

EDUCATION SERIES

Urinary Incontinence: The Impact on the Well-being of Older Adults

Disclaimer

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Statement of Funding

This Educational Series is supported by an unrestricted educational grant from GSK.

Introduction

As anyone who has ever experienced a urinary tract infection (UTI) knows, they can be painful, disruptive, and for some people, highly embarrassing. The impact of UTIs goes well beyond the medical condition itself. At the most personal level, many older adults may be hesitant to bring up UTIs with anyone at all, due to stigma, shame or embarrassment. Depending on how UTI symptoms present, the older person may not even be aware of their condition, or ascribe the symptoms to age or other factors.

Often associated with younger women, many older people may not think of UTIs as conditions which apply to them. Some health care providers may not be as attuned to checking for UTIs in older adults despite their prevalence and negative impacts. Government and health policymakers may not keep UTIs, and their associated treatments, front of mind when they are thinking about health care supports – and may be unaware of the economic impacts of the infection or the need for careful antibiotic stewardship.

In short, UTIs are no joke. They are often medically overlooked, poorly managed and personally underreported. UTIs negatively impact physical, psychological, mental and social well-being. And all of these can be improved with education and awareness, policy change, and destigmatization.

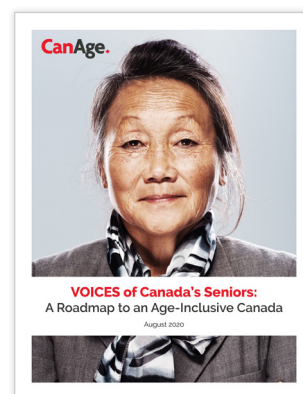
But why is a seniors' advocacy organization focussing on UTIs and incontinence? In short, because UTIs are a growing problem, both in terms of Canada's rapidly aging population in real numbers, and also in terms of impact.

At CanAge, we work tirelessly to educate, empower and mobilize people on the issues that matter most to seniors and their families. As an independent, non-partisan, not-for-profit organization, we believe every Canadian – independent of age – deserves a vibrant, connected, and meaningful life with equitable access to the resources needed to thrive.

As a pan-Canadian organization, CanAge also knows that older Canadians are diverse in their experiences, perspectives, passions, and contexts. As a group, Canadian seniors will represent 23% of the population by 2030. Politically engaged, Canadian seniors are consistently the most active voter group

at the polls, with approximately 72% of seniors indicating that they vote in every election and nearly 80% voting in the last 2 federal elections. The needs of a rapidly aging population must be a key priority for policy-makers.

In 2020, CanAge released its **VOICES of Canada's Seniors: A Roadmap for an Age-Inclusive Canada**. It outlines a way forward for Canada, with 6 Compass Points, 40 Issues and 135 specific evidence-based Recommendations.



The 6 Compass Points of the VOICES Roadmap are:

- V** Violence and Abuse Prevention
- O** Optimal Health and Wellness
- I** Infection Prevention and Disaster Response
- C** Caregiving, Long-Term Care, Home Care and Housing Resources
- E** Economic Security
- S** Social Inclusion



In our UTI 101 series, CanAge explores the effects of incontinence and urinary tract infections amongst each of these 6 Compass Point areas.

V - Violence and Abuse Prevention investigates the links between incontinence, care dependence and elder abuse, neglect and self-neglect.

O - Optimal Health and Wellness digs into issues such as medical under-diagnosis, antibiotic stewardship and co-morbidities and underreporting by individuals due to stigma, embarrassment or conflation of symptomatology.

I - Infection Prevention and Disaster Response explores how long term care IPAC standards intersect with the prevalence, prevention and treatment of UTIs.

C - Caregiving, Long-Term Care, Home Care and Housing Resources delves both how and why avoidable UTIs remain the primary reason for hospital admissions from congregate

care settings and also what we can do to promote urinary health across the housing continuum.

E - Economic Security uncovers both the substantial financial burden UTIs place on the healthcare system as well as the significant cost to an individual for incontinence products and UTI treatments.

S - Social Isolation connects the often tragic and direct links between UTIs on the one hand, and incontinence, loneliness and stigma on the other.

CanAge is committed to the health and well-being of all Canadians as we age. We hope that this series will help to shift minds, policies and treatments options for UTIs and incontinence.

It's time to take this issue on seriously. We hope that this paper, this series and our additional knowledge tools will help to put us on the path to well-being and confidence in aging.

Executive Summary

This paper highlights how urinary incontinence impacts the lives of the older Canadians who live with it. It is for use by stakeholders, government and professionals. It also seeks to be a helpful resource for members of the public.

Urinary incontinence (UI) is the involuntary leakage of urine. The causes of UI are many but the impacts, regardless of the cause, can be debilitating. UI is associated with loneliness, social isolation, feelings such as shame and powerlessness, and financial burden. It is also a condition that can put pressure on caregiving relationships. Sadly, UI is also often simply endured or managed. Barriers to seeking help include the stigma of UI, and the myth that UI is a normal part of aging. Individual experience of these barriers is often influenced by sociocultural factors and sometimes previous negative experiences with the healthcare system. Meanwhile, in institutional care settings, incontinence is contained rather than treated. There are numerous treatment options for UI that run the gamut from pelvic floor exercises to surgical interventions. It is imperative that older Canadians living with UI are able to live stigma free, socially connected lives and are able to explore the options available to them to address their UI.

This paper provides a brief overview of these topics. It is the fourth in a series of papers that explore different aspects of UTIs and incontinence, including: **Urinary Tract Infections 101: Improving Well-Being with Knowledge and Supports**, **Prevention of Urinary Tract Infections: Reducing Risk and Protecting Older Adults** and **Treatment Challenges: Urinary Tract Infections, Older Adults and Antibiotic Resistance**.

For further information on these topics, please refer to the individual papers in the series.

Introduction

Urinary incontinence (UI) is the involuntary leakage of urine.¹ It is a common and often stigmatizing experience that affects many older Canadians. It has many causes and risk factors. This paper seeks to provide a broad understanding of UI and how it is experienced by older people. It focuses on the impact UI has on social well-being, including how it contributes to loneliness, emotional and mental distress, social isolation, financial burden and tension within caregiving relationships. It also examines why many people do not seek help for UI even though there are treatments available. UI is rarely life-threatening but it does threaten the ability of those affected by it to fully engage in their own lives.

Urinary Incontinence: An Overview^{1*}

According to the International Consultation on Incontinence, there are three main types of UI:²

- **Stress incontinence:** involuntary leakage of urine that happens when a person exerts themselves, such as when sneezing or laughing;
- **Urge incontinence:** involuntary leakage of urine that occurs directly after feeling a sudden urge to urinate. People with overactive bladder sometimes experience urge incontinence; and
- **Mixed incontinence:** involuntary leakage of urine that combines both of the above.

Other types of UI include:

- **Incontinence associated with retention of urine:** leakage that occurs when the bladder does not empty completely (also referred to as overflow incontinence);²
- **Functional incontinence:** leakage that occurs because there is a condition preventing someone from getting to a toilet (e.g., mobility issue or arthritis causing difficulty in undoing buttons);²

*This report focuses on urinary incontinence exclusively. Fecal incontinence, the involuntary leakage of solid or liquid feces, is also a topic of concern for CanAge but is beyond the scope of this report.

- **Continuous incontinence:** continuous leakage associated with a variety of conditions such as neurological disorders or a fistula.³

Risk factors for incontinence:

There are many risk factors associated with incontinence. These include, but are not limited to:

- **Female:** age-related changes to the urinary tract, menopause, diabetes, urinary tract infections, obesity, hypertension, level of education.^{2,4}
- **Male:** age-related changes to the urinary tract, conditions/treatments relating to the prostate, diabetes, neurological disease, urinary tract infection.⁵
- **Frail older people (across sexes):** dementia, functional impairment, environmental factors such as inaccessible or unsafe toilets, unavailable formal or informal caregivers, physical restraints.⁶

How common is urinary incontinence?

UI prevalence rates vary significantly. A 2013 Statistics Canada report found 12% of Canadians over the age of 65 had received a diagnosis of UI (the sample excluded people living in institutions).⁷ For Canadians living in long-term care in 2019-2020, 84.7% of residents experience some level of UI with 39.6% being completely incontinent, according to data collected from 6 provinces and one territory through the Continuing Care Reporting System (CCRS).⁸ Prevalence rates of UI, from countries around the world, have been found to be in the 25-45% range for females and 1-39% range for males.²

UI prevalence data should be interpreted with caution. Reasons prevalence rates vary include variability in how the research is conducted and the population being surveyed. For example, some studies define UI as a diagnosed condition, while other studies define UI by a given number of self-reported episodes of incontinence. Prevalence rates might also be affected by the stigma associated with UI as people might under report or not seek help at all for UI.²

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Additionally, studies that include more older people, more women and/or people living in long-term care settings tend to report higher prevalence rates.² Age-related changes to the lower urinary tract (e.g., degenerating muscle tissue) can instigate or exacerbate a UI issue, but there is also evidence that frailty is an important consideration.⁶ The guidelines created by the International Consultation on Incontinence recommend that frailty, not age, govern treatment decisions.⁶ In other words, some people in their 90s may be physically robust, while others in their 60s might be frail (e.g., have weak muscle strength and require help with activities of daily living (ADLs)); the frailer, younger person is more likely to experience UI. Although some risk factors for UI overlap across genders, such as urinary tract infection and functional impairment, prevalence is higher in females across the life course due to experiences like menopause, pregnancy and childbirth that affect the urinary tract and the pelvic floor muscles that support it.^{9,10} This is not to say that males do not have unique experiences with UI. For example, stress incontinence can occur after prostatectomy and reported prevalence rates for dribbling are 7-12%.² Finally, people living in facilities such as long-term care (LTC) homes often experience conditions associated with UI, including frailty and dementia.⁶ Rates of these conditions in Canadian long-term care homes are high: over 50% of LTC residents are “extensively to totally” dependent on assistance for ADLs while just over 60% are experiencing dementia (according to the same CCRS dataset discussed above).⁸

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How Does Urinary Incontinence Impact Well-being?

Loneliness

Loneliness can be defined as a subjective negative feeling associated with a perceived lack in number and/or kind of relationships a person might desire.¹¹ A helpful, though by no means formal, distinction between loneliness and social isolation is that a person can be socially isolated but not lonely (physically alone but not lonely) or surrounded by people but feel lonely. Older Canadians experiencing UI are more likely to be lonely: “34% of men and 53% of women with UI were lonely,

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compared with 24% and 38% of men and women who did not have UI.”(5)⁷ The relationship between loneliness and UI is not entirely clear, although an Irish study hypothesized depression to be an intervening factor.¹² This hypothesis is supported by how people in qualitative studies characterize their experiences of UI as, for example, something they should be able to control.^{13,14,15} A low sense of mastery is associated with depression, and depression is associated with loneliness.¹²

Negative feelings

Beyond being linked to loneliness, people describe a range of negative feelings linked to UI. In research that analyzed 41 qualitative studies (including participants of different ages, genders, and ethnicities), people described feeling depressed and anxious because of their UI, that they had something to hide, worry that others might find out, infantilized, like a failure, exhausted, disgusted and humiliated, embarrassed, ashamed and dirty.¹⁶ There can be impacts specific to particular groups of people as well; an Iranian study exploring the feelings of older women regarding their experiences with UI noted that participants were all Muslim and shared a belief urine is ceremonially unclean. Several participants shared how UI was spiritually upsetting as well as time consuming, due to having to clean themselves and their clothes sometimes several times per day.¹⁷

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Social Isolation

Alongside loneliness and negative feelings, people experiencing UI often cope by limiting their activities to avoid ending up in an embarrassing situation. Examples from the literature include avoiding attending religious services, not using public transportation or paratransit services due to uncertain waiting times, reducing outings, impacts on sexual activity or exercising.^{18, 16, 19, 20} Reducing activities results in social isolation, which is associated with morbidity and mortality. Canadians 65+ who reported being ‘low participators’ (socially isolated) had a shorter lifespan than people who regularly left their house to engage in some kind of activity.²¹ Coping strategies sometimes used to maintain regular activities and avoid isolation can also be harmful to physical health. For example, limiting fluid intake in order to

avoid having to go to the washroom facilitates socializing, but impacts hydration, which is important to neurological, renal and gastrointestinal health.²² Avoiding activities that might affect stress incontinence, such as group exercise activities, might result in lower levels of physical activity, itself an important preventative measure against frailty (which is associated with UI).²³

Financial Cost

Up-to-date data on the costs of UI for individual Canadians was not located, however a 2014 report commissioned by the Canadian Continence Foundation estimated individual seniors living with UI at home will spend an average of \$1,400 to \$2,100 on incontinence supplies.²⁴ Items such as absorbent briefs are tax deductible, but the upfront costs remain a challenge. Other types of costs include medical visits and medication, laundry, bed pads and UI-related devices, barrier creams, and paid caregivers.²⁵ These out-of-pocket expenses can be a challenge for many older adults on fixed incomes and force them to make hard choices about where to spend their money, potentially impacting their ability to participate in meaningful activities. There are also costs associated with missing work due to UI, for both the person living with UI and, if applicable, for caregivers.

When Support is Needed

Some people may need assistance in managing incontinence (eg. changing briefs) or maintaining continence (eg. assistance getting to the toilet), especially those who are cognitively or physically impaired. The level of help needed to manage incontinence can significantly impact important relationships in a person's life. If the severity of incontinence is such that a caregiver (paid or unpaid) provides support, it can represent an added burden, in terms of the time and skills needed to provide care associated with incontinence as well as managing the potential financial and emotional costs.²⁶ Functional dependence, which includes needing help with going to the washroom or cleaning oneself, has a strong association with elder abuse, including emotional, financial and physical abuse.²⁷ Limited literature was located about the direct connection between UI and abuse, however the

idea that functional dependence may contribute to abuse is exemplified by the Model of Attributes to Abuse of Dependent Elders in Continence Care” (MADE-CC). MADE-CC proposes, among others, caregiver exhaustion, resentment, and disgust related to incontinence, the stigma and taboo associated with incontinence and care recipient cognitive health, and severity of incontinence as factors that might perpetuate coercive or abusive continence care.²⁸

In some studies, incontinence has also been identified as a predictor for institutionalization.²⁹ Residential changes, such as moving from home to long-term care, are associated with social isolation.²¹ An Ontario based study found caregiver burden and increased functional dependence were predictors to be on a waitlist for long-term care.³⁰ A Swiss study found older people themselves viewed incontinence as an important factor in considering a move to long-term care.³¹

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Help-seeking Behaviour

In the context of these significant impacts on the social well-being of older people living with UI it is perhaps surprising to learn that research shows many people do not seek help for their UI. One reason is the myth that UI is a normal part of aging, especially for women.³² Another reason is the shame, embarrassment and stigma described above. There is also a body of literature exploring sociocultural explanations for why people do or don't seek help for UI. A few examples include an American study examining perceptions of UI found that viewing UI as a normal part of aging was more common in white participants than in Black and Hispanic participants, while an Australian study found that same myth to be common belief in focus groups with 10 culturally and linguistically diverse groups.^{33,34} Other studies asserted Korean-American women tend to cope with the annoyance of UI due to social and cultural constraints instead of seeking help and a UK-based study found South Asian men, compared to white men, sought help for UI symptoms less, even though perceived need was the same.^{35,36} Additionally, a study analyzing transgender and non-binary patient perspectives about seeking urological healthcare found several barriers to seeking care. Examples include healthcare providers' lack of knowledge and training in both the medical needs and social challenges experienced

One reason is the myth that UI is a normal part of aging, especially for women.³²

by transgender and non-binary people as well as perceiving clinics as non-inclusive spaces.³⁷ Another study reported older people describing their UI concerns being brushed aside by healthcare providers but also not seeing them as important enough to bring up to their doctor.³² Given these examples, it is important to consider how aging impacts and intersects with other identities, such as race, gender and socio-economic status.³⁸

These examples also suggest an important opportunity for healthcare providers to normalize urinary incontinence, address myths about UI and educate their patients with culturally appropriate care. However, there is evidence that suggests that some healthcare providers also view UI as a normal part of aging and do not regularly screen for it.^{32, 39}

Treatment

Clearly, UI has significant negative impacts on the well-being of older Canadians and there are barriers in seeking help. So what can be done? There are many options for UI treatment, outlined in detail by the International Continence Society (2017).² They are supported by varying degrees of evidence, but many can offer improvements in quality of life by reducing or curing UI. It is beyond the scope of this paper to give comprehensive information about treatment, given the variety of types, severity and duration of UI, and the differences across genders and ages. Broadly, however, treatments can be conservative, such as lifestyle and behavioural changes, pharmacotherapy, or complementary or alternative treatments such as acupuncture. Or approaches can be more invasive, including electrical stimulation or surgical interventions. Specific examples include pelvic floor muscle training (PFMT), which has been shown to be effective for multiple types of UI in women, across age cohorts. There is also some evidence to support PFMT for males pre and post radical prostatectomy. For people living with UI related to multiple sclerosis, cannabis-based medicines have shown promising results. For frail older people who have functional urinary incontinence and require assistance, including many people living in long-term care, toileting programs implemented with staff buy-in have been shown to improve UI.

From a quality of life perspective, it is also important to balance treatment with potential impacts of treatment. For example, frail older adults tend to take multiple medications, increasing the risk of drug interactions, so pharmacotherapy to address UI needs to be carefully considered. There is also a difference between containing UI and preventing or curing it. A large UK-based study found using incontinence products such as briefs far exceeded other approaches to managing continence issues. Having adequate staffing to assist people in using the toilet is a commonly cited concern for long-term care staff. In these cases, continence may be possible but is perhaps not prioritized.

Conclusion

There are concrete ways to help many older Canadians living with UI. It does not have to be an isolating condition associated with shame and stigma. UI is often treatable and so are the societal conditions that make people hesitate to discuss and seek treatment for UI. There are opportunities to increase healthcare providers screening for UI and to raise public awareness and knowledge about UI and the treatments available for it. Older Canadians living with UI should not have to suffer needlessly or be denied a vibrant, socially connected life.

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Authored by CanAge.
September 2021

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