



## Original article

## Experiences of women and men living with urinary incontinence: A phenomenological study

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## ABSTRACT

**Aims:** To explore and understand, from a gender-based perspective, the quality-of-life experiences of men and women who suffer from urinary incontinence.

**Background:** Urinary incontinence (UI) is a major health problem with significant social, psychological, occupational, sexual and economic effects leading to a substantial decrease in quality of life. Although this condition is increasingly frequent in men, research has tended to focus on women, adopting a quantitative approach.

**Design:** The data were examined using interpretive phenomenological analysis (IPA).

**Methods:** The data were collected through a semi-structured interview conducted between January and June 2016. An inductive discourse content analysis was performed in three stages: preparation, organization and report. Participants were recruited until data saturation was achieved.

**Findings:** A sample of 33 participants was recruited: 17 women and 16 men. Gender-specific features were found. Six categories emerged: (i) normalization of incontinence; (ii) verbalization of the problem; (iii) social isolation; (iv) experienced feelings and emotions; (v) impact on daily routine; (vi) self-care strategies to address the problem in the most suitable way.

**Conclusion:** Urinary incontinence has a negative effect on the quality of life of men and women. However, there are gender differences as to how this phenomenon is experienced, particularly with regard to its psychological and social dimensions. A comprehensive, targeted assessment of the needs of these men and women is required on the part of professional nurses.

## Why is this research or review needed?

- Urinary incontinence (UI) is a prevalent condition among the population which has significant health, quality of life and economic consequences, and may even act as a contributing factor to increased mortality.
- UI is common in women but this problem also affects men, especially those who have had surgery for prostate cancer. Prostatic neoplasm is the second most commonly diagnosed type of cancer in men worldwide, and is associated with the problems most commonly identified in men with UI.
- Little qualitative research has been conducted on the phenomenon of living with UI from a gender-based perspective. Most of the studies found in the literature adopt a quantitative perspective and place the focus on women.

## What are the key findings?

- Dealing with UI-related problems involves a comprehensive response that helps men and women with this condition to get on with their lives.
  - Our study shows that UI is, in some respects, experienced differently by men, who find it more difficult to accept what they consider to be a female condition.
  - The acceptance and normalization of UI, as well as the verbalization of the problem and the feelings associated with it, is approached differently by men and younger women.
- How should the findings be used to influence policy/practice/research/education?
- Prevention and treatment of UI can improve the quality of life of

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men and women with this condition.

- Health professionals must carry out a comprehensive, targeted assessment of the needs of men and women with UI, by promoting greater involvement and raising awareness of the impact this problem has on these people's quality of life.
- Further research is required on the effects of UI on both men and women. Similarly, future studies should focus on the specific role played by nurses in improving the management of urinary incontinence in different work environments.

## 1. Introduction

Urinary incontinence (UI) is defined by the International Continence Society as the complaint of any involuntary leakage of urine (Abrams, Andersson, Birdler, et al., 2010). UI is a major health problem with a significant social, psychological, occupational, sexual and economic impact (Kao, Hayter, Hinchliff, Tsai, & Hsu, 2015) leading to a substantial decrease in the quality of life of the people who suffer from this condition (Villoro et al., 2016). In certain cases, this problem causes greater impairment than some chronic illnesses such as diabetes or arterial hypertension (Robles, 2006).

Despite the existence of effective treatments, many people with UI, especially women, rarely discuss this problem with healthcare providers and choose to manage it in silence instead of seeking professional help and physiotherapeutic treatment (Howard & Steggall, 2010; Vethanayagam et al., 2017; Xu, Wang, Li, & Wang, 2015). The fact is that UI is still regarded as a taboo problem in many cultural contexts (Wan et al., 2014). Research conducted in Spain has shown that the majority of men and women who suffer from UI prefer to keep secret their urinary symptoms (Elstad, Taubenberger, Botelho, & Tennstedt, 2010).

## 2. Background

Urinary incontinence (UI) is a problem that can affect people of all ages and both sexes. However, its incidence is twice as high in women as it is in men (Thüroff et al., 2011). The origin of IU in women is related to gender and age, given that its occurrence increases in the case of women and the physiological changes inherent to ageing in women foster a higher impact of this pathology (Villoro et al., 2016). Other factors are the ones related to labour and birth and pregnancy, and the ones connected to activities that involve a great physical effort (Cerruto, D'Elia, Aloisi, Fabrello, & Artibani, 2013). A further risk factor for women may be diseases in general such as hypertensive cardiomyopathy treated with diuretics, strokes or diabetes mellitus (Fuentes, 2015).

Evidence points to the difficulty of establishing precise figures concerning the prevalence of this condition due to the heterogeneity of existing research (Fuentes, 2015). A multi-national study has estimated that there are approximately 350 million people worldwide with UI (Irwin, Kopp, Agatep, Milsom, & Abrams, 2011). In Spain, the average prevalence of UI is 15% in women and 11.6% in men (Leirós, Romo, & García, 2017). Its prevalence increases with age in both men and women (Cerruto et al., 2013, Dumoulin, Hay-Smith, Habee-Séguin, & Mercier, 2015).

This condition has a major economic impact on public health systems and individuals alike (Carnicero, Abad, & López, 2012) as it involves the daily use of incontinence pads, a possible drug treatment and, occasionally, surgery. Furthermore, it generates indirect costs resulting from the loss of jobs caused by this problem (Thom, Nygaard, & Calhoun, 2005).

Likewise, quality of life is significantly reduced in people with UI and, in some cases, the extent of this impact is similar in both sexes (Bedretdinova, Fritel, Zins, & Ringa, 2016, Martínez & Rodríguez, 2010). In the social sphere, this problem is seen as taboo, which results in social isolation and limits the possibility of travelling (Orna, Artero,

Usieto, Cuadra, & Isanta, 2011). Aspects impaired by this condition include activities of daily life, both at home and in the workplace, and physical activities, such as exercise and sport (Riss & Kargl, 2011).

As a consequence of the above, the psychological sphere is affected, involving loss of self-esteem as UI gives rise to feelings of embarrassment, sadness, irritability and apathy (Geanini et al., 2013; Sinclair & Ramsay, 2011). The fear of leaking urine and the worry that it might smell causes a lot of distress both socially and at work (Lai, Rawal, Shen, & Vetter, 2016).

Some studies suggest that health professionals should pay greater attention to this problem, which is still stigmatized in society (Higa, Baena, & Dos Reis, 2008; Howard & Steggall, 2010; Wan et al., 2014).

The occurrence of UI has a negative impact in both men and women (Bedretdinova et al., 2016; Park, Chang, Palmer, Kim, & Choi, 2015). Nonetheless, there is little research that contrasts the impact of this disorder in both sexes, the focus so far being mostly placed on women. Similarly, nearly all the studies found in the previous literature are quantitative in nature. Therefore, we believe further research is required that explores the needs and quality of life of men and women with urinary incontinence from a qualitative perspective. A qualitative approach can help to improve nursing care as it allows us to better understand those aspects of the experience of living with UI that have been ignored by quantitative research due to their non-inclusion in standardized questionnaires (García, Fernández, & Martínez, 2017).

## 3. The study

### 3.1. Aim

The overall aim has been to explore, from a gender-based perspective, the quality-of-life experiences of men and women who suffer from urinary incontinence.

### 3.2. Design

Interpretive phenomenological analysis (IPA) was used to examine the data. This methodology enabled us to gather comprehensive material on how individuals experience particular phenomena (Driessnack, Sousa, & Costa Mende, 2007). IPA involves a detailed analysis of the data collected from a qualitative, objective and homogeneous sample (Smith, Flowers, & Larkin, 2009). We believe that IPA is the most suitable approach to explore the personal experiences of men and women with urinary incontinence.

### 3.3. Participants

Thirty-three people who lived with UI were recruited from the urology department at a referral hospital in the Region of Murcia, Spain. After contacting the first author and receiving all the details about the study, those participants who wished to continue were required to give their informed consent. A purposive stratified sample consisting of 17 women and 16 men was recruited. The recruitment criteria were based on the participants' interest in collaborating and providing information (Denzin & Lincoln, 2005). In addition to the sociodemographic data collected prior to the interview, participants were asked to complete the International Consultation on Incontinence Questionnaire-Short Form (ICIQ-SF). This questionnaire consists of three items and measures the frequency and severity of urine loss and its effects on quality of life (Xu et al., 2015). The total score results from the sum of the three first items, ranging from 0 to 21, and a higher severity degree is associated with a higher score. In the translated Spanish version, the three items displayed high internal consistency (Cronbach's alpha = 0.917), this value being very close to the original English version (0.92). The psychometric properties of the Spanish version point to great feasibility, validity, reliability and diagnostic power (Espuña, Castro, & Carbonell & Dilla, 2004). Table 1 shows the data on women and Table 2 on men.

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