

User experience and the impacts of COVID-19



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“The overall experience of people dependent on intermittent catheters is not very good. Catheter users experience an overwhelming amount of challenges in maintaining good health, well-being, and independence associated with bladder management systems. As a person living with a spinal cord injury for over 25 years and working in disability for 20 years, I’ve learned many stories on the challenges and barriers people face in accessing intermittent catheters in Canada.”

~ Peter Athanasopoulos. Director of Public Policy at Spinal Cord Injury Ontario and the Executive Director of the Ontario Spinal Cord Injury Alliance.

Narratives at the end of this report reflect real-life situations and the criticality of addressing four themes:

Theme 1 – the importance of choice

Choice is key in terms of how needs may change over time. Individuals living with a disability vary in age, gender, impairment and lifestyle. Someone with an active lifestyle may choose a specific catheter based on the environment they’re in, the activity they’re involved in, and where they are in life. Choice of product is an essential means of optimizing bladder health in this population and people should have the right to choose the urological approach that best suits their needs.¹⁻⁴ The experiences of users of catheters emphasize the need for catheter choice.¹ Catheter needs will change over one’s lifespan and also based on circumstances.

Education and training regarding management of neurogenic bladder is an ongoing process as lifestyles and needs change over time and across the lifespan.^{2,3} Subsequently, preference of urological supplies is individual and may depend on multiple factors, such as age, sex and gender,

degree of impairment, health status and lifestyle.¹⁻³ Knowledge of the types of products available to support an individual’s urological needs, such as type of intermittent catheter, is important.¹ Training of healthcare professionals and caregivers in the proper technique and use of these urological devices is critical to the health of the individual.²

Theme 2 – the accessibility and affordability to supplies impacts the health of the province

Looking at access and coverage for the single-use catheters. If someone cannot get funding for the catheters that they choose it may force them to reuse catheters, which can lead to health issues and health system costs as a result.

Neurogenic bladder and UTI are not only one of the most common secondary complications of SCI, but also have some of the greatest impact on overall health, quality of life, mental health and health system costs.^{5,6} Clean intermittent catheterization is the preferred method and is associated with the lowest risk of UTIs and long-term complications.⁵⁻⁸ However, the cost of catheters is a barrier and as a result of cost, many individuals reuse or catheterize less

often.^{7,8} UTIs result in frequent emergency visits or hospitalizations costing the healthcare system tremendously.^{5,6} Having access and coverage for single-use catheters could greatly affect individual health and well-being and decrease long-term health care cost.

Theme 3 – bladder health is mental health

The impact of mental health underlies all cases from difficulties accessing or affording catheters. These lead to psychosocial issues which compromises health, participation and independence.

Intermittent catheterization is a personal and private issue, creating mental stress across the lifespan⁴ and ultimately affecting inclusion in all domains (social, vocation, relationship). The psychological impact of a difficult or non-optimal bladder program (lack of supplies, cost, training) on overall well-being and mental health cannot be underestimated.^{1,3,4} Literature has shown that catheter features and individual catheter preferences (easy and ready to use, portability, hygiene features), can enhance autonomy and improve an individual's quality of life and increase the amount of control a person has over their lifestyle.^{1,4}

Theme 4 – the pandemic left many paralyzed and powerless

People in need of bladder care face challenges with supplies, caregiver support, and recurrent UTIs on a regular basis. These matters have been amplified by the effects of the pandemic. That puts them at greater risk for UTIs resulting from a shortage of supplies or unavailable formal supports so individuals have relied on new or informal supports who may not be well trained.

Government program inadequacies

- ODSP was not prepared to manage the volume of supports of medical supplies through a paper-based system;
- ODSP had to waive the Mandatory Special Necessities (MSN) form when the government instituted a 30-day maximum prescription refill from three months. This created a paperwork nightmare and the caseworkers were not prepared to respond to clients and meet privacy regulations from home-based offices. The completion of MSN forms being waved is being applied inconsistently;
- OW, CPP-D benefits, and home care services were not able to meet day to day demands.

Many phone calls were never returned. Email works well with ODSP during COVID but not all clients can access email if they don't have internet, cell phone or computer;

- Hydrophilic catheters are sometimes hard to get approved by ODSP unless proven by the client, support staff and doctors that client requires hydrophilic catheters – based on ODSP workers discretion.

Supply shortage

Spinal Cord Injury Ontario reports that medical supplies have been in short supply during COVID-19, with the shortage of supplies required for bladder care imposing an immediate health risk for people in need of them. Pharmacies ran out of essential related supplies, including gloves, sterilization supplies, gauzes, lubricants, and disinfectants and drainage bags. Individuals depending on ODSP are further impacted as they are unable to stockpile.

New intermittent catheter users were dependant on hospitals for home supplies. Clients visited emergency departments when they ran out of supplies.

Formal caregiver shortage

Individuals of different ages have limited caregiver support in different ways. Children generally depend on their parents or on themselves to the best of their abilities, due to lack of support at home and school. Adults who rely on caregiver support for their bladder care have already been impacted by shortages within the industry in recent years. Consequently, many individuals had serious life-threatening limitations of caregiver supports and options during the initial phase of COVID-19 and continue to rely on emergency departments in phase 2.

Shortages of personal support workers forced family members to provide personal support to their loved ones. Regular caregivers stopped working when the pandemic was announced. Many missed bookings and relied on untrained staff, family and friends to assist them. Caregivers were not able to provide assistance in hospital settings. Clients with fixed incomes could not afford delivery systems or higher costs of goods and services to stay healthy. Clients stayed in hospital longer than necessary because discharge planning to an accessible home was completely compromised. Hospital alternative levels of care for mundane reasons increased.

UTIs and increase in morbidity

Recurrent UTIs are associated with significant morbidity. A direct result of a lack of funding is the reuse of catheters, leading to recurrent UTIs and increased bacterial resistance due to recurrent use of antibiotics. UTIs are recognized as one of the leading causes of hospital readmissions. Hospitalization has been common for individuals with SCI experiencing recurrent UTIs as intravenous antibiotics often become necessary when oral medications fail to treat the underlying infection. As hospitals turn into high-risk areas for contracting COVID-19, individuals with SCI experiencing a UTI, express anxiety in reaching out for medical attention.

UTI's increased in our target population during the pandemic with limited treatment options. Clients started reusing catheters more often and reused more than once because of supply chain disruption. UTIs increased since the pandemic started and people became afraid to get tested at hospital because of the risk of exposure to the virus.

COVID-19 exposed the lack of modernization within our government programs, with many clients becoming solely dependent on charities to pay and find access to vital urinary supplies.

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