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Impact of incontinence on the quality of life of caregivers of older persons with incontinence: A qualitative study in four European countries

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ABSTRACT

The aim of this study was to assess the impact of incontinence management on informal caregivers of older persons with incontinence. In order to investigate this phenomenon in different welfare systems via qualitative interviews and a content analysis methodology, the study was carried out in four European countries (Italy, the Netherlands, Slovak Republic and Sweden). To this purpose, 50 semi-structured interviews were conducted with spouses and children of older people receiving their help to manage the consequences of involuntary urinary and/or faecal leakage. Findings show that incontinence has a remarkably strong effect on caregivers' quality of life, because it results in progressive social isolation, causing them financial problems as well as psychological and physical exhaustion. The lack of appropriate support and the general silence regarding the problem, which is still considered a taboo by many, aggravate the caregivers' situation. It is therefore crucial that caregivers can count on a strong public and private support network, appropriate information and suitable incontinent products, in order to better handle incontinence and care tasks in general.

1. Introduction

1.1. Incontinence among older people

The International Continence Society (ICS) defines Urinary Incontinence (UI) as any involuntary loss of urine (Abrams et al., 2002). According to the standardisation of terminology given by the ICS (Tarnay & Bhatia, 2012), there are five types of UI: Urgent Urinary Incontinence (UUI), Stress Urinary Incontinence (SUI), Mixed Urinary Incontinence (MUI), Nocturnal Enuresis (NE), and Continuous Urinary Incontinence (CUI).

Each UI typology has different signs, symptoms, conditions and treatments. Around the world, UI affects from 3% to 23% of men and from 11% to 52% of women (Burti, Barsante Santos, Pereire, Zambon & Marques, 2011). Prevalence rates are higher in older age. Older women are more likely to report mixed and urgent incontinence, while young and middle aged women generally report stress incontinence. For "daily" incontinence, prevalence ranges from 5% to 15% among middle-aged and older women (Abrams, Cardozo, Khoury, & Wein, 2009). UI is more frequent among persons residing in long-term facilities, especially if they suffer from dementia, limited mobility and co-morbidity conditions. Depending upon the methods used to ascertain incontinence, prevalence in residential settings generally reaches a rate of 50–80% (Abrams et al., 2009).

Common causes and risk factors of UI include very old age, followed by pregnancy and vaginal deliveries, obesity, changes in hormone levels, hysterectomy and menopause, diabetes, urinary tract infections, neurological illness, cognitive and physical impairment, smoking, family history, and genetic and ischemic heart disease (Abrams et al., 2009). This also concerns the prevalence of faecal incontinence, as 16.9% of those over 75 years old people report this problem, which in turn is associated with other co-existing illnesses and vulnerabilities (Stenzelius, Mattiasson, Hallberg, & Westergren, 2004).

Incontinence has been identified as an impairment that can have profound psychosocial implications, including social isolation due to a fear of bad odours, anxiety, embarrassment, stigma and lower self-esteem (Sanders, Bern-Klug, Specht, Mobily, & Bossen, 2012). Incontinence is also a predictor of institutionalisation among the general older population and of death among institutionalised older patients (Tilvis, Hakala, Valvanne, & Erkinjuntti, 1995).

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In the light of the increasing ageing of the world's population—by 2050 in the countries belonging to the Organisation for Economic Co-operation and Development (OECD) the population over 80 years of age is expected to increase from 4% to 9.4% (Colombo, Llena-Nozal, Mercier, & Tjadens, 2011), with particularly high levels in European countries (Eurostat, 2012)—incontinence is going to become a more and more pressing problem as it has societal, psychological and economic implications. A correct, comprehensive management of incontinence is therefore urgently needed, to save costs and reduce the negative impact on all parties involved.

1.2. The additional burden affecting caregivers of older persons with incontinence and its impact on their quality of life

Although elder care presents some differences across countries, in Europe informal caregivers (represented primarily by children and spouses) are the main care providers. In fact, throughout Europe, the tendency to increase home care services for the most vulnerable elderly is widespread, This occurs for two main reasons: to ensure a better quality of assistance and to reduce the costs of institutionalisation. Northern European countries (in particular Denmark and Sweden) started this process many years ago, while Southern European countries (e.g., Italy, Spain and Portugal), where the role of informal caregivers is still prevalent, have been following this trend only recently and with more difficulty (Melchiorre, Di Rosa, Chiatti, & Lamura, 2010).

As a consequence, an increasing number of frail older people affected by co-morbidity and incontinence, and dependent on nursing care and rehabilitation, live at home with their families, who frequently bear the brunt of their relatives' health problems. Across the OECD, more than 10% of all adults are involved in informal caregiving as family members or friends. This figure varies from country to country, with the peak level of 16% recorded in Italy and Spain (countries characterised by a "familistic" welfare model) and a minimum of 8% in Denmark. Caregivers provide help with the basic activities of daily living (ADLs), and high intensity caring can lead to reduced rates of employment and working hours, thus putting caregivers at risk of poverty and of deteriorating their mental health (Colombo et al., 2011).

Many studies have shown that caregiving for a relative with incontinence, in particular, can have a greater negative impact on physical, psychological, social and financial status than caregiving for a relative without incontinence (Gotoh et al., 2009), with significant differences in terms of quantity of informal care provided and related financial costs (Cassells & Watt, 2003; Langa, Fultz, Saint, Kabeto, & Herzog, 2002). Physical exhaustion (Lane, McKenna, Ryan, & Fleming, 2003) and the lack of sleep and leisure (Brittain & Shaw, 2007) are among the most important consequences of incontinence management. This is also related to the constant need for watchfulness (Cassells & Watt, 2003; Hayder & Schnepp, 2008), which makes incontinence one of the main reasons for placing an older patient into an institution, especially individual is also experiencing dementia (Thomas et al., 2004). Furthermore, the embarrassment experienced with regard to leakages and bad odours may lead to decisions that can confine both the caregiver and the care recipient within the boundaries of their home, thus leading to social isolation (Cheater, 2008) due to the difficulty of maintaining a decent social life (Cassells & Watt, 2003).

Among the strategies indicated as appropriate for caregivers to tackle the above difficulties, some refer to the use of high quality absorbent products as these prevent wet beds and negative events affecting social contacts (Lane et al., 2003). Other underline the importance of opportunities for caregivers to ask confidential questions to nursing specialists, counselling agencies, support groups and educational links, also with regard to hints to protect caregivers' health (Steiner et al., 2008). In this respect, the possibility to speak about incontinence seems to have increased in many developed countries compared to twenty years ago, thanks to the visibility given to the issue by the mass media (e.g., magazines, newspapers, radio and television), especially for women, men are still less available and open in this respect (Molander, Sundh, & Steen, 2002).

Despite these improvements, only a minority of women ask their physician for help. Incontinence remains a taboo and the level of shame and embarrassment among sufferers is significantly higher than that reported for depression and cancer (Elenskaia et al., 2011). Many patients are still not properly informed about the cause of and treatment for incontinence. Affected individuals still think that incontinence is an unavoidable age-related problem and only feel "forced" to seek help when leakages become worse and more frequent (Teunissen, van Weel, & Lagro-Janssen, 2005).

1.3. Social and health services for older people affected by incontinence in four European countries

In order to contextualise the qualitative data collected, the survey carried out by van der Veen et al. (2011) in four European countries contains a specific section dedicated to social and health services for older persons with incontinence and their families. Specific services for incontinent people were found in all involved countries including the entitlement to a free supply of incontinent products according to the patients' needs, as prescribed by a General Practitioner or medical specialists.

In each country incontinence products are purchased following a specific procedure, based on Municipal (Sweden), Regional (Italy) or National (Slovak Republic) rules, which also set up country-specific admission criteria to the delivery of continence products by the public health system. In Sweden the number of incontinence pads depends on individual's needs, as prescribed by the urotherapist, district nurse or other registered nurse who has taken a specialist incontinence education course. In the Slovak Republic the number of pads is determined on the basis of the severity of the incontinence, while in Italy the supply is not based on different levels of need. In the Netherlands many of continence aids can also be purchased on web shops.

The main difference between countries lies in the number and quality of the guaranteed products: for instance, in Italy continence products are generally of a poorer quality than those provided in Sweden, where greater attention in the purchasing process is paid to factors such as quality, environmental factors and price. In the latter country the professional that prescribes the assistive devices must be able to assess the user's needs, test them to ensure that the product(s) are individually suited to the particular user in question, instruct and train the user and subsequently follow up and evaluate the prescribed products.

1.4. Support for caregivers

Since this study seeks to understand the impact of incontinence on informal caregivers' quality of life, special attention was paid to services and supports addressing the caregivers of older people suffering from incontinence in the various countries.

In Italy, services specifically addressing the needs of family caregivers of older people are rare, and only present in some of the more advanced regions in the northern part of the country. Nevertheless, a number of laws were introduced in 2000 to promote a better reconciliation between paid work and family care (Santini, Principi, & Lamura, 2011). In the Slovak Republic, attention to family caregivers seems to reach a more structured level. People facing social hardship are entitled to a nursing allowance, a which is means-tested program in which the amount