POLICY·BRIEF

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A life course approach to continence care

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A neglected issue

Urinary incontinence (UI) is a widespread and debilitating condition in Europe but many aspects of the condition are overlooked or poorly understood by policy makers and health care professionals. Moreover, those affected can be 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, it can be difficult for people with incontinence and their carers to navigate their way through often fragmented and inconsistent support systems.

The basics

Urinary incontinence is the involuntary leakage of urine. There are three main subtypes: stress UI is the term given to leakage due to sudden extra pressure such as coughing or lifting; urgency UI describes a strong and sudden urge to urinate; mixed UI is a combination of stress and urgency UI. Across all sub-types, leakage can be mild, 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.

Impact of the ageing population on urinary incontinence

Longer life expectancy in Europe means that currently one in five people are aged 65+ and this is set to rise by 2040 to more than one in four, while 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.[i]

The ageing population is likely to have a significant impact on prevalence of urinary incontinence as older adults are more likely to develop the condition than 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.[ii]

Economic burden of urinary incontinence

Urinary incontinence is a costly problem for individuals, their families and society. Having or caring for a relative with UI can generate significant expenses including the purchase of continence aids and products, laundry expenses, and payment for medication, physiotherapy and other treatments. Indirect costs include lost productivity, hospitalisation and nursing home admission while intangible costs encompass reduced quality of life. Responsibility for payment of the various 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.[iii]

A double burden on women

Urinary incontinence is more than twice as common in women as men: estimates indicate 25-45% of women will develop it during their lifetime.[iv] 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.[v]

Understanding risks associated with urinary incontinence

Anyone can develop the condition but age and gender are the biggest risk factors for urinary incontinence (see Fig. 1).[vi] Older adults are more susceptible as urinary tract muscles lose some of their strength with increasing age. This 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.[vii]

Female physiology makes women more vulnerable to developing UI and they are more likely to develop the condition at a younger age than men. Pregnancy, childbirth and menopause increase both short and long-term risk. Certain behaviours and lifestyles also play a role: these include high BMI, smoking, high impact exercise, and food and beverages such as caffeine, alcohol, and spicy or acidic foods.[viii]

Recognising impacts 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.[ix], [x]

Impacts on female participation in paid employment

UI can impact women’s ability to participate in paid employment: those affected by the condition may not be able to work due to suboptimal incontinence management while those 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.[xi] As well as the short and long term financial consequences including loss of salary and pension entitlement, this can have negative impacts on health and well being for women. Moreover, increasing female participation in the labour force is an important policy objective of the EU’s Europe 2020 strategy.

Impact on independent, active and dignified living

Evidence suggests that the impact of UI on social isolation may be of particular consequence among older populations.[xii] In addition, indirect impacts of urinary incontinence are more common: there is an increased risk of hospitalisation and admission to a nursing home as a result of additional care required and/or due to other consequences of the condition such as fall-related injuries.[xiii] Among institutionalised populations, where prevalence of UI is highest, audits have highlighted a notable absence of UI treatment plans for patients.[xiv]

Increased workload for caregivers

An estimated 15 million people in Europe provide informal care to a person aged 70 or older with incontinence.[xv] Lack of appropriate physical and emotional support can lead to caregivers feeling overwhelmed and overburdened with care responsibilities. Incontinence-related tasks such as changing pads, and 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 to leave the home leading to a reduced social life, especially 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. This heavy workload can have significant negative impacts on caregivers' quality of life.[xvi]

Identifying barriers to accessing appropriate care

Many women with urinary incontinence don't seek any 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.[xvii] However, self-management or presenting for treatment at a late stage reduces the likelihood of being able to effectively manage the condition with conservative options which can lead to progressively worsening of the condition or the need for more invasive treatment.[xviii]

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, benefits may not be fully utilised if the available products are of inferior quality or due to complex reimbursement procedures.[xix]

Promoting person centred approaches to manage 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.[xx,xxi]

A more holistic approach which aims to minimise psychological distress as well as manage physical needs can better support all women to lead normal, active lives. In particular where there are existing co-morbidities and functional limitation, a multi-dimensional assessment that takes these factor 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, better 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. Including an assessment of the caregiver's needs within the context of the care recipient's requirements could help identify particular supports needs and facilitate access to appropriate support networks. Caregivers knowledge, needs and capabilities should also inform 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 while access to a support network which may be formal, informal or both can help to 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.[xii] Better understanding of the physiological processes that increase pelvic floor vulnerability provides new opportunities for intervention, at established life stages such as pregnancy, childbirth, menopause and ageing, and across the life span.[xxiii]

Prevention of urinary incontinence begins with raising awareness among healthy individuals and health care professionals of the risks associated with UI. To date, most programmes have focused on high risk groups and there is good evidence to support effectiveness of interventions such as pelvic floor muscle training (PFMT).[xxiv]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 benefits of prevention strategies.[xxv]

Steps for policy action

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

1. Promote the integration of urinary incontinence prevention measures into general public health campaigns to increase awareness of the condition and its risk factors amongst the general population

2. Support the development of interventions that enable women to minimise risk factors for urinary incontinence, recognise initial symptoms, and seek healthcare early

3. Empower primary care providers with the necessary skills, tools and knowledge for prevention, early detection and appropriate management of urinary incontinence

4. Highlight the need for effective communication between healthcare professionals, patients and informal carers around continence prevention and management

5. Emphasise the role of continence promotion in reducing future health and social care costs associated with an ageing population

6. Prioritise continence care as a key contributor to dignified ageing and independent living in age-friendly policies and services across Europe

7. Encourage the conduct of economic evaluations across prevention and treatment strategies to build evidence of cost effectiveness and ensure best use of public finances

8. Recognise the work of advocacy organisations in highlighting the needs of people living with incontinence and their caregivers, as well as their role in continence promotion

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