Exploring the extent, determinants, and consequences of cost-related non-adherence to prescription medications among people with spinal cord injuries

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Introduction

Prescription medications play an important role in the treatment and prevention of disease, especially for people living with chronic conditions such as spinal cord injury (SCI) (Allin & Liporte, 2011). People with SCI may need to use a wide range of prescription medications, for conditions such as urinary tract or respiratory infections, neuropathic pain, muscle spasm, and urological conditions have been found significantly related to the prescription medication use in SCI (Berkowitz, 1992; Hope & Kallis, 1998; Jensen & Biering-Sørensen, 2014; Rabchevsky, Patel, & Springer, 2011; Rouleau & Guertin, 2011; Jaglal et al., 2009; Krause & Saunders, 2010). Other chronic conditions that may require long term consumption of medications include diabetes; cardiovascular diseases; respiratory problems; autonomic dysreflexia, and thrombosis (Dryden et al., 2004).

Although Canada has a universal public health insurance program, it excludes universal coverage for prescription drugs (Kratzer, Chang, Allin, & Law, 2015). The Canadian Health System covers medically necessary hospital and physician services but not prescription medications (Dewa, Hotch, & Steele, 2005; Morgan, Daw, & Law, 2013). People are either covered by the private plans, mostly provided by employers; or provincial drug benefit plans (Kratzer et al., 2015). As majority of people with disabilities remain unemployed or under-employed, they either have to forgo their treatment because of lack of private insurance or have to rely on provincial drug benefits to cover the costs of their medications (Stats Canada, 2012). Furthermore the extent of coverage varies extensively (Demers et al., 2008; Kratzer et al., 2015), including premiums, copayments and/or deductibles (Alan et al., 2002), often as much as 3% to 13% of annual household income (Daw & Morgan 2012; Hanley & Morgan, 2009; Guilcher et al., 2017; Tang et al., 2013; Withers, 2016).

Financial burden of medications may lead individuals to adopt various rationing or restrictive behaviors (Law et al., 2012). Cost-related non-adherence (CRNA) may include unfilled prescriptions, delayed prescriptions, less frequent and smaller doses (Zheng et al., 2012), practices often undertaken by those receiving social assistance (Tang et al., 2013; Lurk, DeJong, Woods, Knell, & Carroll, 2004). Out-of-pocket expenditure on medicines often lead to reduction in physician visits, increase in hospital admissions (Anis et al., 2005; Campbell et al., 2014), and increase in emergency department visits (Tamblyn et al., 2001, Tang, Ghali &

Manns, 2013). It may also lead to cutting back on other expenses (Soumerai, Ross-Degnan, Avorn, & McLaughlin, 1991; Goldsmith et al., 2017) and an increased risk of food insecurity (Tarasuk et al., 2015).

Conceptual model developed by Piette and colleagues in 2006 will guide the overall study. This model focusses on CRNA to medications in chronically ill patients, according to which cost-adherence relationship is determined by the interplay of factors such as age; income, other health costs; medication usage and costs; clinician factors; and health system factors (Piette et al., 2006).

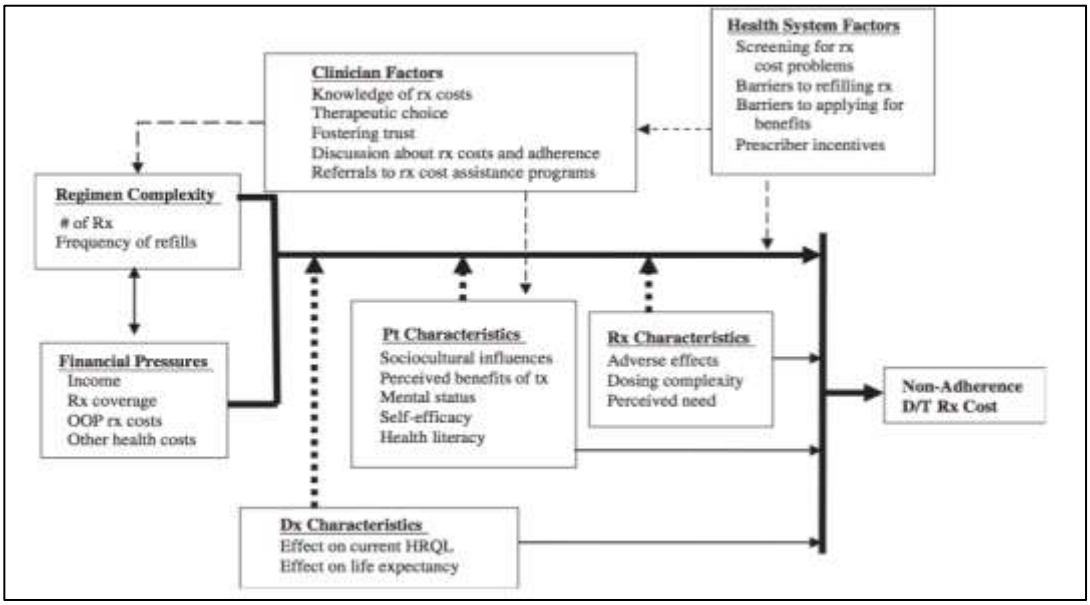

Figure 1. Conceptual framework (Piette et al., 2006)

Research Question: Do people with SCI in Ontario have access to necessary medications to ensure optimum health outcomes?

Objectives:

- To determine the medication use, medication costs, and availability of drug insurance among people with SCI.
- To find out the extent, nature, and determinants of CRNA among people with SCI.
- To find if CRNA leads to any negative health and social consequences for people with SCI.

Phase 1: The sample of the study will be drawn from the population with SCI living in Ontario. Participants will be recruited with the help of SCI Ontario and other community organizations working for people with SCIs. The study will also be advertised through a variety of community and health care settings; free local websites (kijiji or craiglist); social

media websites; and local newspapers. The criteria for inclusion in the study will include individuals with SCI at age of 18 years or more, sustaining SCI for more than 12 months, and having Ontario Health Insurance Plan at the time of survey. The individuals who have not been prescribed any medications, or living in a nursing home, or hospitalized at the time of survey will be excluded. Based on recent estimates, prevalence of SCI in Ontario is around 33,140 (Farry & Baxter, 2010). The proposed sample size for the study is 120 participants.

Data will be collected using a survey questionnaire which will be developed based on the conceptual model of the study and literature review on CRNA in Canada. The most common factors that have been observed in Canadian studies to be associated with CRNA include: (1) socio-demographic attributes (2) employment (3) presence of a chronic health condition (4) availability and type of insurance (5) importance of drug (6) burden of drug cost (7) individual financial flexibility and (8) out-of-pocket costs borne by the patient (Dewa et al., 2005; Goldsmith et al., 2017; Hennessy et al., 2016; Kapur & Basu, 2005; Kemp et al., 2010; Kennedy & Morgan, 2006, 2009; Law et al., 2012; Millar, 2005; Tamblyn et al., 2014; Zheng et al., 2012; Zhong, 2012). Therefore, data will be collected on participants' socio-demographic characteristics, spinal cord injury related characteristics, prescription medication use, availability of insurance, out-of-pocket costs on medications, cost-related non-adherence to medications (if any), social consequences of medication cost pressures; and their health services utilization in last 12 months

CRNA will be measured by asking participants about their inability to afford prescribed medication within the past 12 months. Type of CRNA will include unfilled prescriptions, skip or split doses, delayed prescriptions, less frequent and smaller doses. Participants will be asked to identify medications for which non-adherence is reported and reasons for which non-adherence is reported. As per the conceptual framework of the study, reasons for non-adherence may include medication related factors, participants' perceptions, cost-related barriers, system-related barriers or physician related factors. Frequency (always, sometimes, rarely) and timing (past, present) of CRNA will also be measured.

Phase 2: In the second phase of the study, semi-structured interviews will be conducted with the participants who will report CRNA to prescription medications. This phase will add to the depth of inquiry to understand the experiences of individual participants with CRNA.

Ethical considerations. The principles laid by the privacy legislations of Canada will guide the overall methodological and technical considerations of this study, at every stage of the research process. The ethical clearance for the study will be obtained from Health Sciences Research Ethics Board of Queen's University.

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