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The path to modernize Ontario public coverage for intermittent catheters and related supplies



SPINAL CORD INJURY ONTARIO
LÉSIONS MÉDULLAIRES ONTARIO

33,000

people use intermittent catheters every day in Ontario¹



FIVE

average number of catheters needed per day¹



\$2,500

potential monthly out of pocket cost in bladder management supplies



intermittent catheters are approved as single-use medical devices in Canada

4x

time difference to insert an uncoated catheter versus a coated catheter

57%

of people who use uncoated catheters experience four or more urinary tract infections per year

86%

say catheters are a huge financial burden due to a lack of public coverage



82%

state that challenges on accessing the appropriate number of catheters impact their ability to be independent and self-reliant

90%

agree that all users of catheters must have access to a specialty nurse for teaching and clinical support

78%

support moving to a model where approved distributors can bill the government directly for product shipped to end users





The path to modernize Ontario public coverage for intermittent catheters and related supplies

The following provides the Ontario government with a path forward for **modernizing** the funding available for individuals needing to use intermittent catheters and related supplies.

If implemented, government programs will reduce red tape, improve procurement practices, achieve greater value for the government and provide people with what they need; ***simply and efficiently***.

Reducing red tape and finding system efficiencies

1. Conduct an examination of the overlapping government programs for intermittent catheters to uncover hidden costs and opportunities to reduce red tape.
2. Prioritize the implementation of a new modern funding program for intermittent catheters that delivers system and financial efficiencies for better patient care.
3. Leverage best practice from other jurisdictions, e.g., Saskatchewan style program via approved distributors.

Optimizing procurement to achieve greater value

4. Procure for a comprehensive medical supply coverage program that both allows for consistency of product choice through the continuity of care and prevents patients from needing to reuse single-use catheters.
5. Support the Health Canada, nursing and physician position that single-use catheters should not be reused as they are approved to be used only once and then discarded.

Providing patient-centred care

6. Ensure access to specialty nurses with knowledge, skills, and judgment in bladder health and continence.
7. Improve the hospital to community transition of Indigenous Ontarians who have suffered a spinal cord injury or other health conditions that cause bladder dysfunction.
8. Increase access to specialist nurses to improve assessment and timely access to products and supplies by filling out and submitting forms correctly.
9. Determine how to better support Ontarians who work seasonally and who may have limited access to current funding information.



Executive summary



This policy report presents a comprehensive and compelling case to modernize public coverage for those whose bladder health is managed through intermittent catheters and related supplies.

Individuals with a neurological condition, including a spinal cord injury (SCI), may not be able to empty their bladder on their own which can lead to chronic urinary retention and serious health problems such as bladder damage or kidney disease.

To prevent these problems from happening a catheter is used up to five times a day to drain the bladder, a process called intermittent catheterization. This represents a significant change to how a basic bodily function is managed, and for some people can be overwhelming. The procedure leads to challenges in mental health, relationships, intimacy, body image and self-esteem. Service providers, clinicians, and government must build the right systems for people to live a happy and healthy and productive life as an intermittent catheter user.

To support a person's ability to access enough intermittent catheters, a modern public coverage model is needed. This report helps to visualize a new streamlined program to improve patient access.

The recommendations in this Policy Report build upon examining the access and affordability of intermittent catheters from the disputed 2019 Health Technology Assessment by Health Quality Ontario (HQA) on *Intermittent Catheters for Chronic Urinary Retention*.¹ Users of intermittent catheters emphasize that the choice of product is critical. Through a #pee4free Queen's Park day in 2018, Spinal Cord Injury Ontario (SCIO) was invited to develop a comprehensive review with recommendations to modernize public coverage in Ontario. We are responding to that request.

There is a misconception that once a person has a disability, all supplies will be covered. Access to medical supplies, including urinary catheters, is confusing and expensive. The plethora of funding programs across the province are not integrated. The pandemic of 2020 has impacted all aspects of life in Ontario, especially those with spinal cord injuries with limited mobility. This document includes insights from the community on the impacts of COVID-19, which exacerbated issues in the accessibility

of intermittent catheters, related supplies and caregiver shortages. What happens in Toronto is vastly different from people in northern Ontario communities, so the needs of Indigenous peoples and rural communities are also imperative.

People don't catheterize themselves in controlled environments. To contribute to society and maintain mental health, these members of our population must catheterize in public spaces, on trains, planes, in our academic institutions, community centres and in the workplace. Narratives at the end of the report reflect real-life situations and the criticality of addressing four themes:

- the importance of choice;
- the accessibility and affordability to supplies impacts the health of the province;
- bladder health is mental health; and
- the pandemic left many paralyzed and powerless.

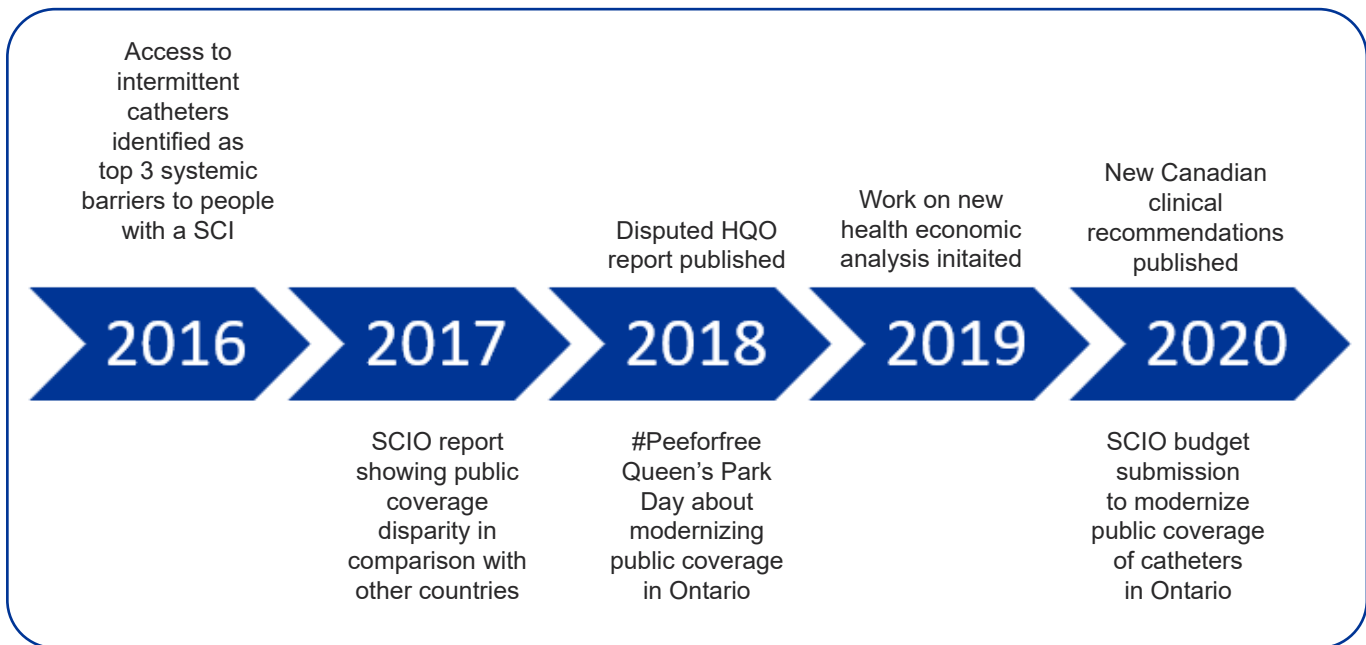
A single-use medical device is designed, manufactured and approved for sale by Health Canada to be used once on a single patient

and then to be discarded. The Canadian Urological Association (CUA), nursing associations and industry unite that it is inappropriate for the health system to necessitate intermittent catheter users to clean and reuse a single-use medical device.^{2,3,4}

What is immediately apparent is that these programs have not been designed with people at the centre in the Province of Ontario. Different programs managed by different government agencies are layered one upon another.

A summary of nine critical recommendations is presented for the Government of Ontario to work with the stakeholders to modernize public coverage to reduce red tape, improve procurement and provide people with what they need; simply and efficiently. The consequences of doing nothing are far more severe to a person's health and the economy when the system of services available for intermittent catheters is inefficient.

SCIO Steering Committee
February 2021



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3. Clean Intermittent Urethral Catheterization in Adults – Canadian Best Practice Recommendations for Nurses. Developed by Nurses Specialized in Wound, Ostomy and Continence Canada, Canadian Nurse Continence Advisors, Urology Nurses of Canada, and Infection Prevention and Control. 1st Ed. 2020 Retrieved from <http://nswoc.ca/wp-content/uploads/2020/05/Clean-Intermittent-Urethral-Catheterization-Adults-for-Nurses-BPR-May2020-lr.pdf>.
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Sections

Funding pathways for intermittent catheters and related supplies

There are a plethora of intertwined programs that have not been designed with people at the centre in the Province of Ontario. Different programs managed by different government agencies are layered one upon another. This complexity creates wasteful administration meaning modernization is warranted so that the criteria are simple and effective.

Latest economic analysis

The estimation on the impact of hydrophilic catheters on lost time to receive treatment for urinary tract infections (UTI) suggests that providing the individual with SCI requiring intermittent catheterization the choice of hydrophilic catheters would result in potential long-term cost savings to the Government of Ontario.

User experience and the impacts of COVID-19

"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."

Meeting the needs of Indigenous & rural populations

What happens in Toronto is vastly different than the experience of people in northern Ontario communities. The needs of Indigenous peoples and rural communities deserve improved community transition and access to specialist nurses.

Clinical best practice recommendations

The Canadian Urological Association (CUA) and Nurses Specialized in Wound, Ostomy & Continence Canada (NSWOCC) have both published new 2020 clinical recommendations. They state that they cannot support the reuse of catheters licenced for single use in any setting.

Health Canada single-use medical devices

Collectively, the industry members represented through Medtech Canada have developed a position paper calling for the Government of Ontario to address patient safety and potential liability risks associated with individuals for financial reasons having to reuse catheters.

The current support programs for people in Ontario requiring intermittent catheters and related supplies

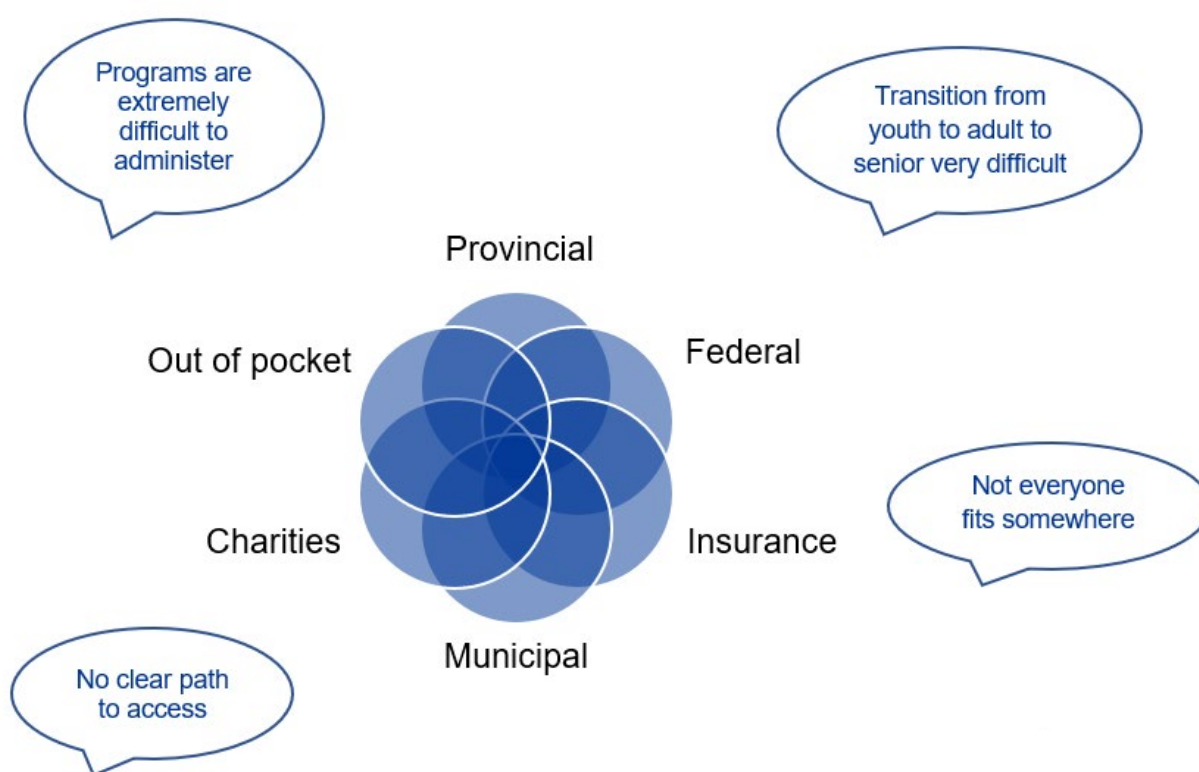


Table 1 examines the eligibility of each of the provincial and federal program eligibility, pros and cons. This work is knowingly incomplete. The difficulties in piecing it together speaks to the complexity of navigating and comprehending it. Interwoven into these programs are insurance benefits. For ease, we have limited them to WSIB and employer health benefits. We provide an illustration of a grant program provided by municipalities.

The transition from youth to adult to seniors is especially problematic. Individuals struggling with support from these programs invariably turn to charitable organizations seeking assistance to make up the shortfall.

A modernized public coverage is critical to reduce red tape, improve procurement and provide people with what they need; **simply and efficiently**.

Table 1 - The current support programs for people in Ontario requiring intermittent catheters and related supplies

Provincial Programs	Eligibility	Pros	Cons
Ontario Disability Support Program (ODSP)	Medical benefits based on income and assets for those 18-65 years old.	Can only earn \$300 per month to stay on ODSP. Regular vendor quotes.	People have a hard time leaving ODSP because of the medical supply benefit. Most work benefits don't fully cover medical supplies. Hard to justify the need for hydrophilic catheters. Continuous reporting and physician signature.
Ontario Works (OW)	Emergency benefit based on a demonstrated inability to work, income, assets and cost of housing.	With OW, you can apply for emergency benefits, which includes medical supply benefits.	Less resources than ODSP. Benefits limited to a small number of catheters per day. Continuous reporting and physician signature. Regular vendor quotes.
Trillium Drug program	High prescription drug costs relative to household income.	Possible to gain coverage.	Very difficult to get approved.
Statutory Accident Benefit	Motor vehicle accident victims.	Full coverage, including intermittent catheters.	High settlements are exhausted within 2.5 years. Thereafter, out of pocket. Precludes funding from other sources. Continuous reporting and physician signature.

Provincial Programs	Eligibility	Pros	Cons
Assistance for Children with Severe Disabilities (ACSD)	Severely disabled child living at home based on family income.	Consistent with little reporting.	Coverage limited to \$25-500 per month.
Home care provided via Ontario Health	Requires physician order.	Enables access to healthcare practitioners or personal support workers at home and provides free related supplies including intermittent catheters..	Supplies are no longer covered through home care. Once the nursing visits or personal support worker support stops, so does the medical supplies. Not all urological and related supplies are provided so many still paid for out of pocket if no other insurance coverage.
Incontinence Supplies Grant Program (Easter Seals)	Children 3-18 with an Ontario Health Insurance Plan (OHIP) card with a chronic disability that results in irreversible incontinence or retention problems, lasting longer than six months.	Incontinence supplies include diapers, pull ups, attends, swimmers and catheters including straight, foley and drainage bags.	The grant does not cover gloves, wipes, creams, clothing, bed linens, laundry detergent. Not eligible to children whose health coverage is through the Interim Federal Health Program or covered under the Workplace & Insurance Board (WSIB) for a work related injury.

Insurance Programs	Eligibility	Pros	Cons
WSIB	Injury in the workplace funded by employers.	Comprehensive coverage for 5 million Ontarians employees between ages 15-65+.	Continuous reporting and physician signature. Coverage on reaching 65 examined on a case by case basis. For those newly injured over 65 receive coverage for two years.
Employer Health Benefits	Employees of companies paying premiums for health coverage through third-party plans, e.g., Manulife, Sunlife etc.	Comprehensive coverage.	Extremely inconsistent. Depends on the third-party insurance provider. Rarely 100% funded. Cannot be used to top up coverage on other funding programs. Employer programs are subject to change without notice and often don't have flexibility to cover non-standard requests or supplies that are not on the standard list.

Federal Programs	Eligibility	Pros	Cons
Long-term disability	Medical supply benefits based on diagnosis	60-70% income replacement for up to 2 years.	<p>People have a hard time leaving ODSP because of the medical supply benefit. Most work benefits don't fully cover medical supplies.</p> <p>Hard to justify the need for hydrophilic catheters.</p> <p>Continuous reporting and physician signature.</p>
Old Age Security (OAS)	Medical supply benefits for recipients of ODSP when they turn 65.	Replaces medical supply benefit through ODSP for those turning 65.	Most over 65 rely on charity donations for supplies.
Canadian Pension Plan Disability (CPP-D)	Made Canadian Pension Plan (CPP) contributions in three of the last 6 years of employment.	If the amount from CPP-D is less than the ODSP eligibility, ODSP tops up to ODSP basic amount and eligible for medical supplies.	<p>You must apply to CPP-D first for consideration of approval to Ontario Works.</p> <p>If amount from CPP-D is more than the eligibility of ODSP, you have no medical supply benefits.</p> <p>Continuous reporting and physician signature.</p>
Veterans	Canadian Armed Forces member or Veteran, a current or former member of the Royal Canadian Mounted Police, Second World War or Korean War Veteran or certain civilians who served in the Second World War.	<p>Pain & suffering compensation.</p> <p>Disability pension.</p>	
Non-insured health benefit (NIHB)	Registered First Nations, Métis and Inuit with Indian status card, including children and seniors.	Can reclaim out of pocket expenses within 12-months with original receipts.	<p>Require access to a physician, nurse practitioner (NP) or Nurse Specialized in Wound Ostomy and Continence (NSWOC) for signatures.</p> <p>Problematic for those in rural communities without internet access.</p>
Interim federal health program (IFHB)	Groups such as asylum seekers who aren't eligible for provincial or territorial health insurance.	Health benefits to groups of people who aren't eligible for provincial or territorial health insurance.	Limited, temporary coverage.

Municipal Programs	Eligibility	Pros	Cons
Example - Hamilton Special Supports Program	City residents living independently in the community to improve their quality of life, health, wellness, safety and self-sufficiency.	Provides a wide range of health related benefits that may include Bathroom assistive devices such as grab bars, commodes etc., surgical, incontinent and ostomy supplies, wheelchair batteries and repairs, medical taxi transportation.	Does not fund equipment, devices or services that have already been ordered or purchased. Do not order or purchase equipment prior to receiving funding approval.

Provincial programs

ODSP <https://www.mcsc.gov.on.ca/en/mcsc/programs/social/odsp/>

OW <https://www.mcsc.gov.on.ca/en/mcsc/programs/social/ow/>

Trillium Drug Program <https://www.ontario.ca/page/get-help-high-prescription-drug-costs>

ACSD <http://www.children.gov.on.ca/htdocs/English/specialneeds/disabilities.aspx>

Statutory Accident Benefit <https://www.ontario.ca/laws/regulation/100034>

Incontinence Supplies Grant (administered via Easter Seals) <https://services.easterseals.org/incontinence-supplies-grant/>

Insurance program

WSIB Ontario <https://www.wsib.ca/en>

Federal programs

Long-term disability <https://www.canada.ca/en/financial-consumer-agency/services/insurance/disability.html#toc2>

OAS <https://www.canada.ca/en/services/benefits/publicpensions/cpp/old-age-security.html>

CPP-D <https://www.canada.ca/en/employment-social-development/services/my-account/cpp-oas.html#Applying-for-CPP-disability>

Veterans <https://www.veterans.gc.ca/eng/health-support/physical-health-and-wellness/compensation-illness-injury/disability-benefits>

IFHB <https://www.canada.ca/en/immigration-refugees-citizenship/services/refugees/help-within-canada/health-care/interim-federal-health-program/coverage-summary.html>

NIHB <https://www.sac-isc.gc.ca/eng/1590168766044/1590168799917#s13-2-3>

Example of a Municipal program

<https://www.hamilton.ca/social-services/support-programs/special-supports-program>



Funding pathways for intermittent catheters and related supplies

Funding pathways for intermittent catheters and related supplies

There are a plethora of intertwined programs that have not been designed with people at the centre in the Province of Ontario. Different programs managed by different government agencies are layered one upon another. This complexity creates wasteful administration meaning modernization is warranted so that the criteria are simple and effective.

Urinary catheters are readily available. That's not the issue. Catheters are available in every make, brand, style of catheter you could imagine in any country in the world are available in Canada. They're available through a wide network of distributors, retailers, wholesalers, so they can be shipped anywhere overnight to any part of the country. Availability should not be confused with accessibility.

Every support program illustrated in Table 1 has a different application process and can be interdependent, meaning that eligibility is based on a denial from another program. Which funding pathway applies depends upon a spectrum of criteria including age, diagnosis, income, insurance, where you live, access to the internet and immigration or Indian status.

"Come back to us if this group doesn't pay for you or if you get denials from these three areas, then you can come back to us for funding."

Current situation in Ontario

1. The issue is reimbursement. There is no reimbursement for intermittent catheters and related supplies that Ontarians are able to navigate **simply and effectively**.
2. The cost of catheters in Ontario is an imposition for people, particularly for people

who have to pay out of pocket. Most people can't afford a hydrophilic catheter at today's price points out of pocket. Even if the price of medical supplies fell, this still leaves many intermittent catheter users in a difficult position. HQO estimated pricing to be \$7/catheter or approximately \$35/day rather than the \$17/day reported by manufacturers.¹ Previous attempts to gain reimbursement may have been hindered by an overinflated price tag on the cost of intermittent catheters;

3. Lack of access to specialty nurses for ongoing assessment and education compounds these issues as end-users receive inconsistent education and support across Ontario and Canada.

Due to the inability to afford or access enough single-use catheters, end-users report the need to reuse catheters, despite Health Canada approving and manufacturer's instructions for use clearly stating that these products are single-use devices. Healthcare professionals, despite single-use indications, are conflicted about these practices and how to support best practices. End-users experience increase risk of infection and other complications (e.g., urethral trauma) secondary to the reuse of single-use catheters.

“As a health care professional, I’m conflicted, despite the single-use indications, the problem is best practices are telling me that for the safety of my patients that I shouldn’t be teaching them to reuse because of their increased risk of infection and other complications, such as a urethral trauma. On the other hand, if I don’t teach someone to reuse, then there is perhaps an even greater chance that they’re going to run into complications.”

Saskatchewan Aids to Independent Living

Saskatchewan Aids to Independent Living (SAIL) provides assistance to people with physical disabilities to live a more active and independent lifestyle. It also helps people in the management of certain chronic health conditions.²

The SAIL program has worked effectively for several years in Saskatchewan where it is considered simple and effective. The model is worthy of detailed exploration as a template for an accessibility program in Ontario.

The Province of Saskatchewan operates the SAIL program where approved distributors participate in a government program.² Those who meet the basic criteria are assessed by specialty nurses and are then prescribed and provided with catheters. Distributors must be knowledgeable and willing to provide access to a specialty nurse. The program is underpinned by access to specialist nursing in the community to support intermittent catheter users.

We are seeking a centralized comprehensive medical supply coverage program where all government programs can feed into. One that:

- a. reduces red tape.
- b. improves procurement.
- c. collects user data.
- d. improves patient assessment and outcomes.

Recommendations

This envisions a scenario where the Government of Ontario is paying for single-use intermittent catheter like virtually every other Westernized nation in the world.

1. Conduct an examination of the overlapping government programs across the different departments to assess hidden costs and opportunities to reduce red tape.
2. Prioritize the implementation of a new modern funding program for intermittent catheters that delivers system and financial efficiencies for better patient care.
3. Leverage best practice from other jurisdictions e.g., Saskatchewan style program via approved distributors.
4. Procure for a comprehensive medical supply coverage program that:
 - a. allows for consistency of product choice through the continuity of care; and
 - b. prevents patients from the need to reuse single-use catheters.
5. Support the Health Canada, nursing and physician position that single-use catheters should not be reused as they are approved to be used only once and then discarded.

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Latest economic analysis

Taken from The Path to Modernize Ontario Public Coverage for Intermittent Catheters and Related Supplies. February 2021. Spinal Cord Injury Ontario

Latest economic analysis

The estimation of the impact of the use of hydrophilic catheters on lost time to receive treatment for urinary tract infections (UTIs) suggests that providing an individual with a SCI requiring intermittent catheterization the choice of hydrophilic catheters would result in potential long-term cost savings to the Government of Ontario.

This report builds upon and evolves the need for examining the access and affordability of intermittent catheters from the disputed 2019 Health Technology Assessment by HQO on Intermittent Catheters for Chronic Urinary Retention.¹

Approximately 80% of individuals with SCI will develop neurogenic bladder conditions. Of those with neurogenic bladder conditions, 60% require catheterization to urinate. Currently, intermittent catheterization is considered the gold standard. There are two main types of intermittent catheterization: uncoated and coated catheters. Uncoated catheters have an increased risk of bacterial infection due to the need to self-lubricate. On the other hand, hydrophilic coated catheters have a decreased risk of bacterial infection because they don't need to be self-lubricated. However, hydrophilic catheters are more expensive per unit compared to the uncoated catheters.

The objective of a review conducted by Xi et al., was to identify and critically evaluate economic evaluations, examining the cost-effectiveness of hydrophilic versus uncoated catheters for individuals with SCI.² To date, there have been two other studies that have had a similar objective: the HQO report that was published in 2019 and a study by Saadat et al. (2018).^{1,3} Neither of these two studies critically evaluated the economic evaluations that they included.

A scientific literature search in November 2019 identified publications in peer reviewed journals that conducted an economic analysis (i.e., cost / cost-effectiveness studies) on intermittent catheters in the spinal cord injured population. This review included any study that conducted a full economic

evaluation of any urinary catheter for individuals with spinal cord injury.

To date, there have been eight health economic analysis studies comparing the different types of intermittent catheters. All eight studies conducted a cost-utility analysis, assessing cost-effectiveness in various countries across the world, including two studies out of Canada. Six of the eight studies concluded that intermittent catheters with hydrophilic coating were cost-effective or cost-reducing in their respective settings.

Three potential reasons for the discrepancies were postulated.

- 1. Comparator used.** One study concluded that hydrophilic coated catheters was not cost-effective compared with off-label reuse of single-use uncoated catheters. Off-label means that the device is being used outside of the licenced manufacturer's instructions for use. After follow-up interviews with stakeholders, the National Institute for Health and Clinical Excellence (NICE) was concerned that physicians would be liable for infections if they were advising patients to ignore the single-use symbol, and the evidence towards cleaning was lacking in terms of how to adequately reuse a catheter. The final recommendation stated that individuals should be able to choose hydrophilic or gel reservoir catheters. All other studies included approved uses of uncoated catheters as the comparator.
- 2. Consideration of long-term impacts of catheter use.** Five studies incorporated the long-term impacts of catheterization to the economic evaluation. These analyzes considered the secondary complications

of catheterization on renal function. Hydrophilic catheters have been shown to have fewer long-term consequences, including a reduced risk of UTIs and other renal complications, in comparison to the uncoated catheters, leading to increased calculated benefits. These studies provided the most comprehensive evaluation of the economic impact of catheter use.

Two studies on the other hand focused on only the short-term consequences. Additionally, these two studies considered the presence of at least one UTI as the primary clinical outcome, but excluded the number of UTIs that individuals would experience. These model input decisions limit the observed health benefits of hydrophilic catheters resulting in the author's description that hydrophilic catheters were not cost-effective.

3. **Cost difference between hydrophilic and uncoated catheters.** In the most recent study to conclude that hydrophilic catheter was not cost-effective, the researcher included a unit cost difference of hydrophilic and uncoated catheters that was the highest in all studies identified in the review. In fact, in this study it was 3.8 times higher than the study with the next highest cost difference (also conducted in the same year and jurisdiction). Not surprisingly, the much higher unit cost of hydrophilic catheters selected by the study authors contributed to the conclusion that intervention was not cost-effective. However, the cost of hydrophilic catheters used in this study appear to be inconsistent with previous studies.

A re-examination of the health economics is warranted

In summary, the discrepancies observed in individual cost-effectiveness studies are a result of the type of comparator, time frame of the analysis and unit cost of hydrophilic catheters chosen by the researchers. Studies that have included a comprehensive assessment of the full impact of hydrophilic catheters compared with single-use uncoated catheters using a reasonable unit cost of catheter have concluded that although the total health care costs for individuals receiving hydrophilic catheters may be higher than individuals using uncoated catheters, the additional health benefits are great enough to consider the intervention cost-effective. In other words, the transition to a funding model to provide individuals with more choice in catheter type may cost more for individuals opting to use hydrophilic catheters compared to uncoated catheters. This additional cost though is considered acceptable given the expected gains in health.

The scope of the identified studies is limited to the direct public healthcare payer costs associated with catheter use. These studies do not speak to the potential indirect cost impacts such as the lost time due to the treatment of UTI, out of pocket costs to receive medical care, and reduced social isolation / increase in self-reliance with greater convenience in catheter administration. In a cost-effectiveness study of hydrophilic catheters led by Dr. Welk and colleagues, the cost impact of lost time for treatment of urinary tract infection was considered in a secondary analysis.⁴ The researchers observed that when lost time was valued in their model, there was a lower average lifetime cost for individuals receiving hydrophilic catheters compared to uncoated catheters. There was an expected cost savings from a societal perspective. Experiencing less UTIs may also result in lower out of pocket costs for parking, transit and attendant assistant costs related to attending medical appointments to treat this complication. For individuals with limited upper limb function, the convenience of applying a hydrophilic catheter may also result in greater self-reliance and lower dependence on paid caregivers reducing the costs associated with this care. Greater convenience in catheter application may also give the individual confidence in pursuing interactions with others, thus reducing social isolation and the negative associated health consequences. The magnitude of these impacts need to be further explored in future studies. However, these examples along with the estimation of the impact of the use of hydrophilic catheters on lost time to receive treatment for UTIs suggests that providing an individual with a SCI requiring intermittent catheterization the choice of hydrophilic catheters would result in potential long-term cost savings to the Government of Ontario.

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User experience and the impacts of COVID-19



User experience and the impacts of COVID-19

“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 wave 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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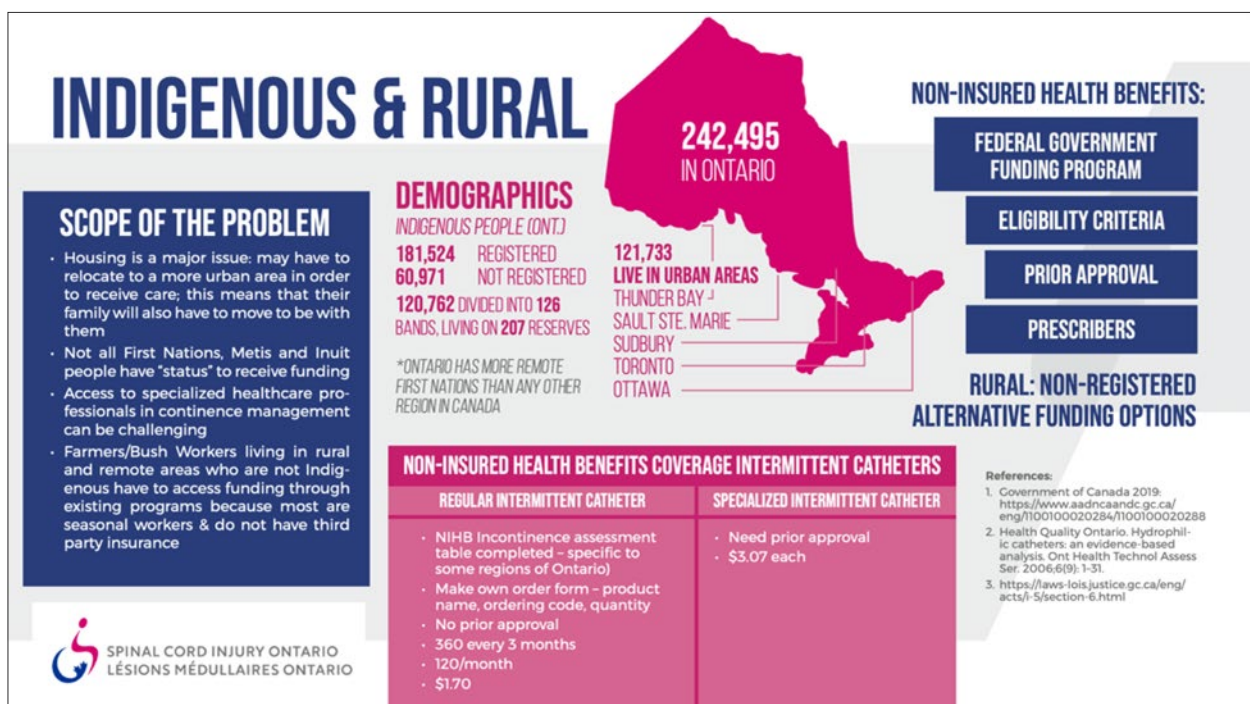
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Meeting the needs of Indigenous & rural communities

Meeting the needs of Indigenous & rural communities

What happens in Toronto is vastly different than the experience of people in northern Ontario communities. The needs of Indigenous peoples and rural communities deserve improved community transition and access to specialist nurses.



In Canada, we have about 1.2 million Indigenous Canadians and about a quarter of them live in Ontario. Ontario has the largest population of First Nations, Métis and Inuit people. 181,524 are registered with the federal government and have an Indian status.¹

There has been an increase of Indigenous Canadians who have moved into urban areas to access better housing and supplies. An Indigenous person who has a SCI may not be able to stay on the reserve or in a remote area. They may have

to be transferred by plane to a more urban area in order to receive appropriate care. The entire family is likely to follow. Ahmed et al. (2020) looked at SCI in Aboriginal populations and non-Aboriginal populations.² The statistically significant difference was the ability of the Aboriginal population to be discharged back into the community. Work is needed to address this.

The NIHB is a federal program for all Indigenous people covering the provinces and territories for a range of medically related items, including

intermittent catheters. The Medical Supplies and Equipment program lists who can authorize or prescribe medical supplies and how much money is put against each supply. It can be very challenging to get the paperwork completed to access the funding. There is an eligibility criterion for non-insured health benefits that must be met which are available on the NIHB website. Uncoated straight tipped intermittent catheters are covered and approved in a quantity of 120/month for 3 months and reimbursed at \$1.70 each. However, specialized intermittent catheters, which include the recommended hydrophilic catheters require prior approval. An NSWOC, NP or physician can complete assessment forms covering hydrophilic catheter, reimbursed at \$3.07 each.³

Access to specialist nurses

There is a lack of access to specialized healthcare professionals who are trained in continence management. There are 50 nurses from across Canada who are dedicated to improve wound, ostomy and continence health for Indigenous Canadians. NSWOC launched an Indigenous Core Program in 2018. The NSWOC national standards of practice due for publication in 2021 also address Indigenous Cultural Safety.

It is evident that nurse practitioners or physicians without a specific background in continence may not order enough products which can be problematic since some of these areas are serviced by supply chains. NIHB added NSWOC to the list of prescribers in 2018 of products for continence issues to improve access to specialized care and supplies.

Farmers, bush workers and unregistered Indigenous people

Farmers and bush workers who are working in rural and remote areas, who are not Indigenous, may not have access to funding through the third-party insurance programs because they're seasonal workers and they're not offered the opportunity to have third-party insurance. They may not have access to the internet or are reliant on healthcare professionals educating them on sources of funding. There are 60,971 unregistered Indigenous people in Ontario unable to access funding from the NIHB program.

Recommendations

1. Improve the hospital to community transition of Indigenous Ontarians who have suffered a spinal cord injury or other health conditions that cause bladder dysfunction.
2. Increase access to specialist nurses to improve assessment and timely access to products and supplies by filling out and submitting forms correctly.
3. Determine how to better support farmers / bush workers and non-registered Indigenous Ontarians who work seasonally and who may have limited access to current funding information.

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A photograph of two women in a clinical or office setting. One woman, with long blonde hair and glasses, stands on the left wearing a grey cardigan and blue jeans, holding a tablet. The other woman, with dark curly hair, sits in a wheelchair on the right, wearing a black top and green pants, smiling and looking at the tablet. The background features a whiteboard with a line graph, a potted plant, and a white shelving unit with binders.

Clinical best practice recommendations

Taken from The Path to Modernize Ontario Public Coverage for Intermittent Catheters and Related Supplies. February 2021. Spinal Cord Injury Ontario

Clinical best practice recommendations

The Canadian Urological Association and Nurses Specialized in Wound, Ostomy & Continence have both published new 2020 clinical recommendations in which they state that they are unable to support the reuse of catheters licenced for single use in any setting.

Canadian Urological Association Perspective

A urologist named Lapides came up with the concept of intermittent catheterization in the 1940s.¹ Previously, there was significant morbidity and mortality associated with the neurogenic bladders and the inability to drain them or the long-term use of indwelling catheters. Intermittent catheterization has changed the way people manage their bladders and their quality of life in a dramatic way. The management does centre around improving both the quality of life and social rehabilitation. They have become cornerstones and priorities for the urologic management of these patients. There are certainly advantages of intermittent catheterization over indwelling urinary catheters. There's a reduced risk of common indwelling catheter-related complications such as catheters becoming dislodged. There's less of a barrier to intimacy and sexual activity when you do not have an indwelling catheter. There is the potential for reduced lower urinary tract symptoms between catheterizations.

Neurogenic lower urinary tract dysfunction (NLUTD) is associated with increased risk of recurrent UTI, stones and compromised kidney function. Management of neurogenic bladder dysfunction has an incredible economic burden on the healthcare system and quality of life. Assisted bladder drainage remains the cornerstone for urological management of the neurologically impaired patient. Various approaches have been

described to manage neurogenic lower urinary tract dysfunction in neurological populations, including clean intermittent catheterization, indwelling urethral catheters, suprapubic catheterization along with pharmacotherapy. Improving patient quality of life and social rehabilitation has become a priority for the urological management of the neurologically impaired patient.

The **Canadian Urological Association Best Practice Report: Catheter Use** reviews the evidence around the use of long-term urinary catheters in patients with chronic conditions and make practice recommendations for physicians in Canada who manage intermittent catheter populations.² It is based on data obtained from numerous published meta-analyses and original studies identified through a literature search. The narrative review concentrates on systematic reviews, related guidelines and comparative studies. Articles were reviewed using a methodology consistent with the Grading of Recommendations, Assessment, Development and Evaluations (GRADE) tool. It pays specific attention to the best evidence of the available techniques, design, material, and practices of intermittent self-catheterization and its position in the treatment pathway. Discrepancies are highlighted and discussed in the context of patient reported outcomes and health economics.

Intermittent catheterization is the gold standard for the management of NLUTD. Optimal catheter

material, cleaning method and catheterization technique remain controversial topics in urology. The preferred intermittent catheterization strategy varies by settings and practices. There is no evidence that there is one best catheter for all patients with NLUTD. The reuse of catheters is still considered in different clinical practices despite concerns regarding efficacy and compliance with cleansing techniques. Intermittent catheterization using single-use sterile catheters remains the optimal strategy until the emergence of new evidence supporting multiple use catheters. Long-term cost-effectiveness of single-use hydrophilic catheter or urinary catheters was established from the perspective of several international healthcare systems. Debate continues to linger regarding the best catheter material and technique in which upper urinary tract deterioration can be prevented while minimizing treatment-related morbidity.

The CUA has had instruction manuals dating back many years, yet there have never really been clear guidelines. Some of those manuals include how to re-sterilize and clean your catheter. There was a push to update and modernize the approach to intermittent catheterization guidelines. The CUA Best Practice Group report divides the recommendations into the following five sections; types of catheters, catheter-related complications, patient perspective, economic perspective and conclusions.

Those requiring catheters for a neurological reason are associated with an increased risk of recurrent infection, stones and compromised function. And although these complications are no longer the leading cause of death, they do represent a significant economic burden on the healthcare system as well as the quality of life. Assisted bladder drainage has become the cornerstone of urologic management, and intermittent catheterization is the gold standard.

It is a common misconception that putting a catheter in and out will increase the rate of UTI. In fact, having an indwelling catheter significantly increases the risk of having colonization and infection. Intermittent catheters provide fewer barriers to intimacy and sexual activity.

The body of evidence points to intermittent catheterization using pre-lubricated, hydrophilic,

are associated with fewer urinary tract infections compared to other modalities, and therefore it should be used whenever possible. It is the preferred means of draining the bladder. The evidence is limited with regards to hydrophilic vs. non-coated when it comes to trauma and stricture formation. The paper by Kessler (2009) showed high rates of satisfaction with the initiation of clean intermittent catheterization.⁴ Most users, properly taught, find intermittent catheterization easy to do and incorporate into their daily activities. There is minimal to no pain and their overall quality of life is shown to improve. A large systematic review by Walter & Krassioukov (2019) reported high-level evidence for studies comparing the different types of catheters.⁵

International perspective on the reuse of single-use devices

The issue of reusing single-use products is problematic for urologists. The wording from the U.S. Food & Drug Administration (FDA) states that single-use devices cannot be reprocessed safely and they shouldn't be reused. The U.K. NICE recommends that to make an off-label recommendation for the use of these catheters again is problematic. Single use should be the recommendation for intermittent catheters. Several urologic societies worldwide have stated that reuse of these single-use catheters is considered off-label.

According to the FDA, single-use devices that cannot be reprocessed safely should not be reused under any circumstances. NICE states that to make an off-license recommendation using these catheters, there needs to be a better quality of evidence. In keeping with these recommendations, the CUA guidelines favour single-use hydrophilic coated catheters.

Intermittent catheterization enhances bladder emptying for the patient. It relieves associated symptoms which could otherwise impair quality of life. It is widely accepted that intermittent catheters lessen restrictions on daily activities. They promote patient independence, improve sleep, social functioning and overall quality of life. The success of intermittent catheterization requires acceptance and if the patient is satisfied with the treatment they will be compliant in the long-term. Patients reported a negative impact on quality of life

owing to social, psychological disturbances as well as from infections. Single-use hydrophilic catheters can improve the acceptance of intermittent catheterization for patients.

Wherever possible, hydrophilic coated or pre-lubricated catheters should be proposed to patients as a first treatment option. Evidence shows they have a lower risk of infection, less urethral trauma and a higher convenience and ease of use compared to conventional uncoated catheters.

Intermittent catheterization is the gold standard. There's no optimal material, cleaning method, or technique. Recommending the most straightforward, safest, ease of use, is hydrophilic single-use catheter. There is no evidence that one catheter is better over another. And so, we don't recommend or endorse a single type of product. As a category, whenever possible, hydrophilic coated or pre-lubricated catheters should be proposed to the patient as the first treatment option for these reasons.

Patient adherence to cleaning method cannot be predicted and further amplifies the risk of complications and their burden on the healthcare system. The CUA recommends a patient-centred approach to consider single-use hydrophilic coated catheters as the first and preferred option while considering the patients' and caregivers' ability to accommodate the usage of technique. In updating their best practices, the CUA is in lockstep with the nursing professionals discussed next.⁶

CUA take-aways

1. Intermittent catheterization is the gold standard for patients with incomplete bladder emptying able to catheter themselves.
2. Endorses the use of single-use hydrophilic coated or pre-lubricated catheters, with a clean technique to decrease the likelihood of developing a UTI.
3. The use of single-use hydrophilic coated catheters is recommended to reduce the risk of hematuria and trauma.
4. Hydrophilic or pre-lubricated catheters are convenient and easy to use.
5. From an economic analysis, the CUA recommends offering patients, if possible, hydrophilic coated catheters as cost-effective

compared to single-use uncoated catheters due to the decreased incidence of infections improved quality of life.

6. There is no evidence that the type of catheter impacts urethral stricture formation. And from a patient perspective, the CUA recommended offering hydrophilic or pre-lubricated catheters to patients because of improved bladder related quality of life.

Nursing professional perspective

The *Clean Intermittent Urethral Catheterization in Adults* | *Canadian Best Practice Recommendations for Nurses* published in May 2020 is the result of a collaboration between Nurses Specialized in Wound, Ostomy & Continence Canada (NSWOCC), Canadian Nurse Continence Advisors (CNCA), Urology Nurses of Canada (UNC) and Infection Prevention and Control Canada (IPAC Canada).⁶

These best practice recommendations help guide qualified nurses in Canada to provide education and improve patient outcomes for adult intermittent urethral catheterization.

The document assists regulated professional nurses in diverse practice settings to provide evidence-based care to adults requiring intermittent urethral catheterization.

Project team members came from four different organizations, all of whom we collaborated with through the Canadian Network of Nursing Specialties run under the Canadian Nurses Association. The recommendations from the four cooperating associations established a Canadian nursing perspective building on the *Catheterization Urethral Intermittent in Adults Dilatation Urethral Intermittent in Adults - Evidence-Based Guidelines for Best Practice in Urological Health Care*, published by the European Association of Urology Nurses (EAUN).

The researchers conducted a literature search between 2010-2018 using the research question. "What is the evidence that supports nursing practice to use and to teach the use of clean, intermittent urethral catheterization?" The initial search turned up 1,449 studies in which the abstracts were reviewed for review of 93 studies by two reviewers was conducted, and 54 studies were included.⁶

The chapters covered in the nursing best practice recommendations include:

1. Methodology.
2. Indications, contraindications and complications.
3. Infection prevention and control.
4. Impact of intermittent catheterization: patient quality of life.
5. Catheter materials and types of materials.
6. Management of intermittent catheterization.
7. Patient education.

There is some variation among Canadian healthcare professionals about the recommended frequency of intermittent catheterizations, acceptable post-void residuals, and adequate urine per catheterization. The nursing expert's recommendation is to achieve a catheterized volume of no greater than 500 ml per catheterization. Usually, this works out to four to six catheterizations in 24-hours. Recommendations include the use of a record to track output.

The best practice recommendations are a great starting point to review any nursing policies and procedures related to intermittent catheterization in adults. Local policy should be observed before starting any catheterization as intermittent catheterization is governed by provincial legislation

Nursing perspective on the reuse of single-use devices

One of the most important recommendations is that a single-use pre-lubricated catheter should be recommended for patients, especially for those with repeated symptomatic urinary tract infections. The authors could not find any intermittent catheters in Canada marketed for reuse in patients performing intermittent catheterization.

Health Canada has licenced single-use catheters to be used only once. They are not designed to be reused. It is against the manufacturer's instructions to reuse. From a professional practice liability standpoint, the authors of the Canadian best practice recommendations for nurses cannot support the reuse of catheters.

The collaborating associations recognize that they cannot support the reuse of catheters licenced for single use from professional and practice liability perspectives. Health Canada licences a single-use catheter because it is to be used only once and then disposed of after use. Single-use catheters are

not designed to be reused, and it is strictly against the original equipment manufacturers' instructions. The reuse of single-use catheters is a contentious and evolving subject.

The collaborating nursing associations recognize that from professional and practice liability perspectives, they are unable to support the reuse of catheters licenced for single use in any setting.

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Health Canada single-use medical devices



Taken from The Path to Modernize Ontario Public Coverage for Intermittent Catheters and Related Supplies. February 2021. Spinal Cord Injury Ontario

Health Canada single-use medical devices

An integral player in the ecosystem supporting those with SCI are the medical supply companies. Collectively, these industry members represented through Medtech Canada have developed a position paper calling for the Government of Ontario to address patient safety and potential liability risks associated with individuals for financial reasons having to reuse catheters designated as single-use devices.

The Medtech Canada position paper provides compelling evidence as to why the Government of Ontario should review public coverage of intermittent catheters, including:¹

- Single-use urinary intermittent catheters are designed, manufactured and approved for sale by Health Canada to be used only once on a single patient and then to be discarded;
- Potential liability risk with clinicians recommending the reuse of a single-use device particularly if promoting this off-label use poses a patient safety risk e.g., UTIs;
- UTIs not only have a negative impact on a patient's quality of life and associated complications, there is an increasing concern about UTIs and the link to the global crisis of antibiotic resistance;
- The Government of Ontario is advancing a bold initiative to modernize the supply chain which can be leveraged to optimize procurement practices, achieve greater value and improve care for patients.

Recommendations put forward for how the government can embark on this important work, aligned with both the physician and nursing guidelines include:

1. Funding should provide enough coverage to prevent patients from needing to reuse single-use catheters for financial reasons.
2. Patients should have a choice and be able

to continue to use a catheter that is working for them as they move through the system.

3. The public coverage model should be built collaboratively and according to updated Canadian guidelines.

Medtech Canada is the national association representing Canada's innovative medical technology industry. It represents approximately 100 medical technology companies, both Canadian owned and multinational. Medtech Canada works closely with federal and provincial governments, healthcare professionals, patients and other stakeholders to deliver a patient-centred, safe, accessible, innovative and sustainable universal healthcare system supported by medical technology.

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Nicole, 14, is a teenager born with spina bifida. She always required intermittent catheterization to manage a neurogenic bladder. Through her life, she has used many different types of catheters. Children transition from having others perform it to learning self-catheterization.

Catheterization is a fundamental part of her life, taking time away from activities such as school or play as well as the health issues, the stigma and emotional consequences. Nicole recalls missing childhood milestones like birthday parties or sleepovers due to not having the right catheter. Now, Nicole needs the choice of different catheters for different situations. A compact catheter to be discrete or a closed system catheter when no accessible toilet available. Catheters are expensive. Work insurance benefits provide her parents with coverage for Nicole's catheters and supplies. Her parent's employers have changed providers/plans a couple of times. When this happens, due to inconsistencies on the funding catheters they need to advocate for why she needs those catheters. Her parents are worried about the future when she can no longer be covered under their insurance.

Sarah, 25 has a very active lifestyle. She works full-time, plays several sports and is an avid traveller. Sarah has done her research and discovered there are many types of catheters available. She tested several and found she prefers different types depending on her circumstance. Sarah irrigates her bladder every morning and requires a syringe tipped catheter for those specific catheterizations. Sarah finds the standard non-coated catheters enough to meet her needs the days that she spends at home as she has lubricant and additional supplies on hand. When Sarah is out at work or playing sports, she prefers to carry around and use the coated catheters since it is less baggage. She has found hydrophilic catheters

help reduce her risk of infections, particularly in situations where the accessibility of public bathrooms is less than ideal. When Sarah travels, she finds the all-in-one coated catheter with a collection bag to be the most convenient and functional, especially on long flights. However, Sarah's insurance company will only fund her one non-coated catheter a day and expects her to reuse her catheters. Sarah has noticed an increase in urinary tract infections whenever she tries to reuse her catheters. Still, she struggles to cover the additional costs for single-use catheters and the other specialty catheters that suit her lifestyle. This leaves her frustrated and miserable as she has had to cut back on her travel and other activities she enjoyed doing.

John, 62, receives dialysis three times a week to stay alive. John had an SCI 25 years ago that resulted in paraplegia. A complication of the injury was a neurogenic bladder, requiring him to catheterize. Over the years, John continued to work. In a job with no health insurance benefits, he struggles with the costs of catheter supplies, and as a result, he reuses catheters. He had many UTIs over the years with a few becoming chronic and resistant to most antibiotics. The specialists warned him that if he continued to reuse catheters, he could face kidney failure. John has never been able to find employment with coverage that allowed him to catheterize using single-use catheters or as often as he needed. John is worried as he now has severe kidney damage.

Martin, 30, is paralyzed from the neck down. He has a neurogenic bladder, and he uses external catheters for urine drainage. He requires intermittent catheterization twice per day performed by a personal support worker. The cost of bladder care supplies can be a challenge for Martin. Supplies include external catheters, catheters for intermittent catheterization, iodine solution and sterile sponges for sterilization, and gloves. As Martin is under seasonal employment, his supply funding is only periodically covered by the ODSP. He has chosen reusable catheters as he needs an economical and sustainable means of purchasing supplies for his personal care. This choice results in recurrent urinary tract infections. The pandemic has exacerbated his issues as he has had difficulty obtaining some supplies, especially gloves and hand sanitizer, as they were on backorder. Under ODSP, he cannot stockpile supplies for an emergency and financially unable to purchase extra supplies. The stress of worrying if his supplies will arrive before he runs out is enormous. One of his regular caregivers stopped working when the pandemic was announced, which has left Martin scrambling for a replacement. He missed bookings and relied on untrained staff, family and friends to assist him. UTIs have increased since the pandemic started and he has been afraid to get tested at hospital because of the risk of exposure to the virus. He is often on more than one antibiotic to treat his infections without getting tested, which has put him at risk for a chronic urinary tract infection resistant to most antibiotics.

COVID-19 magnified the disparity of what works well and those areas warranting modernization. The narratives about Martin emphasized how the pandemic exacerbated his issues as he has had difficulty obtaining some supplies.

Glossary

Terms

Description

ACSD	Assistance for children with severe disabilities
CNCA	Canadian Nurse Continence Advisors
CPP	Canada Pension Plan
CPP-D	Canada Pension Plan Disability
CUA	Canadian Urological Association
EAUN	European Association of Urology Nurses
FDA	Food and Drug Administration
GRADE	Grading of Recommendations, Assessment, Development and Evaluation
HQO	Health Quality Ontario now Health Ontario Quality
IFHN	Interim federal health benefit
IPAC Canada	Infection Prevention and Control Canada
MSN	Mandatory Special Necessities
NICE	National Institute for Health and Care Excellence
NIHB	Non-insured health benefits
NLUTD	Neurogenic lower urinary tract dysfunction
NP	Nurse practitioner
NSWOCC	Nurses Specialized in Wound, Ostomy & Continence Canada
OAS	Old Age Security
ODSP	Ontario Disability Support Program
OHIP	Ontario Health Insurance Plan
OW	Ontario Works
SAIL	Saskatchewan Aids to Independent Living
SCI	Spinal cord injury
SCIO	Spinal Cord Injury Ontario
UNC	Urology Nurses of Canada
UTI	Urinary tract infection
WSIB	Workers Safety and Insurance Board

Steering committee

An expert steering committee led the development of this report on *The path to modernize Ontario public coverage for intermittent catheters and related supplies* on behalf of Spinal Cord Injury Ontario. The group included persons living with a SCI, physicians, nurses, parents of users, expert consultants, and industry representatives.

The Steering Committee comprised the following members

Blayne Welk, MD – Associate Professor of Surgery (Urology) and Epidemiology & Biostatistics, Western University

Dean Elterman, MD – Staff Urologist at Toronto Western Hospital

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