of Toronto Research Ethics Board, Health Canada and Public Health Agency of Canada, Dalhousie University, Concordia University, and the Health Research Ethics Authority (Newfoundland and Labrador) [18].

2.2. Setting

In Canada, the Canada Health Act requires provinces and territories to provide medically necessary services, which includes inpatient hospital and inpatient drug care, and physician services ('Medicare' system), in exchange for federal cash transfers. Prescription drugs provided in the inpatient hospital setting are covered through Medicare; however drugs outside of hospitals are funded through private plans, public benefits or out-of-pocket [15], with drug coverage varying by provinces and territories [15]. Provincial drug benefit plans typically cover persons 65 years of age or older, persons of low income and/or those who have specific medical needs [15,19]. These plans have different eligibility requirements and patient cost-sharing models (e.g., premiums, co-payments, co-insurance and deductibles) [15]. Provincial and territorial governments provide coverage through public drug benefits programs for approximately 31%–45% of overall prescription drug costs and these drug benefit plans vary in cost-sharing arrangements and eligibility requirements [15]. The federal government only funds approximately 2% of prescription drug costs [15], providing coverage for the Canadian Armed Forces, veterans, the Royal Canadian Military Police, First Nations and Inuit, federal inmates and refugees. Approximately 22% of drug costs are funded out-of-pocket, and 36% through private insurance [20].