



POLICY·BRIEF

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Women and Incontinence in the EU

Women and Incontinence in the EU - Policy Brief 2018

Women and Incontinence—A Hidden Societal Challenge

Urinary incontinence (UI) is a widespread disabling and debilitating condition affecting 10% to 20% of people across Europe.¹ In 2016, about 60 million people in Europe experienced urinary incontinence (UI), which is two times more common in women than in men. Not only are women more likely than men to develop UI, women are also disproportionately burdened by the caregiving of those living with UI as women provide the majority of both formal and informal care to people living with UI.

A lack of understanding, awareness and support surrounds the condition. Many aspects of UI are overlooked or poorly understood by both policymakers and health professionals. Moreover, those affected by UI are often reluctant to seek help due to embarrassment or a belief that UI is a normal consequence of ageing and/or childbirth. Even when help is sought, people with incontinence and their carers can struggle to navigate their way through often fragmented and inconsistent support systems.

What is Urinary Incontinence?

Urinary incontinence (UI)—or overactive bladder (OAB)—is the involuntary leakage of urine. There are three main subtypes of UI:

- **Stress UI (SUI):** a term given to leakage due to sudden extra pressure such as coughing or lifting;
- **Urgency UI:** describes a strong and sudden urge to urinate; and
- **Mixed UI:** a combination of stress and urgency UI.

Across all sub-types, leakage can be mild (slight), moderate or heavy: **severity** can be assessed by how much it impacts a person's quality of life and/or by measuring the **amount** and **frequency** of leakage.

Incontinence may be provoked by other medical conditions such as diabetes, obesity, vaginal and urethral inflammation, dementia, and Alzheimer's disease.² Certain behaviours and lifestyles can also increase the risk of development of UI, including obesity, smoking, high impact exercise, and diet, such as caffeine, alcohol, spicy and acidic foods.³

Sex, Gender and Incontinence

Sex and gender are important risk factors for the development of urinary incontinence.⁴ Women are physiologically more vulnerable to developing UI than are men and more likely to develop the condition at a younger age than are men. UI rates in women increase with age; it is estimated

that one quarter of young women, half of middle-aged and post-menopausal women, and three quarters of older women in nursing homes experience involuntary urine loss.⁵ Pregnancy, childbirth and menopause increase both the short and long-term risk for UI development.

Age and Incontinence Across a Woman's Lifespans

Incontinence in Children

Children can experience nocturnal enuresis (bed-wetting) even without a history of bladder or lower urinary tract issues. About 90% of children experience primary nocturnal enuresis, which is usually resolved by the age of 5 when sphincter control is achieved.⁶ Children may also experience overactive bladder syndrome, or urgency with or without urge incontinence, which often occurs frequently throughout the day and/or night.⁷ UI is twice as common in boys as it is in girls.⁸ UI in children has repercussions for both children and their caregivers.

Incontinence and Pregnancy

Pregnancy can result in the development of stress incontinence or overactive bladder (OAB) syndrome. OAB causes a need to urinate more often due to uncontrollable spasms in the bladder and problems in the muscles surrounding the urethra. As the uterus expands during pregnancy, pressure is put on the bladder, which can overwhelm the muscles supporting the bladder and pelvic floor, and additional pressure may lead to stress incontinence. Vaginal delivery is a major cause of stress urinary incontinence in women. After childbirth, women may continue to suffer from incontinence or OAB due to nerve damage around the bladder, movement of urethra and bladder during delivery, or an episiotomy (the cutting the pelvic floor muscles during delivery).⁹

Incontinence in Older People

Due to longer life expectancy and an ageing population, one in five people in Europe are aged 65 and older. The population 65 and older is set to rise by 2040 to more than one in four, and the proportion of those over the age of 80 is predicted to double. At the same time, there will likely be proportionately less people of working age, affecting the tax base for funding public services and the number of people able to provide formal and informal care.¹⁰

The ageing population is likely to have a significant impact on the prevalence of urinary incontinence (UI) as older adults are more prone to develop the condition than are any other age group. Frail older people are particularly vulnerable; they are at higher risk of developing UI and they are less able to self-manage.¹¹ Europe has the highest proportion of older women in the world, so the implications of UI for older women are particularly important.

Economic Burden of Urinary Incontinence

Urinary incontinence is a costly problem for individuals, their families and society broadly. Although the economic burden of incontinence is difficult to measure, it was estimated to have cost Europe approximately £13 billion in treatment and lost productivity as of 2008.¹² Having UI or caring for a relative with UI incurs significant **direct expenses**, including the purchase of continence aids and other assistive products, laundry expenses, and payment for medication, physiotherapy and other treatments. **Indirect costs** include lost productivity, hospitalisation and nursing home admission. **Intangible costs** encompass a reduced quality of life. Responsibility for payment of costs differs between countries; in some, costs are borne by health and social care systems, while in others the economic burden on individuals and families can be significant.¹³

A Double Burden on Women

Urinary incontinence is more than twice as common in women as in men, and estimates indicate 25-45% of women will develop it during their lifetime.¹⁴ As well as being more likely to develop the condition themselves, women provide the majority of both formal and informal care—including to people with UI—leaving them at risk of being doubly burdened.¹⁵

Understanding the Risks Associated with Urinary Incontinence

Anyone can develop the condition, but age and sex/gender are the biggest risk factors for urinary incontinence.¹⁶ Older adults are more susceptible to UI than younger people as urinary tract muscles lose some of their strength with increasing age. This older population group is more likely to have other risk factors for UI, including certain medical conditions and medications as well as functional and cognitive impairments.¹⁷ Female physiology makes women more vulnerable to developing UI, and they are more likely to develop the condition at a younger age than are men.

Recognising the Impact of Urinary Incontinence on Women's Lives

Urinary incontinence can impact many aspects of women's lives including physical exercise, work productivity, sleep, social interaction, travel, and sexual health. Women with the condition consistently report having a lower quality of life (QoL) compared with those who are continent. A range of physical and psychosocial issues influence how UI affects QoL: type and severity, age, and concurrent medical conditions are important considerations but individual personality and coping strategies, social support, and culture also affect women's perception and management of the condition.^{18, 19}

UI has major repercussions on the physical, mental, and social well-being of women. Those with UI can experience feelings of stigma and humiliation. It can also cause sufferers to withdraw or develop anxiety of being in public.²⁰ There is a large body of evidence connecting UI, depression and stress. Women with UI also have increased levels of depression and panic disorders. For example, a study of women ages 50 to 69 with severe UI found a 80% increase in the development of depression.²¹ Depression also affects the patient's perception of the impact of her condition and hence, the quality of life.

UI also has implications for the physical health of women. A European study found that 60% of women with medium to severe symptoms of UI had activity restrictions, such as physical exercise. Over 85% of those with severe UI viewed it as the central obstacle to physical activity. Another study found that about a third of women with UI avoid athletic exercise.²² UI is common amongst female athletes with rates highest in those participating in high impact sports.²³ Studies have found that more than 40% of female athletes experience UI.²⁴ However, the condition remains underreported to health professionals due to stigma and lack of awareness.²⁵

UI can also have a substantial impact on relationships and on the sex life of those suffering from the condition. An estimated 25-50% of women with UI experience sexual dysfunction, and 1/5 of women reported reduced intimacy in relationships.^{26,27}

The Impact of Urinary Incontinence on Female Employment

UI can both directly and indirectly impact women's ability to participate in paid employment, which can further exacerbate existing gender pay gaps and socio-economic inequalities. Specifically, those affected by the condition may not be able to work due to suboptimal incontinence

management while other providing care to a family member may not have time to take on additional work and are less likely to re-enter the workforce after ceasing their caring role.²⁸

Up to 30% of women with UI have to take time off of work, losing on average 28.7 hours annually. Studies of women with UI found it had implications for concentration (19%), performing physical tasks (29%) and work interruptions for toilet breaks (34%). Women with UI have higher levels of sleep deprivation, which can further impede concentration, effectiveness and activities.²⁹

In addition to the short and long term financial consequences like loss of salary and pension entitlement, UI can negatively impact the health and well-being of women, which need to be adequately tackled since increasing female participation in the labour force is an important policy objective of the EU's Europe 2020 Strategy.

The Impact of Urinary Incontinence on Independent, Active and Dignified Living

Evidence suggests that the impact of UI on social isolation may be of particular consequence among older populations.³⁰ A common risks for urinary incontinence are hospitalisation, admission to a nursing home as a result of additional care required and consequences of the conditions such as fall-related injuries.³¹ Amongst institutionalised populations where prevalence of UI is highest, studies have highlighted a notable absence of UI treatment plans for patients.³²

An Increased Workload for Carers

An estimated 15 million people in Europe provide informal care to persons aged 70 and older with urinary incontinence.³³ The lack of appropriate physical and emotional support can cause caregivers to feel overwhelmed and overburdened with their responsibilities. Incontinence-related tasks—such as changing pads, extra cleaning and washing—add to the burden of caregiving. Carers can feel particularly vulnerable at the onset of the disease due to a limited knowledge regarding incontinence management.

In addition, environmental and social barriers associated with UI can make it difficult for a carer to leave the home, leading to a reduced social life, particularly for carers who live with the care recipient. Moreover, urinary incontinence in older adults is strongly associated with poor mobility and cognitive impairment, which can make tasks more difficult to complete. The heavy workload of caregiving for someone with UI can have a significant negative impact on a caregiver's quality of life.³⁴

Identifying Barriers to Accessing Appropriate Care

Many women with urinary incontinence are slow to seek medical care, while others wait until symptoms worsen before doing so, managing the condition themselves by adapting and restricting their behaviours. Slow onset of symptoms, especially if mild in nature, lack of knowledge regarding other UI treatments and feelings of embarrassment, shame or resignation around the condition can act as barriers to accessing appropriate care.³⁵ However, self-management or having recourse to treat at a late stage reduces the likelihood of being able to effectively manage the condition with conservative options, which can lead to a progressive worsening of the condition or the need for more invasive treatment.³⁶

For many women, appropriate containment strategies will be the focus of care. Lack of consistency across health and social care systems with regard to guidelines, access to information and products and reimbursement entitlements have been highlighted by advocacy groups as significant barriers to managing incontinence for individuals and their caregivers. Even where costs are borne

by the state and/or domestic health system, benefits may not be fully utilised if the available products are of inferior quality or due to complex reimbursement procedures.³⁷

Promoting a Person-Centred Approach to Managing Urinary Incontinence

Focused public health and primary care programmes are needed to make it easier for women to seek and access treatment. In addition to general awareness raising and de-stigmatising strategies, emphasis should be placed on encouraging women to seek treatment at the onset of symptoms. Given that many women who seek help will be managed by primary care providers, there is a need for more widespread access among healthcare professionals to clinical management procedures. Guidelines have been developed to inform best practice but more needs to be done to promote their use beyond specialist groups.^{38, 39}

There is a need for a more holistic approach which aims to minimise psychological distress as well as manage physical requirements to provide needs can better support for all women to lead normal, active lives. In particular where there are existing co-morbidities and functional limitations, a multi-dimensional assessment that takes these factors into account can reduce the burden of self-management and care required. Acknowledging individual needs, circumstances and expectations can help to tailor treatment more effectively. Access to appropriate aids and products can be facilitated by providing more information, involvement and choice for individuals and their caregivers.

Supporting Caregivers

For caregivers, improved physical and emotional support, appropriate information, and access to high quality products can help to lessen the burden of care and improve their quality of life. This includes an assessment of the caregiver's needs within the context of the care recipient's requirements could to help identify particular support needs and facilitate access to appropriate support networks. A caregiver's knowledge, needs and capabilities can also impact decisions regarding appropriate treatment, management and selection of products. Specific education and training for caregivers on incontinence management may be useful, especially in the early stages when access to a support network which may be formal, informal or both to help meet practical and emotional support needs.

Reducing Women's Risk of Developing Urinary Incontinence

Understanding the risk factors associated with UI is key to reducing the risk of developing urinary incontinence. **Most of the behavioural risk factors for UI—including poor diet, alcohol consumption, obesity, insufficient physical activity and smoking—are common to other chronic conditions and already the target of general health promotion messages but the links to urinary incontinence prevention are rarely made.**⁴⁰ An improved understanding of the physiological processes that increase pelvic floor vulnerability can provide new opportunities for intervention, at established life stages such as pregnancy, childbirth, menopause and ageing, and across the entire life span.⁴¹

Prevention of urinary incontinence begins with raising awareness among healthy individuals and health professionals about the risks associated with UI. To date, most programmes have focused on high risk groups and there is good evidence to support the effectiveness of interventions such as pelvic floor muscle training (PFMT).⁴² There is now increasing interest in developing and implementing broader population-based continence promotion measures beyond these groups, however further research and economic evaluations could help to better determine the benefits of prevention strategies.⁴³

Steps for Policy Action

Better continence care across Europe will help those affected to live active, independent and dignified lives and help to reduce the burden for family caregivers. There are a number of areas in which policy makers can help to bring about positive change.

1. Raise awareness of the issue of urinary incontinence and the challenges that the condition poses for both patients, their families and caregivers.

Member States and the EU should actively engage and collaborate with civil society, government officials, health authorities, health professionals, NGOs, patient organisations, industry and other key stakeholders in order to increase awareness of urinary continence and to encourage the exchange of best practice. Support for advocacy for this condition is urgently needed. The needs of people living with incontinence and their caregivers as well as their role in continence promotion must be highlighted.

2. Support those with urinary incontinence by providing good continence care.

Women with UI face many physical, psychological and financial burdens. Support must be available to those with UI. Provisions, such as care products, assistance as well as economic support should be provided to help patients independently manage their condition for as long as possible. In order to reduce health inequities, Europe must also encourage and support improved education, research, prevention, screening, treatment and care targeting disadvantaged groups of women, their families and communities. Programming should account for factors like sex, gender and age. Projects like WOMEN-UP, a European project that promotes the cost-effective self-management of urinary incontinence, should be encouraged.

3. Promote active and healthy ageing, which includes support for the prevention, early intervention and management of urinary incontinence.

Urinary incontinence rates rise with age. As Europeans increasingly age, urinary incontinence will also rise. Women account for the majority of older people in Europe, particularly above the age of 80. Women also represent the largest caregiving community supporting those with UI. Patients and their caregivers need to be empowered. Prioritise continence and care as a key contributor to dignified ageing and independent living in age-friendly policies and services across Europe.

4. Develop early interventions that enable women to minimise the risk factors associated with urinary incontinence, recognise initial symptoms and seek healthcare early to reduce the burden of UI.

Improved continence care across Europe will help those currently affected to continue to live active, independent and dignified lives for as long as possible help to reduce the burden of family caregiving. Sharing knowledge on prevention and early intervention strategies should be supported and encouraged.

5. Encourage Member States and the EU to implement policies and programmes to support both informal and formal caregivers.

Education and training for caregivers on incontinence management, particularly during the first years of care giving need to be developed. Formal and informal information networks that provide practical and emotional support to caregivers should be supported. Care giver's knowledge, needs and capabilities should be employed to inform decisions regarding appropriate treatment, management. Assess a care giver's needs to facilitate access to support. The disproportionate burden women face of providing unpaid care must be reduced urgently.

6. Harness the knowledge of physiotherapists, health and social welfare professionals by imparting knowledge on urinary incontinence.

Health professionals must be empowered with the necessary skills, tools and knowledge for prevention, early detection and appropriate management of urinary incontinence. The importance of effective communication between health professionals, patients and informal carers around the prevention and management of incontinence must be highlighted. Health professionals should be encouraged to adhere to the European Association of Urology (EAU) Guidelines on Incontinence.⁴⁴

7. Provide better data on urinary incontinence, including factors like age, sex and gender. Support research on effective urinary incontinence policy, programming and practice, accounting for factors like sex, gender and age.

Efforts must be made to better understand the development, prevention, progression and treatment of urinary incontinence by employing a life-course approach from young through to older age. Research must not only explore the biological aspects of UI, but also the psycho-social and economic implications for those with the condition in order to promote active and healthy ageing. Research that evaluates prevention and treatment strategies to build evidence of cost effectiveness to ensure effective use of resources must be encouraged.

8. Develop a comprehensive report on women and incontinence to raise awareness and encourage action across Europe.

The existing evidence base of research on incontinence and women in Europe must be reviewed. Incontinence should be explored across the lifespan, including its link to other health conditions. The biological, physiological, social, caregiving, employment and economic factors must be examined in relation to incontinence. Highlight current challenges and give examples of best practice. Based on the existing evidence based, policy, programming and practice solutions must be proposed and supported, particularly those that foster collaboration with relevant stakeholders.

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