# INCONTINENCE: THE CANADIAN PERSPECTIVE

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## **OVERVIEW**

Incontinence is a prevalent health condition that is rarely discussed as people living with the condition are often embarrassed to discuss it with their healthcare providers; for many it is a medical taboo, not to be spoken aloud. Incontinence includes the more common, urinary incontinence (UI) and the less common, fecal incontinence (FI); overactive bladder (OAB) refers to the frequent need for voiding without leakage. Many incontinent people will have both urinary incontinence and fecal incontinence, with or without urinary leakage.

The continence care community generally agrees that the prevalence of incontinence in Canada is about the same as in the United States – about 10% of the population. That means approximately 3.5 million Canadians experience some form of incontinence. Individual research estimates for the prevalence of incontinence in Canada range from 2% to 50% of the population, depending upon the study, the research method, and the questions posed. For example, asking the question "are you incontinent?" will garner a dramatically lower rate of positive responses than the question "do you suffer from occasional leakage of urine?" There tends to be a greater prevalence of incontinence amongst women than men; it is believed that this difference is related to female child-bearing and other consequences specific to women.

The number of individuals living with incontinence is likely to increase as the population ages, since the prevalence of the condition tends to increase with age. One study indicated that incontinence occurs in more than half of community-dwelling women 45 years old and older; almost one of five women in the community reported UI affecting normal activities<sup>1</sup>.

The most common form of incontinence, urinary incontinence (UI), affects individuals' ability to function in daily life. Canadians with urinary incontinence have more frequent visits to their physicians and spend more time in hospitals and nursing homes than those Canadians without UI.

Even though incontinence is not life-threatening or overly disabling per se<sup>2</sup>, it has a major impact upon the quality-of-life for those affected – physical, social, mental, and emotional. The care of incontinence in the community is often funded out-of-pocket which can be a burden on seniors, in particular, on low, fixed incomes. With elders, family care giving is often strained resulting in institutionalization and the accompanying loss of independence.

Direct costs associated with urinary incontinence are significant. Each year, a senior with UI living at home will spend an average of \$1,400 to \$2,100 on incontinence supplies. Further, the cost of a senior with incontinence living in a long-term care facility can total an average of \$4,000-\$14,000 per year for supplies and nursing care. Factoring in laundry, clothing and linen changes as well as supply costs and nursing time, the total direct costs of UI in Canada is over \$1 billion per year. <sup>3</sup>

Indirect costs such as loss productivity, absenteeism, presenteeism, and individual, familial, and societal impacts are more difficult to measure, but it is estimated that the combined direct and indirect costs of incontinence total \$2.6 billion per year.

This does not include the costs associated with fecal incontinence. With both direct and indirect costs being about the same for both UI and FI, but fecal incontinence affecting only about 40% of as many people as UI does<sup>4</sup>, then the total costs to Canada of both UI and FI would be about **\$4 billion** annually.

Considering that continence does not yet have a high profile in Canada, it is important that Canadians are given accurate information on the true burden of the condition, the treatment options available, as well as health policy and funding issues.

#### **URINARY INCONTINENCE**

#### What is Urinary Incontinence?

Your two kidneys produce urine. The bladder is the urine storage reservoir; the urethra is the passage through which the bladder is emptied; supportive structures and pelvic and periurethral muscles are responsible for preventing leakage. Urinary incontinence (UI) is the loss of bladder control due to changes in the underlying muscles and/or nerves. The International Continence Society medically defines UI as the "complaint of any involuntary leakage of urine"<sup>5</sup>.

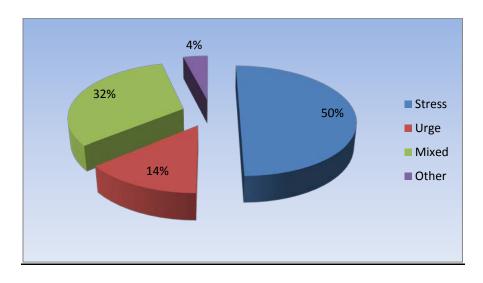
UI can be transient or established. Transient UI is precipitated by a reversible factor such waiting too long and not making it to a bathroom in time while on a long road trip. Sometimes transient UI can be induced by infections or medications. The following are the main types of established UI:

- Stress Urinary Incontinence (SUI) 50% of individuals with UI have SUI, which is the leaking of urine when coughing, sneezing, straining, exercise or any other type of exertion;
- Urge Incontinence (UI) the leaking of urine associated with the sudden uncontrollable urge to empty the bladder that cannot be delayed, and leakage occurs; UI is a key symptom of the overactive bladder syndrome (OAB);
- Overflow Incontinence (OI) the constant leaking or dribbling from a full bladder implying that normal urination is impossible;
- Mixed Incontinence (MI) a combination of stress and urge incontinence.

#### Other types of incontinence include:

- Functional incontinence denotes incontinence related to causes outside
  of the urinary system i.e. a person may have trouble controlling urine, but this
  problem is exacerbated by functional factors, such as physical barriers to the
  toilet, a lack of mobility, an unwillingness to us the toilet due to depression or
  anxiety, medication issues, etc.; this type of incontinence may be managed
  by addressing the functional factor, such as improving the patient's
  mobility, motivating the patient, improving access to the toilet, modifying
  meds, etc.
- **Nocturnal enuresis** bed-wetting in children who are old enough to be "potty trained" and adults who have loss of control at night.

#### Comparative Prevalence of Different Types of Urinary Incontinence



Source: Minassian, VA, Drutz, HP (2003) Int J Gynecol Obstet 82:327-338

#### What causes urinary incontinence?

Urinary incontinence can be caused by a weakening of the pelvic muscles and urethra muscles (the tube that connects the bladder with the outside) or by damaged ligaments. When weakened, the pelvic muscles and urethra cannot contract enough to hold urine when stress is placed on them, such as during a strong cough or sneeze. UI can also occur when a person cannot control the bladder muscle. In these circumstances, the bladder will empty when it has reached a certain degree of filling (such as it does in children before toilet training) or when something happens to make the individual feel the need to urinate.<sup>6</sup>

The following factors<sup>7</sup> are associated with incontinence:

- Increasing age;
- Menopause;
- Weakened pelvic muscles;
- Pregnancy/childbirth;
- Certain medicines (e.g. diuretics);
- Build-up of stool in the bowels/constipation;
- Urinary tract (bladder) infection;
- Diabetes:
- Stroke:
- Smoking;
- Physical conditions affecting mobility and dexterity (e.g. Multiple Sclerosis, arthritis);
- Obesity;
- Caffeine intake;
- Fluid intake;
- High impact physical activities;
- Occupations that involve heavy lifting and straining, and,
- Neurological injury or disease;

One study's results, published in *Canadian Family Physician*, found that urinary incontinence was associated with strokes, arthritis, and back problems in both sexes<sup>8</sup>. Physicians should be aware the UI might be a side effect of certain therapies (such as brachytherapy or cryotherapy for prostate cancer)<sup>9</sup> and also that patients with common conditions such as arthritis, back problems, or respiratory problems associated with coughing should be asked if they also have incontinence.

Another study found a link between depression and incontinence; women with incontinence were twice as likely to be depressed as those without <sup>10</sup>. Younger women with incontinence are also more likely to be depressed than older women with the condition, and the combination of incontinence and depression were found to be associated with many negative effects (stress, increased visits to the physician, and lost days from work).

If you think you have urinary incontinence, see your family physician or other healthcare provider immediately.

#### **OVERACTIVE BLADDER**

#### What is Overactive Bladder?

Like incontinence, overactive bladder (OAB) is a condition – not a disease - that affects millions of Canadians; and as with UI, people suffering from OAB are often embarrassed about the condition and so do not ask for professional help. Others suffer silently because they do not think that there are any treatments for OAB. OAB can affect your work, social life, relationships, exercise and sleep. There are treatments available including changing your lifestyle, medications, and therapy.

Overactive Bladder (OAB) is the name given to a group of troubling urinary symptoms. It has been estimated that amongst Canadians aged 35 years or older, 18.1% have an overactive bladder (21.2% of women and 14.8% of men.)<sup>11</sup> The major symptom of OAB is a sudden, strong urge to urinate that you can't control. You may also worry that you will not be able to get to a bathroom in time. You may or may not leak urine after feeling this urge. You may also experience:

- **Urge incontinence** (see above)
- **Frequent urination**: needing to go to the bathroom many times during the day; many experts agree that going to the bathroom more than eight times in 24 hours is "frequent"
- Nocturnal urination: waking from sleep to go to the bathroom more than once a night is another symptom of OAB.<sup>12</sup>

#### **What causes Overactive Bladder?**

When the bladder is not full of urine, it is relaxed. When your bladder is becoming full, you feel that you need to urinate. That feeling comes from nerve signals between your bladder and your brain, letting you know you have to go to the bathroom. The bladder muscles then squeeze and push urine out through the urethra. The urethra has muscles, called sphincters that help keep the urethra closed so urine does not leak before you are ready to go to the bathroom.

OAB can happen when these nerve signals tell your bladder to empty before it is full. OAB can also happen when your bladder muscles are too active causing your bladder muscles to contract and to pass urine before your bladder is full. This sudden, strong need to urinate is called "urgency." Sometimes OAB symptoms can result from a urinary tract infection (UTI), an illness, nerve damage, or a side effect of a medication.

The risk for symptoms of OAB increases with age, for both men and women. Post-menopausal women, men who have had prostate problems, and people with neurological diseases, such as stroke and multiple sclerosis (MS), have a greater risk of OAB. A diet rich in caffeine, alcohol and highly spiced foods can also increase some people's OAB symptoms.<sup>13</sup>

If you think you have overactive bladder, see your family physician or other healthcare provider immediately.

## **FECAL INCONTINENCE**

#### What is Fecal Incontinence?

The bowel is the part of the body that stores feces, or stools. Fecal incontinence (FI) is the inability to control the bowel, resulting in feces to leak unexpectedly from the rectum. FI is also known as bowel incontinence. Fecal incontinence can range from an occasional leakage of stool while passing gas to a complete loss of bowel control. FI may be accompanied by other bowel problems, such as diarrhea, constipation, gas and bloating<sup>14</sup>.

For most adults fecal incontinence is experienced only ever during an occasional bout of diarrhea. For others, the situation is much more serious with them having recurring or **chronic FI**. In these cases the loss of bowel control can be due to changes in the underlying muscles and/or nerves. A person with chronic FI cannot control the passage of gas or stools, which may be liquid or solid, from their bowels and may not be able to make it to the toilet in time.

A possible complication of FI is **skin irritation.** The delicate and sensitive skin surrounding the anus, after repeated contact with stool and wiping, can lead to pain, itching, and potentially sores or ulcers that require medical treatment.

For some people, including children, fecal incontinence is a relatively minor problem, limited to occasional soiling of their underwear.

For others, the condition can be devastating due to a complete lack of bowel control. The loss of dignity associated with losing control over one's bowel movements can lead to embarrassment, shame, frustration, anger, isolation and depression. Fecal incontinence can be extremely embarrassing which prevents many who suffer from it going to a healthcare provider for help. Treatments are available that can improve fecal incontinence and the sufferer's quality of life. If you, your child, or other family member or friend, develops fecal incontinence see your family physician or other primary healthcare provider. Often, new mothers and elderly people are reluctant to tell their doctors about fecal incontinence but the sooner you are evaluated, the sooner you may find some relief from your symptoms.

#### What causes fecal incontinence?

The most common contributing factors to fecal incontinence include diarrhea, constipation, and muscle or nerve damage. The muscle or nerve damage may be associated with aging or with giving birth 15.

• **Diarrhea:** As solid stool is easier to retain in the rectum than loose stool, the loose stools of diarrhea can cause or worsen fecal incontinence.

- Constipation: Chronic constipation may lead to the formation of impacted stool - a mass of dry, hard stool in the rectum that cannot be passed stretching and eventually weakening the muscles of the rectum and intestines, allowing watery stool, from farther up the digestive tract, to pass around the impacted stool and leak out.
- Muscle damage: If the rings of muscle at the end of the rectum (anal sphincter) are injured then it may become difficult to hold stool back properly. This sort of injury can occur during childbirth, especially if an episiotomy is performed or forceps are used, or during surgery, such as to remove hemorrhoids.
- Nerve damage: If the nerves that sense stool in the rectum or those that
  control the anal sphincter are injured, this too can lead to fecal incontinence.
  This kind of nerve damage can be the result of childbirth, constant straining
  during bowel movements as a result of chronic constipation, spinal cord injury,
  or stroke.
- Some diseases, such as diabetes and multiple sclerosis, also can affect these
  nerves and cause damage that leads to FI. Surgery, such as that to remove
  hemorrhoids, can also damage the nerves in this area.
- Reduced rectal storage capacity: The rectum stretches to accommodate stool. If your rectum has been scarred, or your rectal walls have stiffened from surgery, radiation treatment or inflammatory bowel disease, the rectum cannot stretch as much as it needs to, and stool can leak out.

There are a number of risk factors associated with the development of FI:

- Age. FI can occur at any age but it is most common in middle-aged and older adults; approximately 1 in 10 women, older than age 40, has fecal incontinence.
- **Female.** FI is slightly more common in women than in men, because it can be a complication of childbirth, but most women with fecal incontinence develop it after age 40, so other factors may be involved also.
- Dementia. FI is often present in late-stage Alzheimer's disease and dementia.
- Physical disability. Being physically disabled may make it difficult to reach a
  toilet in time; an injury that caused a physical disability may have caused rectal
  nerve damage leading to fecal incontinence.

If you think you have fecal incontinence, see your family physician or other healthcare provider immediately.

## **FOCUS ON URINARY INCONTINENCE**

Compared with many other conditions, accurate statistics on the prevalence of incontinence (percentage of the population with incontinence) are difficult to source. One of the main reasons for this is the perceived social stigma associated with incontinence and thus the suspected under-reporting of it. Even people with symptoms of incontinence often will not admit to it, or seek treatment for it. According to the Canadian Urinary Bladder Survey only 26% of those with any bladder problem had seen a doctor or health care professional. <sup>16</sup>

Patients are often reluctant to discuss this issue with their family, friends and physician and, as a result, the under-reporting of symptoms is highly prevalent. Shame, denial, embarrassment and begrudging acceptance are the key deterrents of seeking help. In fact, more than half of women with Stress Urinary Incontinence do not seek help from a healthcare professional.<sup>17</sup>

Variations in how incontinence is defined also leads to significant disparities between studies. For example, the number of people who suffer from symptoms of incontinence daily will vary significantly from those who experience symptoms weekly or even less frequently. Depending upon definition and frequency, differences in the prevalence of incontinence have ranged from 5% of the population to 50% of women over 45 years of age. <sup>18</sup>

In 1997 a telephone survey of urinary incontinence was conducted in Canada among a random and representative sample of adult women. Nearly 9% of all respondents reported urinary incontinence, 56% of whom were below 55 years of age. Over half of the respondents had never consulted a physician about their incontinence, which underlines the poor self-reporting of the problem. Based upon these findings, the actual prevalence of urinary incontinence was therefore considered to range between 10% and 20% of the female population. <sup>20</sup>

The benchmark Canadian Urinary Bladder Survey (CUBS) reported in 2003 that 8% of all respondents initially acknowledged having a bladder problem. However, 52% responded "yes" to having one or more bladder symptoms with the commonest symptoms being nocturia (38%), urgency (16%), frequency (14%), stress incontinence (13%), and urge incontinence (7%).<sup>21</sup>

The following table shows the percentage of males and females with any degree of incontinence stratified by age as determined by the Canadian Urinary Bladder Survey:

	Age (years)			
	18-40	41-64	≥65	
Males	10%	16%	30%	
Females	16%	33%	55%	

Statistics Canada collects information about health at the community level every year and publishes an annual Canadian Community Health Survey (CCHS). The last year in which information on incontinence was collected was 2008/2009<sup>22</sup>; it was published in 2013 but only focussed on seniors; 2005 was the last year in which full demographic data on UI was collected. The five year lag between data collection and reporting is a problem with measuring an accurate prevalence for UI in Canada; data is always out-of-date. Furthermore, there is no continuous longitudinal, comparative data collected or available for the public, with the latest being 10 years old.

The most recent study, of women aged 20 or more years, reported that 36.5% admitted to having symptoms of UI of which three-quarters considered themselves to be incontinent.<sup>23</sup>

The following data is derived from combining the 2005 and 2008/2009 study results and applying it to Canada's population in 2014. Although statistically this is not totally reliable, with only a 3 year gap in data collection this probably creates the best picture available for the current prevalence of UI in Canada. In 2005 the overall prevalence of urinary incontinence in Canada was just under 3%, with women having significantly higher rates than men. This figure is significantly lower than the prevalence figures cited above by other researchers. This may be due to the manner in which the question was asked (i.e. a more appropriate question may have been "have you ever experienced involuntary leaks of urine"), or due to shyness in responding to this question to a government surveyor. The prevalence of urinary incontinence increases rapidly with age — particularly once adults reach the age of 65 years. Canadians who live to be 85 years or older will have a 21% chance of being incontinent.

#### <u>Urinary Incontinence: Overall Prevalence & By Gender, 2014 estimate</u>

Has urinary incontinence	Population	% of Total	Female Population	% of Total Female	Male Population	% of Total Male
YES	1,047,768	2.98%	714,255	4.03%	331,294	1.90%
NO	34,077,072	96.92%	16,993,243	95.88%	17,086,075	97.99%
DON'T KNOW	24,612	0.07%	8,862	0.05%	13,949	0.08%
REFUSAL	7,032	0.02%	3,545	0.02%	1,744	0.01%
NOT STATED	3,516	0.01%	1,772	0.01%	3,487	0.02%
TOTAL*	35,160,000	100.00%	17,723,450	100.00%	17,436,550	100.00%

<sup>\*</sup>totals rounded

## **Urinary Incontinence: by Province & Gender, 2014 estimate**

Province of	Population		Females		Males	
Residence	with UI	%	with UI	%	with UI	%
Newfoundland & Labrador	16,230	3.08	10,882	4.0	5,348	2.01
Prince Edward	5,090	3.48	3,613	4.8	1,477	1.99
Nova Scotia	29,316	3.11	19,227	4.0	10,089	2.12
New Brunswick	21,260	2.82	14,288	3.7	6,972	1.83
Québec	220,974	2.69	157,240	3.7	63,734	1.52
Ontario	417,201	3.05	272,865	3.9	144,336	2.10
Manitoba	39,102	3.05	30,463	4.6	8,639	1.35
Saskatchewan	45,128	4.01	29,802	5.2	15,326	2.71
Alberta	113,346	2.75	73,572	3.5	39,774	1.94
British Columbia	149,591	3.23	105,087	4.5	44,504	1.91
Total*	1,047,768	2.98	714,255	4.03	331,294	1.90

<sup>\*</sup>totals rounded

#### Urinary Incontinence: Prevalence by Age & Gender, 65 or older, 2014 estimate

Age	Population		Females		Males	
Cohort	with UI	%	with UI	%	with	%
65 to 74	208,000	8.2	130,000	9.8	78,000	6.4
75 to 84	222,000	14.4	143,000	16.6	79,000	11.6
85 or older	108,000	21.0	75,000	22.3	34,000	18.7
Total*	538,000	11.7	348,000	13.8	190,000	9.2

<sup>\*</sup>totals rounded

## THE BURDEN OF URINARY INCONTINENCE

The Canadian Urinary Bladder Survey estimated that, 10 years ago, UI cost Canadians \$1.5 billion per year. In 2014 dollars that would be \$2.3 billion – but that is just the direct treatment and management cost. When assessing the burden of any condition, it is important to consider not only the direct costs, but also the indirect costs to both the individual and society, even though these are often much harder to quantify.

A study conducted in 1995 estimated that the annual direct and indirect costs associated with urinary incontinence for individuals over the age of 65 in the United States totalled \$26.3 billion, or \$3,565 annually per incontinent individual.<sup>24</sup> Another study conducted in the US in 2000 presented similar numbers.<sup>25</sup> In 2014 dollars these amounts would be, respectively, \$40.8 billion and \$5,530.<sup>26</sup> Given that the Canadian population is approximately 1/9<sup>th</sup> of that of the US, and converting to Canadian dollars, the estimated direct and indirect costs associated with UI in 2014 would be \$5.13 billion in total, or \$6,263 per incontinent individual per annum.<sup>27</sup>

The combination of Canada's ageing population and the tendency for urinary incontinence to become more prevalent with age, means that incontinence will likely become an increasing burden on society as well as for the individuals suffering from UI, their families and caregivers. In some jurisdictions, already, the amount of money spent by consumers on adult diapers is greater than the amount spent on baby diapers.<sup>28</sup>

#### **Direct Costs**

#### **Physician Care**

The direct costs of physician care related to urinary incontinence include the time spent with patients by general practitioners, family physicians and other primary care providers to diagnose the condition, develop treatment or management strategies, and/or refer them to specialists. Often several visits to the doctor's office will be required to determine the etiology and treatment plan. If a patient is referred to a specialist, then the incremental physician care costs would include the time spent by the specialist on their assessment of the patient, evaluation for treatment, implementing the treatment and patient follow-up.<sup>29</sup> Below is the diagrammatic clinical practice guideline for managing adult UI developed for Canadian family physicians.

#### **Medications**

Recent innovations in the molecular design of and new dosage forms of UI medications offer the promise of fewer and less severe adverse effects and, thus, better treatment outcomes for patients. Additionally, the availability of multiple agents within a therapeutic class offers health care providers a spectrum of choices with which to personalize treatment for each individual patient. Alternate dosage forms, which include patches and sustained-release formulations, may benefit patients who have difficulty chewing, swallowing, or remembering to take medications.

#### **Hospital Care**

While conservative treatments such as bladder retraining and pelvic muscle exercises are the first treatments of choice for incontinence, surgical options are available for those who do not respond to other types of treatments. Surgical options for SUI include colposuspension (retropubic suspension) and slings. Cost-effectiveness, risks, and side effects all influence the appropriateness of a surgeons' recommendation to a patient.

#### Urinary incontinence with: Presenting Womer Physical Mixed Urgency/ Other or unclear Isolated post-void symptoms General history Physical Examination + Complex history + Focused incontinence history Investigations, urinalysis &/orculture/sensitivity significant pelvic organ prolapse W possible obstruction M Voiding diary Goals & expectations of Environmental/functional assessment General assessment Quantification of urine loss Qualification of urine loss hematuria Fluid intake (amount/type) Specific assessment: Medications pelvic pain significant post-void E Focus on: w vaginal inspection Associated urinary symptoms voiding diary & fluid intake Previous medical history W Feeling of prolapse Bowel function/fecal incontinence w pelvic examination residual nost-void residual recurrent urinary tract infections floor strength assess for depression & cognitive function Chronic conditions pelvic irradiation neurologic con ogic condition Impact on quality of life M genital exam clinical M rectal exam assessment radical pelvic surgery suspected fistula vironmental/ functional factors fecal incontinence complex psychiatric causes complex comorbidities E polypharmacy drug interactions comorbidity constipation/fecal musculoskeletal exam/gait impaction (atrophic vaginitis, discharge) Signs of leakage Trapping urine Stress Mixed Urge Incomplete factors ■ in posterior etiology incontinence incontinence incontinence emptying urethra Environment & lifestyle interventions; pelvic floor muscle training; bladder retraining Treatment/ devices w estrogen w tricyclics w treat both etiologies or anticholin alpha blockers finasteride M environmental ■ urethral massage includes modifications specific treatment of containment & skin care refer for surgical refer indwelling catheter non-urological exercises evaluation refer for surgical factors mprove mobility E + Lifestyle Interventions (fluid intake, caffeine, alcohol, cigarettes, weight loss, diet, scheduled treat depression toileting, bowel management); focus on: reduced Drug Dosage nanage dementia 🖪 Number of pads/type used; voiding diary Goals/expectations met? Subjective/objective report of improvement Evaluation refer for geriatric Second-line management or care or continuing management (in community or long-term care); multidisciplinary approach

#### Clinical Practice Guideline for Managing Adults with UI

#### **Long-term Care**

Urinary incontinence is currently the most common cause of admission to long-term health care centres in Canada and the United States. According to the Public Health Agency of Canada the incidence of incontinence rises dramatically - nine to ten times - for seniors resident in long term care facilities compared to seniors residing "at-home" in the community. 30

Shih et.al. in the U.S. calculated both incremental labour and supply costs associated with caring for individuals with incontinence in long term care facilities versus those without incontinence.<sup>31</sup> Applying the same inflationary and currency exchange factors, as above, to this U.S. cost data yields an average annual incremental cost to Canadian long-term care of \$10,000 per resident with UI.

New pharmacologic and surgical treatment options for UI have the potential to allow greater independence for older persons who reside at home and to delay or avoid admission to long-term care facilities. Although these newer products and treatments are generally more expensive than older forms of therapy, they typically have more favorable cost-effectiveness ratios. Access to these new medications and surgical treatments may help to reduce the economic and social burden of UI care.

People in long term care centres can develop incontinence if their mobility is limited and healthcare providers do not have time to take them to the bathroom when needed. Incontinence and immobility lead to rashes, decubitus ulcers – or pressure ulcers - and urinary tract infections that add further, mostly preventable costs. <sup>32</sup>

#### Individual expenses

Each year, a senior living at home with UI will spend on average \$1,400-\$2,100 on incontinence supplies, including:

- adult diapers;
- catheter supplies;
- mini and maxi pads;
- additional laundry expenses;
- additional dry cleaning expenses;
- additional toilet paper and paper towels;
- incontinence products:
- homecare services; and
- medications/treatments not covered by healthcare plans.

#### Counseling

It is not uncommon for people with UI to feel socially stigmatized and/or to be depressed. The cost of counseling may be an additional cost that must be covered by the patient.

#### **Indirect Costs**

#### Loss of productivity

The Canadian economy suffers losses related to UI through reduced employee productivity. According to a 1998 U.S. research study on the cost of just SUI, the average workplace loss was approximately \$4,929 per person. Again, using inflationary and currency exchange factors, this loss of productivity amounts to \$7,654 in 2014 for each Canadian with SUI. This cost to the economy can manifest either in the form of increased absenteeism or presenteeism.

#### Absenteeism

Absenteeism refers to the loss of productivity that results from an employee taking off unplanned days. While it is expected that employees will miss some days at work due to illness, conditions such as UI tend to increase this dramatically.

#### Presenteeism

Presenteeism refers to the loss of productivity that results from an employee being on the job but, because of medical conditions, is not able to function at their normal level.

#### Family caregiver

Depending on factors such as the type or severity of UI, or the age of the person, it may be necessary for a family member to act as a caregiver. If the family member must stay home full-time, their ability to provide income for their family is impeded. Even if the family member only needs to stay home part-time, it can reduce their income, influence their performance at work, and/or affect their career development.<sup>35</sup>

#### Falls

People with UI symptoms often rush to the bathroom thus, especially amongst seniors, increasing their risk of falls that can lead to fractures and even admission to long-term care facilities.<sup>36</sup>

## **QUALITY-OF-LIFE ISSUES**

Although incontinence is not life-threatening<sup>37</sup>, it can have a significant negative impact on one's physical, psychological, sexual, social and overall quality-of-life.<sup>38</sup> Healthcare professionals use two quality-of-life questionnaires (ICIQ-UI and IIQ-7) when investigating the impact of UI.

Women with chronic incontinence may avoid social situations for fear of having an 'accident' causing emotionally devastating social isolation. Sexual activity may be restricted or avoided entirely. Women living with incontinence are much more likely to suffer from depression than their continent peers.<sup>39</sup> In fact, urinary incontinence, Alzheimer's disease, and stroke are the 3 chronic health conditions that most adversely affect an individual's health-related quality of life.<sup>40</sup> Amongst men, as symptoms of UI increase with age so self-reported, health-related quality-of-life decreases.<sup>41</sup>

As a result of UI, some people may restrict their activities:

- Limit physical fitness (reluctance to exercise due to potential triggering of condition);
- Limit ability to work (due to potential triggering of condition and social perception);
   and/or
- Limit social engagement.

Living with UI also results in a decrease in ability to maintain an independent lifestyle. <sup>42</sup> Dependence on caregivers for activities of daily life increases as incontinence worsens. Spouses and other intimates may share the burden of UI in a loved one.

All of this culminates in loneliness amongst Canadian seniors with UI. In 2008/2009 Statistics Canada reported that community-living seniors with UI were much more likely to be lonely than those without the condition. Amongst senior women with UI, 53% felt lonely whereas 36% of senior men with UI did. The odds of being lonely were almost double for seniors with UI than those without regardless of age, gender, education or living arrangements within the community. Loneliness is highly associated with negative health outcomes. It is quite likely that UI has a much broader impact upon healthcare costs overall than previously thought. Addressing UI earlier and more comprehensively amongst Canadian seniors could go a long way to reducing loneliness and related downstream health outcomes.

#### TREATMENTS AVAILABLE

A wide spectrum of treatment options is available for men and women with UI. New concepts in continence mechanisms, behavioural treatments, and new medications have led to advances in treatment. If conservative options such as behavioural treatments and pelvic floor exercises are not effective, less conservative treatments may then be considered. Diapers or pads are used throughout many treatments. Patients who are treated successfully may still require full briefs or disposable products, but to a lesser extent.

#### **Behavioural Treatments**

Behaviour modification is sometimes overlooked as the first treatment option for patients with urge incontinence. In a study assessing the treatment of urge incontinence, drug therapy was the first-line treatment for 50% of patients studied, and only 13% were treated with behaviour therapy first.<sup>44</sup>

The Canadian Continence Foundation, and other national and international bodies, recommend conservative (behavioural - non-drug, non-surgical) treatment as the first response to managing UI. There is evidence that conservative management including

behaviour training, education, scheduled voiding, positive reinforcement and pelvic muscle exercises with various techniques can help control urinary incontinence, but it may not work for everyone. For example, pelvic floor exercises are effective in managing stress incontinence and mixed incontinence; however, it is unclear whether they can help women with urge incontinence.

Behaviour therapy seems to be effective in some groups of patients, but not in others. Behaviour therapy requires resources such as staff (i.e. administrative staff, nurse continence advisors, trained physiotherapists and other specialists) and clinic space in order to effectively teach patients new behaviours. According to a study performed in Australia, it was found that physiotherapy was effective in treating stress urinary incontinence in 80% of cases<sup>46</sup>. Physiotherapy has further been found to be effective in helping treat persistent post-natal stress incontinence<sup>47</sup>.

### **Lifestyle Changes**

"Lifestyle changes" combine education on healthy bladder behaviours with positive reinforcement and a scheduled voiding routine. Healthy bladder behaviours include:

- Limiting or avoiding caffeine/alcohol (coffee, tea, carbonated drinks);
- Drinking non-caffeinated fluids six to eight cups (1.5-2.0 litres) per day;
- Trying to avoid getting up more than twice a night;
- Not "pushing" when urinating;
- Maintaining a healthy weight;
- Not smoking; the chronic smoker's cough is a risk factor for incontinence; and,
- Eating more fibre to avoid constipation, which strains and weakens the pelvic floor.

#### Bladder retraining

Bladder retraining requires training, motivation and continued caregiver effort and includes:

- Timed Voiding: Voiding on a schedule based on time between incontinent episodes (for cognitively intact individuals);
- Bladder retraining: Increasing bladder capacity and awareness; encouraging the patient to ignore the fist urge and void on their second urge;
- Prompted voiding: Reminding or asking the patient if they need to void on a schedule based on their voiding pattern (for cognitively impaired individuals).

## **Pelvic Floor Retraining**

Pelvic floor retraining is the use of Kegel exercises, first introduced over 50 years ago to

strengthen pelvic floor muscles and prevent urinary leakage. Some women may be familiar with them from their exercises during and after pregnancy or in the gym. The proper use of Kegel techniques requires education and proper training, such as that provided by a physiotherapist or nurse continence advisor. Performing Kegels along with behavioural interventions can help prevent and improve UI.

The following is an example of a Kegel exercise:

- Sit on a firm chair so you can feel your buttocks; keep feet flat on the floor;
- Pretend you need to stop gas from passing and squeeze those rectal muscles by pulling in;
- Try not to tighten your abdominal and buttock muscles;
- Hold for three counts, relax for three counts; remember to breathe;
- Gradually over time increase the hold and rest intervals to 10 seconds;
- You should feel a tweaking at the front of the pubic bone when you are holding;
- Repeat this squeezing exercise ten times; this equals one set;
- Do 3 sets (30) three times per day.

#### Intermittent Self-Catheterization

Some women experience a problem with an inability to empty their bladder completely. In severe cases, the amount of urine left in the bladder is so large that it causes frequent urination and possibly, overflow incontinence. Intermittent self-catheterization involves passing a small disposable catheter through the urethra and into the bladder to empty it. This procedure can be done several times each day to keep the bladder from getting too full. It must be done in a clean environment to avoid infection.<sup>48</sup>

#### **Medical Treatments**

#### Injectables

Injecting bulking agents, such as collagen, to narrow the urethral walls has been shown to be successful and is minimally invasive. However, when compared to surgical options, research studies have shown limited efficacy for bulking agents. After 3 years following the treatment, fewer than half of the women who underwent the procedure maintain continence. Another barrier to this approach in Canada is that the cost of the injectable is usually borne directly by the patient, and this can be as much as \$2000 or more. Overall, up to 75% of women with SUI may benefit from injectable treatment for short periods of time. There are various agents available (collagen, silicone rubber particles, ethylene vinyl alcohol, non-animal stabilized hyaluronic acid). Many physicians use Botox also, although it is not yet approved.

Botox is a purified form of Botulinum toxin type A. Botox blocks the transmission of nerve cells, and causes muscle relaxation. Botox received Health Canada approval in 1990 for treating a number of medical conditions but not for urinary incontinence. The

use of Botox in treating UI is considered "off-label". It was first reported used for incontinence caused by neurological disease, such as multiple sclerosis, in 1999 and for non-neurological incontinence in 2001. This treatment is therefore limited to a small number of specialists with an interest in these bladder conditions, and it is only offered to patients with specific types of incontinence, and only after other approved therapies have been tried. As the use of Botox in UI is not an approved use by Health Canada, coverage by government or private insurance plans is limited to certain situations only.

#### Estrogen

While it has been used as a treatment, there is no compelling, objective evidence that exogenous estrogen is effective in treating urge or stress incontinence.<sup>49</sup> Topical vaginal estrogen may improve urogenital aging symptoms such a vaginal dryness and some sensory bladder symptoms.

#### **Pharmaceuticals**

There are several types of drugs used to treat patients with overactive bladder with symptoms of urgency, urgency incontinence, and urinary frequency:

- Anticholinergic/antispasmodic medications reduce feelings of urgency and inhibit contraction of the detrusor muscle (e.g., oxybutynin, tolterodine, trospium, flavoxate, darifenacin, fesoterodine, solifenacin);
- *Tricyclic antidepressants* can exert an anticholinergic effect by blocking norepinephrine or serotonin amine uptake (e.g., imipramine);
- *Mirabegron* is a potent and selective beta 3-adrenoceptor (AR) agonist indicated for the treatment of OAB.

Recent innovations in molecular design and new dosage forms of UI medications offer the promise of fewer and less severe adverse effects (such as dry mouth, blurred vision, dry eyes, decreased sweating, and gastrointestinal effects) and, thus, better treatment outcomes for patients as they will more likely stay on their medication. Additionally, the availability of multiple agents within a therapeutic class offers health care providers a spectrum of choices with which to personalize treatment for each individual patient. New pharmacologic treatment options for UI have the potential to allow greater independence for older persons who reside at home and to delay or avoid the costs of admission to long-term care facilities. Alternate dosage forms, which include patches and sustained-release formulations, may benefit patients who have difficulty chewing, swallowing, or remembering to take medications.<sup>50</sup>

Drug therapy is effective and safe for many patients with urge incontinence, and with advances in drug technology, ideally the adverse effects of these drugs will continue to decline. Nonetheless, there is still a subset of patients for whom drug therapy does not work to control their urge incontinence.

#### **Mechanical Treatments**

#### **Pessary**

A vaginal pessary is a nonsurgical way to treat certain problems caused by weak pelvic muscles, such as urinary incontinence. A pessary is a device made from medical grade plastic, rubber or silicone that is inserted into the upper vagina where it touches the cervix. Some pessaries are inflatable and may be easier to insert. The pessary presses on the urethra through the vaginal wall and holds up the bladder neck and uterus, if present. It may also pinch the urethra closed to help retain urine in the bladder. It is usually not necessary to remove the pessary to urinate. Normal bladder contractions can usually force urine out through the pinched-off urethra.

Pessaries help to keep the pelvic organs in place and can reduce the discomfort caused by a prolapsed uterus, bladder, or rectum (where these organs slip or protrude). These devices also: can provide patients with an interim solution until it is convenient to schedule surgery; or, help healing after surgery.

Side effects that are shared among most different types of pessaries are risks of increased vaginal discharge, vaginal irritation, ulceration, bleeding, and dyspareunia (painful intercourse for the male or female).

#### **Surgical Treatments**

Surgery may be the best option for many women with Stress Urinary Incontinence to become incontinence-free. However, there are always potential complications with any surgery. Various surgical procedures have been devised to help patients become incontinence-free, including:

#### Retropubic suspension technique

During this procedure, stitches are placed into the vaginal wall on the side of the urethra and sutured to either the *symphysis pubis* or to the front of the pelvic bone to provide a rigid backboard to the urethra. These techniques have been shown to have good long-term efficacy. The two most common types of this surgery are known as the Burch procedure (colposuspension) and the Marshall-Marchetti-Krantz procedure (MMK). The Burch procedure used to be the procedure of choice until the introduction of mid-urethral slings (see below).

## Slings

This technique involves using a graft of fascia (strong tissue lining muscles) that is placed under the urethra for support. The sling is fastened to the abdominal wall.

#### Mid-urethral sling

The mid-urethral sling procedure (TVT, or tension-free vaginal tape surgery) is the most common surgery for incontinence and is a minimally-invasive, outpatient procedure,

highly effective at reducing the symptoms associated with stress urinary incontinence in women who have failed conservative treatments for SUI, such as pelvic floor muscle therapy and behaviour modification. This technique involves the use of a loose-weave polypropylene mesh tape, or ribbon, placed under the urethra, which is supported via the retropubic space by the abdominal wall. This application requires limited vaginal dissection and only light anaesthetic requirements. A polypropylene mesh is applied around the mid-urethra in order to hold it securely. This provides support without fixation of the bladder neck; the whole procedure takes much less time than a Burch procedure, and costs less.<sup>51</sup>

Although the mid-urethral sling procedure has been successful for many women, Health Canada has issued several warnings about the complications and side-effects, which have also been noticed with non-mesh procedures as well. According to Health Canada there have been "reports of acute or chronic pain, mesh erosion (extrusion or exposure), infection, voiding dysfunction, dyspareunia (pain during sexual intercourse), organ or blood vessel perforation, neuromuscular damage, bleeding or hemorrhage, as well as recurrent SUI. Mesh contraction is an additional complication and its occurrence has been associated with reports of vaginal tightness and/or shortening. The presence and severity of the complications may vary from patient to patient. Revision surgery may be required and may not fully correct some complications. Single-incision mini sling procedures are novel techniques for the treatment of SUI and may carry higher risk of complications than the traditional mid-urethral sling procedures. Surgeons performing transvaginal mesh sling procedures should have adequate training specific to the devices used at your institution, be familiar with the labeling of each device, in particular, sections concerning warnings and implantation technique." 52

#### Transobturator approach

Rather than supporting the mesh tape via the abdominal wall, as above, a number of French surgeons devised a technique to support it via the pelvic bone, or transobturator area. This minimally invasive outpatient procedure allows the surgeon to stay out of the abdominal cavity, thereby reducing the small risk of bleeding and other complications

#### Transurethral resection of prostate

Transurethral resection of the prostate (TURP) has been suggested as a treatment for overflow incontinence in men. The TURP procedure is usually used to treat benign prostatic hypertrophy (enlargement of the prostate that interferes with urine voiding). During the course of the procedure, the surgeon threads a thin tube through the penis, up the urethra to the prostate. The tube has a looped wire attached to it that is heated with an electric current and used to cut away a small portion of the prostate.

#### **Sacral Nerve Modulation**

During Sacral Nerve Modulation (SNM), a device is implanted to electrically stimulate the sacral nerves in an attempt to manage voiding conditions. It is a reversible procedure, in that the device can be removed without permanent injury. The role of SNM is to manage patients who have not been treated successfully with behaviour therapy, drug therapy, or external stimulation (for urgency incontinence). There are three types of bladder problems for which this treatment may help: OAB with or without incontinence, Painful Bladder Syndrome/Interstitial Cystitis, and Voiding Dysfunction.

The sacral nerves play an integral role in micturition (process for discharging urine). The micturition reflex is a 2-part cycle consisting of: filling (storage) and emptying. For the reflex to function properly, both systems must be intact. First, the receptors and neurotransmitters must be balanced for the muscles to operate properly. Second, the neurosensory pathway along the brain, spinal cord, and bladder must be intact. The receptors in the bladder signal the sacral nerves that the bladder is full or empty. An interruption in this process causes voiding difficulties. SNM aims to correct the disruption between the nervous system and the bladder so that normal voiding can resume. By stimulating the sacral nerve with electrical pulses, the device mimics the signals required for normal micturition.

#### Stem cells

New treatments for female SUI and MUI using stem cells to regenerate muscles in the urethra are currently in initial phases of research and development. Stay tuned.

## **HEALTH AND PUBLIC POLICY ISSUES**

#### **Underreporting of Incontinence**

Developing an accurate count of the number of people affected by all forms of incontinence is a challenge since it is a condition that is often underreported due to the stigma involved resulting in denial, acceptance and shame. This also, partially, is a result of a general lack of awareness and how some survey questions are worded and (i.e. "Have you been diagnosed with SUI?" versus "Have you experienced any leakage?").

#### **Public Education**

Urinary incontinence is a condition that not many people are aware of and also one that not many people ask their doctor about — even if they have it. Similarly, there is a general lack of information that is readily and privately available to women and men living with incontinence.

The Canadian Continence Foundation provides public education but a well-funded public health awareness campaign would help to de-stigmatize the condition and educate people about some of the effective treatment options.

### Long wait times for care

If a patient overcomes their reticence and discusses their incontinence with their physician, they will often have to wait 6-9 months before they will see a specialist. Another 4-6 month wait is generally required to assess their incontinence, and if surgery is an option, patients can wait up to two years to receive the surgical treatment that they require. <sup>53</sup>

#### Reimbursement

Many incontinence treatments (such as injectable bulking agents, which cost as much as \$2,000 and more) are not covered by government or many private health insurance plans, meaning that the patient will need to cover the full cost of the treatment out-of-pocket.

#### Access

Most of the drugs for OAB and the symptoms of UI that are reimbursed for seniors and low-income patients by government are older, less effective drugs, and have more negative side effects. Provincial governments are slow to adopt newer, more effective drugs that are available in other developed countries and even approved by Health Canada. If a person suffering from incontinence does not have private health insurance and wants to use these newer, more effective drugs, they must pay for

them out-of-pocket. As the prevalence of incontinence increases with age, it is often seniors living on fixed incomes who would want to take these medicines, but often lack the financial ability to do so. If you find yourself in this situation, see if the manufacturer of the drug can assist.

#### **Cost of products for incontinence**

Each year, an individual with incontinence living at home will spend an average of \$1,400 to \$2,100 on incontinence supplies. Incontinence supplies are not covered by the provincial government health plans, or by most private insurance companies, meaning that the full cost of supplies is borne by the individual.

#### Lack of Physician Knowledge

According to a survey of family physicians' knowledge, attitudes and practices, most family doctors reported that incontinence was common in their practices, but less than half indicated that they clearly understood incontinence and just 38% had an organized plan for incontinence problems. Only 35% of respondents felt very comfortable dealing with incontinence. So, when a person suffering with incontinence finally gathers the courage to ask their doctor about their condition, the vast majority will not be provided with appropriate education or treatment as there are such variations in knowledge, and comfort level among family physicians dealing with this condition.

#### **Initiation of Long Term Care**

Loss of bladder control is one of the most common reasons why caregivers institutionalize their elderly parents – a situation that is psychologically difficult for all parties because of feelings of humiliation and guilt.<sup>55</sup> Further, older adults who have to get out of bed to use the bathroom in the middle of the night are more likely to fall in the dark than those who do not have this problem. Falls can lead to broken hips, which is another major cause of institutionalization of older adults, and loss of independence.

If an elderly patient arrives at a long term care facility without being incontinent, it is likely that they will develop incontinence in the first year of their stay. Risk factors for developing incontinence during the first year of admission include bring male, dementia, mobility impairment and poor adjustment to the centre. Furthermore, as behavioural treatment is considered to be the first treatment of choice, it is often not implemented in nursing homes as it can be resource-intensive (requires time from staff, and access to trained nurses or physiotherapists in order to be most effective.) However, if incontinence is not treated, it can lead to other much more costly conditions such as depression, falls, fractures and skin lesions.

## CONCLUSION

Incontinence is a prevalent and important condition that affects the lives of many Canadians. Increased awareness of this condition and its affects is required at the public, health care provider, and decision maker levels. Canadians with incontinence need not suffer in silence anymore; there is a variety of treatments now available ranging from the conservative (pelvic floor exercises, behavioural training) to medications to minimally-invasive surgical interventions. Treating this condition will allow incontinence sufferers the chance to live without bulky aids such as adult diapers and pads, decrease their personal health care costs and costs for the overall system, increase their quality-of-life, and return them to symptom-free living.

## THE CANADIAN CONTINENCE FOUNDATION

Founded in 1986, The Canadian Continence Foundation (formerly The Simon Foundation for Continence Canada) is the only national non-profit organization serving the interest of people experiencing incontinence. The organization is led by people with incontinence and by professionals from all health disciplines. The Canadian Continence Foundation is supported by donations from public healthcare professionals and private industry.

The mission of the Canadian Continence Foundation is to enhance the quality of life for people experiencing incontinence by helping them, and/or their caregivers, to confidently seek and access cures and treatment options. To this end, the Foundation will implement and encourage important public and professional education, support, advocacy and research to advance incontinence treatment and/or management.

#### **ACTIVITIES:**

- The Canadian Continence Foundation offers a wealth of information on incontinence. Books, videotapes, and newsletters are available. We operate a toll free number which is **1-800- 265- 9575.**
- Each year the Canadian Continence Foundation responds to thousands of requests for information and education from people experiencing incontinence, healthcare professionals, and industry.
- The Foundation interacts with the media to increase public awareness and knowledge of incontinence and to encourage people to seek help. It also provides individuals with lists of specialists in their local area.
- The Foundation initiated and now coordinates Incontinence Awareness Month in November of each year promoting public and professional awareness-building and educational activities about incontinence around the country.
- The Canadian Continence Foundation encourages and supports research to advance incontinence management/treatment.

## THE CAMERON INSTITUTE

The Cameron Institute is a not-for-profit, public policy think tank specializing in the independent study of health, social, and economic issues. It is the goal of The Cameron Institute to provide decision makers with analyses that will better inform choices. The Institute is also dedicated to educating and better preparing patients, providers, and payers to make appropriate clinical decisions. The Cameron Institute's values are:

Freedom, Choice, Responsibility

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