


# From stigma to the spotlight: A need for patient-centred incontinence care

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## Abstract

Incontinence is not a single disorder but a family of related conditions with different etiologies and treatments; it is a chronic disability that carries an enormous stigma. In few disorder/treatment pairings, there is the need to reinvent care more urgent and clear than in the area of incontinence. Patient-centred care has been realized to improve outcomes, quality of care, and patient satisfaction while concurrently reducing healthcare costs. To improve continence care and move it away from “cleaning up accidents” to a patient-centred care model, in which the disorder is managed to best practice guidelines, does not require investigative or developmental prowess but a simple, concentrated effort to diffuse existing knowledge to close the knowledge gaps, both at the clinical language level for clinical nurses and family physicians, as the gatekeepers to specialist care, and in simplified layperson’s language for the healthcare worker, family carer, and person living with incontinence.

There are in fact two things, science and opinion; the former begets knowledge, the latter ignorance.

- Hippocrates

## Introduction

Incontinence is a chronic disability that carries an enormous stigma.<sup>1</sup> Incontinence negatively affects many parts of a person’s life: ability to work, travel, and play sports; social interactions; sex life; and participation in community life. Women living with incontinence are more likely to have depression than their continent peers.<sup>2</sup> In one study, Urinary Incontinence (UI), Alzheimer disease, and stroke were the three chronic conditions found to most adversely affect an individuals’ health-related Quality of Life (QOL).<sup>3,4</sup> Evidence shows that dementia, falls, social isolation, and incontinence are closely related among the frail elderly population.<sup>5-7</sup> Incontinence is a predictor of Long-Term Care (LTC) admission.<sup>8</sup> It is a misconception that incontinence is a normal part of the aging process; incontinence is usually a result of a combination of pathologic, physiologic, and pharmacologic factors.

“Incontinence” is not a single disorder but a family of related conditions with different etiologies and treatment approaches: UI, Fecal Incontinence (FI), and overactive bladder. Within “UI,” there is stress incontinence, urge incontinence, overflow incontinence, mixed incontinence, functional incontinence, and nocturnal enuresis.<sup>9</sup> There are many levels of incontinence: mild, moderate, severe, and very severe.

Individuals are often reluctant to discuss their incontinence with family, friends, and physician. Treatment is usually only sought once incontinence becomes severe or interferes with sexual function.<sup>10</sup> As a result, there is significant under-reporting of symptoms; only about 25% of women and men living with incontinence seek help.<sup>11</sup> There have been over 1 million cases of incontinence reported, but it has been estimated that the real figure is closer to 3.5 million—nearly 10% of the Canadian population in 2018. A conservative estimate of

the prevalence of moderate to severe, daily incontinence in Canada among women is 7% and 3.5% for men.

Incontinence is costly to individuals spending \$1,400 to \$2,100 per year on purpose-made products (with some using inappropriate feminine hygiene products as a result of lack of proper knowledge). Incontinence costs Canadian employers over 11.5 million person-days of lost work and over \$2 billion in lost productivity. On a yearly basis, incontinence adds \$3.8 billion to healthcare costs nationally. In total, incontinence costs Canadians nearly \$8.5 billion annually<sup>12</sup> (see Figure 1).

## Patient-centred care

The concept of Patient-Centred Care (PCC) is simple. According to the Institute of Medicine, PCC is “(p)roviding care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions” and “includes listening to, informing, and involving patients in their care.”<sup>13</sup>

The concept of PCC, or patient-focused care as it was originally coined, is not new. The PCC concept evolved from the focus on the restructuring and reinventing of healthcare as well as the continuous quality improvement movement—none of which have had the success deemed possible by its early advocates.<sup>14</sup> It was first implemented at Florida’s Lakeland Regional Medical Center in 1983. The first scholarly article about PCC was published in 1991.<sup>15</sup> Hawaii’s Castle Medical Center, an Adventist 160-bed acute care hospital with home care programming, was the first institution to completely reorganize to be patient focused. Lathrop published his seminal monograph in 1993.<sup>16</sup> In February 2006, the International

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Incontinence Costs in Canada, 2014	
Costs to the individual	\$2,584,476,950
Costs to the employer	\$2,103,292,400
Costs to the “healthcare system”	\$3,843,075,600
<b>Total</b>	<b>\$8,530,844,950</b>

Source: Web site. <http://www.canadiancontinence.ca/pdfs/en-impact-of-incontinence-in-canada-2014.pdf>. Accessed July 5, 2018.

**Figure 1.** Incontinence cost in Canada, 2014.

<ol style="list-style-type: none"> <li>1. <i>Respect</i> - respect patients' unique needs, preferences, values, autonomy and independence;</li> <li>2. <i>Choice and empowerment</i> – Patients have a right and responsibility to participate as a partner in making healthcare decisions that affect their lives within a healthcare system which provides suitable choices in treatment and management options that fit with patients' needs;</li> <li>3. <i>Patient involvement in health policy</i> – Patients and patients' organizations must share the responsibility of healthcare policy making through meaningful and supported engagement in all levels and at all points of decision-making, to ensure that they are designed with the patient at the centre;</li> <li>4. <i>Access and support</i> – All patients must have access to the healthcare services warranted by their condition including access to safe, quality and appropriate services, treatments, preventive care and health promotion activities; and,</li> <li>5. <i>Information</i> – Accurate, relevant and comprehensive information is essential to enable patients and carers to make informed decisions about healthcare treatment and living with their condition.</li> </ol>
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Source: Web Site. [https://www.iapo.org.uk/sites/default/files/files/IAPO\\_declaration\\_ENG\\_2016.pdf](https://www.iapo.org.uk/sites/default/files/files/IAPO_declaration_ENG_2016.pdf) Accessed July 7, 2018.

**Figure 2.** International Association of Patient Organization's (IAPO) 5 principles for patient-centred care (abridged).

Association of Patient Organizations (IAPO) launched its *Declaration on Patient-Centred Healthcare*. The Declaration contained five principles for PCC as summarized in Figure 2.

The PCC is 35 years old; regrettably, the concept-in-practice is still foreign to most healthcare situations, particularly with respect to involvement in policy and access to care,<sup>17</sup> even though the promise of PCC has been realized to improve outcomes, quality of care, and patient satisfaction while often concurrently reducing the healthcare bill.<sup>18</sup>

### Improving continence care

In few disorder/treatment pairings, there is the need to reinvent care more urgent and clear than in the stigmatized area of incontinence. A search of the most cited literature for UI and FI over the past 5 years yields an overwhelming preponderance of articles regarding the treatment of the etiology and iatrogenesis

of incontinence such as rectal cancer, sphincter malfunction, and prolapse; very little on the management of incontinence. In practising PCC, it is important not only to consider incontinence management from a clinical point of view but also from an individual's perspective. Several Canadian qualitative and social research studies have been published focusing on the knowledge, understanding, competence, and confidence in managing continence.

One study showed that UI is prevalent, poorly understood, and under-reported in Canadian women because of inadequate public knowledge with consequent delay in management.<sup>10</sup>

Focusing on LTC residents, another study stressed the importance of public education, provider training, and the understanding of elder denial to improve the delivery of FI services to residents.<sup>19</sup>

A third paper identified room for improvement in the management of both UI and FI in LTC residences and recommended changes in community college curricula for Personal Support Workers (PSWs or healthcare aides) which are being adopted in Ontario.<sup>20</sup>

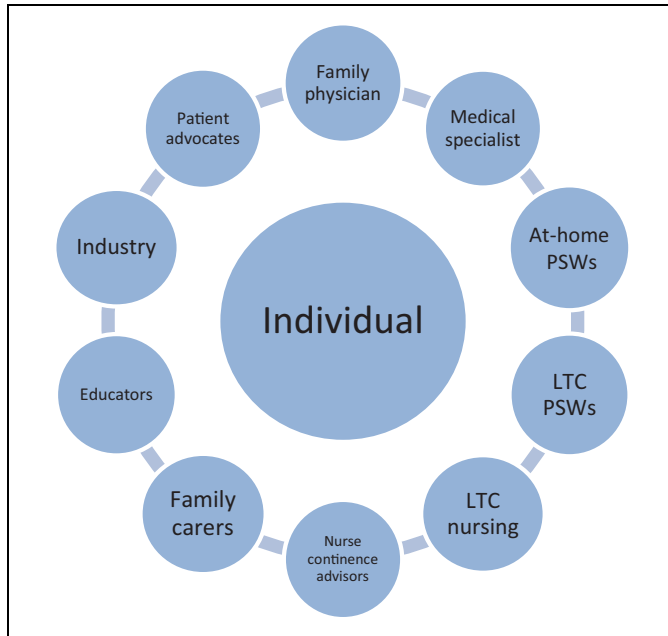
The most recently published research demonstrated a need for ongoing education and training of both paid and volunteer FI caregivers; a long overdue de-stigmatization of FI and the proper listing of it as a disability that impairs livelihood and QOL; and public-private-not-for-profit collaboration to optimize the care provided elders living at home with FI.<sup>21</sup>

Juxtaposing the findings from these studies against IAPO's principles for PCC, the gap between PCC and the status quo in caring for those experiencing incontinence, both urinary and fecal, is instructive: patient needs were sacrificed or ignored in preference to provider needs; a cookie-cutter approach to care denied choice; barriers to access, including financial, were numerous; and, information for patients, families, and care workers was lacking (none of the studies looked at patient involvement in policy). There was no consistency in how people accessed care, who provided that care, or how patients were assessed and managed.

### Knowledge levels and gaps

For a PCC approach to continence care, the desired outcome must be more than just a “reduction in the mean number of incontinent episodes per week.”<sup>22</sup> Although the actors are numerous and heterogeneous in the provision of continence care, as identified in the research reviewed and shown in Figure 3, this complexity need not impair progress. The driving issue identified was the same across all studies and actors—knowledge.

The biggest issue identified across all of these recent studies,<sup>23</sup> especially among the elderly patients, both at home and in residential care, was the length of time spent sitting in soiled continence products while waiting to be cleaned and changed. Not only was this a question of available resources (staffing, availability of friends and family, rationing of product by facility budget or one's own budget) but also the lack of knowledge of how to actually manage incontinence rather than



**Figure 3.** Key actors in patient-centred continence care.

just clean up after an “accident” as per best practice care guidelines already in existence.<sup>24-28</sup>

One study of both continent and incontinent women showed that one-third of those surveyed in both categories were unsure about the definition, causes, or treatment outcome of UI.<sup>10</sup> In a study of LTC facilities, two-thirds of those interviewed—residents with FI, their families, and their attendant PSWs—believed that FI was a normal part of aging. This knowledge barrier to seeking timely help for FI emphasized the need for better training and education.<sup>19</sup> This finding was corroborated when PSWs in both LTC<sup>20</sup> and community settings<sup>21</sup> reported that their formal in-class education and placement training failed to prepare them adequately to deal with incontinence. Interviewees believed they received most of their education and training in resident continence care “on-the-job” once they had been hired by their employer, an episodic process that only reinforced “the way we have always done things” and stifled innovative thinking or treating the person as a whole. Family carers reported even less knowledge, confidence, and competence in helping their incontinent family member to manage their condition; they simply coped.<sup>21</sup>

The PSWs, or any other carer, need to understand the causes of incontinence; that it is not just “something that happens with age”; be given appropriate education; and develop the ability to manage incontinence through proactive toileting and individualized care to overcome constraints imposed by the physical environment.

Based upon the analysis of the above studies, the knowledge levels (and therefore gaps) are qualitatively summarized in Figure 4.

	Urinary Incontinence	Fecal Incontinence
Patient	Fair	Low
Family carer	Fair	Low
LTC PSW	Good	Fair
Community PSW	Fair	Fair

**Figure 4.** Knowledge levels (gaps) in continence care among patients, Personal Support Workers (PSWs), and family carers.

### Implications for healthcare leaders

To improve continence care and move it away from “cleaning up accidents” to a proper PCC model, in which the disorder is managed to best practice guidelines designed to promote continence, does not require investigative or developmental prowess but a simple, concentrated effort to diffuse existing knowledge to close the knowledge gaps, both at the clinical language level for clinical nurses and family physicians, as the gatekeepers to specialist care, and in simplified lay-person’s language for the PSW, family carer, and person living with incontinence. There needs to be further focus on proactive toileting methods designed to promote continence; sitting for hours in soiled product should not be acceptable in 2018. Formal healthcare and support care curricula and continuing education modules need to include this information. Public service knowledge transfer needs to appear intensively and repeatedly across all media platforms bringing UI and FI into the light—an ideal opportunity for public-private-not-for-profit collaboration.

Existing government support, such as financial subsidization of continence products, is limited and piecemeal across the country. Every province and/or region needs to move away from supports that are silo-budgeted, intervention-centric, and bureaucratically cumbersome to a patient-centric model of funding whether in the community or in residential care. How a government health department is organized in the back office and how it presents itself as a service to the citizen can be, and needs to be in this case, two different organizational concepts.

As the research clearly showed over 1 million Canadians suffer silently with moderate to severe incontinence as they delay seeing a general practitioner about their condition or have received inadequate assistance from one. Counselling and navigating existing bureaucracy could be an ideal role for the growing profession of continence nurse advisor. Classifying incontinence as a disability would also be of great benefit to many.

Can the \$8.5 billion cost equation for incontinence be reformulated? Yes it can, but doing so will beg the flexibility, innovativeness, and transformational qualities of such management paradigms as the LEADS framework, which are well enunciated on paper but put into practice less than needed by the Canadian patient population—a shift in mentality from cookie-cutter, bedside, or toilet-side procedure to the person; from product and its unit cost to the cost of not providing

someone QOL; from the needs of the bureaucrat, administrator, and care provider to the needs of the patient.

## Conclusion

The stigma of incontinence needs to be replaced with facts, compassion, understanding, and proactive care management to improve the QOL of those living with incontinence, their family and friends, and those who care for them.

All that is missing is leadership, this time, from the top.

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