



Revista Latino-Americana de Enfermagem

ISSN: 0104-1169

rlae@eerp.usp.br

Universidade de São Paulo

Brasil

Higa, Rosângela; Baena de Mores Lopes, Maria Helena; Ribeiro Turato, Egberto  
Psychocultural meanings of urinary incontinence in women: a review  
Revista Latino-Americana de Enfermagem, vol. 16, núm. 4, agosto, 2008, pp. 779-786  
Universidade de São Paulo  
São Paulo, Brasil

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## PSYCHOCULTURAL MEANINGS OF URINARY INCONTINENCE IN WOMEN: A REVIEW

Rosângela Higa<sup>1</sup>

Maria Helena Baena de Mores Lopes<sup>2</sup>

Egberto Ribeiro Turato<sup>3</sup>

Higa R, Lopes MHB, Turato ER. Psychocultural meanings of urinary incontinence in women: a review. Rev Latino-am Enfermagem 2008 julho-agosto; 16(4):779-86.

*The purpose of the present study was to identify and analyze studies in health literature about the psychocultural meanings reported by women who experience urinary incontinence (UI). A bibliographical search was executed in the following databases: Lilacs, Medline, Pubmed and Medscape. The present review showed that studies note several meanings. The articles were grouped in three categories defined as significant: according to age experiences, cultural-religious experiences and experiences in self-care. The studies revealed that the degree of anguish and the range of the difficulties experienced are related both with age, ethnic group or religion and with the perception each individual has of her incontinence, which will lead to different levels of emotional disorders and to seeking (or not seeking) treatment. Besides, barriers regarding self-care are perceived. It is concluded that the UI may cause suffering and incontinent women have difficulties to deal with this problem.*

**DESCRIPTORS:** nursing; women's health; urinary incontinence; review literature; psychosocial impact

## SIGNIFICADOS PSICO-CULTURALES PARA LA INCONTINENCIA URINARIA FEMENINA: UNA REVISIÓN

*El objetivo del presente trabajo fue identificar y analizar estudios en salud que trataban sobre los significados psico-culturales de mujeres que pasaron por incontinencia urinaria (IU). Fue realizada una búsqueda bibliográfica en las bases de datos: Lilacs, Medline, Pubmed e Medscape. La presente revisión mostró estudios que presentan pluralidad de significados. Los artículos fueron agrupados en tres categorías: vivencias según el grupo étnico, vivencias culturales-religiosas y vivencias sobre el autocuidado. La investigación mostró que, el grado de angustia vivida y las dificultades se encuentran relacionadas con la edad, etnia o religión, así como por la percepción que cada individuo tiene sobre la incontinencia, lo cual lo llevó a diferentes grados de trastorno emocional y a buscar (o no) tratamiento. De la misma forma se perciben barreras en cuanto a su autocuidado. Se concluye que la IU puede causar sufrimiento y que las mujeres con incontinencia enfrentan dificultades para manejar este problema.*

**DESCRIPTORES:** enfermería; salud de la mujer; incontinencia urinaria; literatura de revisión; impacto psicosocial

## SIGNIFICADOS PSICOCULTURAIS DA INCONTINÊNCIA URINÁRIA FEMININA: UMA REVISÃO

*O objetivo do presente trabalho foi identificar e analisar estudos da literatura em saúde que abordassem significados psicoculturais relatados por mulheres que vivenciam a incontinência urinária (IU). Realizou-se busca bibliográfica nas bases de dados Lilacs, Medline, Pubmed e Medscape. A presente revisão identificou que estudos apontam polissemia de significados. Os artigos foram agrupados em três categorias eleitas como relevantes: vivências segundo a faixa etária, vivências cultural-religiosas e vivências quanto ao autocuidado. A pesquisa revelou que o grau de angústia experimentado e a amplitude das dificuldades estão relacionados tanto com a idade, etnia ou religião, quanto com a percepção que cada indivíduo tem de sua incontinência, o que levará aos diferentes níveis de transtorno emocional e por procura (ou não) de tratamento. Além disso, há barreiras percebidas na manutenção do autocuidado. Conclui-se que a IU pode gerar sofrimento e que as mulheres incontinentes enfrentam dificuldades para lidar com esse problema.*

**DESCRIPTORES:** enfermagem; saúde da mulher; incontinência urinária; literatura de revisão; impacto psicossocial

<sup>1</sup> RN, Campinas State University, doctoral student, e-mail: rosangelahiga@bol.com.br; <sup>2</sup> RN, Free Lecture, Associate Professor, e-mail: mhbaena@fcm.unicamp.br; <sup>3</sup> Physician, Free Lecturer, Faculty, e-mail: erturato@uol.com.br. School of Medical Sciences, Campinas State University, Brazil.

## INTRODUCTION

**U**rinary incontinence (UI) affects the world population, especially the female population: One out of five women has already experienced symptoms of this disease<sup>(1)</sup>. In women, UI may occur more frequently due to: stress urinary incontinence, i.e. exerting pressure on the abdominal region, sneezing, coughing, laughing or doing sports; in cases of overactive bladder, with urge-incontinence, it occurs with a strong, uncontrollable urge to urinate, with a high chance of losing urine if a restroom is not found; and mixed incontinence, when there is loss of urine associated to both situations, i.e. it is preceded by efforts and symptoms of urgency<sup>(2)</sup>.

The occurrence of urinary loss in these situations implies psychosocial consequences that are more devastating than physical health sequelae, with multiple and widespread effects that restrict daily activities, social interaction, the self-perception of the state of health and quality of life for the incontinent woman, when compared with a continent. Considering people over 60 years old, according to the evaluation of quality of life measured by the *Incontinence Impact Questionnaire* (IIQ), emotional factors were shown to be the most affected. Nearly one third of the respondents mentioned nervousness, shame or frustration because of their UI; the social dominance and fear of the odor scored as highest impact<sup>(3)</sup>, since urinary loss restricts contact with co-workers<sup>(4)</sup> and physical proximity with people in general<sup>(5)</sup>.

Incontinence affects people of all ages, regardless of socioeconomic and cultural conditions, and it frequently affects the groups with more limitations in the search for help more intensely, such as elderly or physically disabled people. Since it is one of the so-called silent problems in Geriatrics, caused by the physiological decline of the elderly

person, it can influence a certain lack of interest by healthcare professionals<sup>(6)</sup>, particularly nurses, who, in turn, base themselves on old myths and stereotypes, such as the belief that the elderly accept UI as a natural consequence of their advancing age<sup>(7)</sup>. Consequently, it can also influence the validity of investing in UI treatment for people in this age range<sup>(6)</sup>.

Such factors may lead the nurse to an incorrect evaluation of the care for incontinent elders, both in the identification of the problem and its handling. The conflict of establishing clinical priorities for the nursing team, as well as educational deficits for UI, is mentioned as a barrier to promote continence. Therefore, the professional team needs to be aware of the impact of not treating UI for the elderly, and should then promote the state of continence and develop strategies for the containment of urinary loss<sup>(7)</sup>.

Since this is a delicate problem, often hidden because the symptoms are disregarded due to lack of knowledge or shame, the fact suggests that this is a "hidden" problem, underestimated both by the carrier and by nurses and other healthcare professionals. Knowledge about the impact of UI in the population, its types and causes, are fundamental aspects to be considered when evaluating the problem and, consequently, when diagnosing appropriate actions<sup>(6)</sup>.

In view of what was exposed about this urinary dysfunction, the need to analyze studies involving narratives of women with UI is considered a priority and relevant to understand their experiences, as well as emotional reactions associated to episodes of urinary loss and the meanings related to the phenomenon. Thus, important contributions will be gathered so that healthcare professionals can improve their psychological focus and the interest in further knowledge about the topic.

The authors understand that studies performed with women suffering from UI are tools to evidence views and feelings of incontinent people about their problem and their attitudes in the face of urinary loss. Therefore, the goal of the present study was to identify and analyze healthcare literature studies about the psychocultural meanings reported by women experiencing UI.

## METHOD

This is a literature review, aiming to gather and synthesize existing knowledge about the proposed topic: the meanings of UI for women. The reviews were carefully developed, since the amount of studies about the topic considered here is not large.

To support the discussion, a literature review was performed in the following databases: Lilacs (Latin-American and Caribbean Literature in Healthcare Services), Medline (International Literature in Healthcare Sciences), Pubmed and Medscape. Articles were selected by using the keywords *urinary, incontinence, female, qualitative study and quality of life* according to the authors' methodological option. Regarding the objects of study, the articles selected should have been written in Portuguese, Spanish or English, and published after 1990.

The results of the electronic searches were evaluated and selected to retrieve articles considered relevant and exclude those of lesser academic importance in the authors' view. Four stages were then performed: (a) selection of the articles in the chosen databases and, based on their titles, inclusion and analysis of the texts that referred to UI in women, excluding those focusing on UI in children and men; (b) selection of the articles by carefully reading the abstracts, with the studies being done under a qualitative methodological focus, i.e. those covering

the reported experiences and restrictions caused by urinary loss. Articles with an epidemiological focus, instrument validation and evaluation of quality of life using scales were excluded. (c) When looking for integral articles for the location of the publications, the following resources were used: the bibliographic commuting service and the archives of the library of the Faculty of Medical Sciences at the University of Campinas (UNICAMP), searches in Capes' Portal of Journals through the search engine of the Electronic Library of Unicamp and the *Scientific Electronic Library Online* (SciELO); and (d) critical evaluation of the articles, after reading them integrally. Seventeen studies were therefore included in a final analysis, performed with a qualitative focus, as well as two recent Brazilian journals, whose fundamentals and argumentation matched the proposed theme and complemented the relevant themes of the qualitative approach. Finally, 19 bibliographic references were considered pertinent for this article.

After re-reading the *corpus* (the full set of collected material), studies were observed to point out a variety of meanings, as expected from research results in Humanities. The data were analyzed according to the results that emerged in the published studies and grouped in categories/topics. Aiming to understand the meanings the women attributed in issues related to their experience with urinary loss, the data analysis was based on psychosocial references.

The categorization of the studies consisted in the definition of the information, taking into account the experiences reported in the qualitative studies, grouped by thematic relevance; occasionally in the repetition of the addressed topic, as well as the clinical experience of the research professionals' theoretical knowledge. The studies gathered were grouped in three categories, seen as prominent: (1) Experiences according to age range; (2) Cultural-religious experiences and (3) Experiences related to self-care.

Table 1 – Publications according to the title of the article, the method used, themes addressed, journal and year of publication, 2007

Title of the article	Method	Approach	Journal	Year
1. Discovering older women's experience of urinary incontinence	Qualitative study; semi-structured interview; content analysis	Age range Self-care	Research Nursing & Health	1991
2. The meaning of incontinence: a qualitative study of non-geriatric urinary incontinence sufferers	Qualitative study; semi-structured interview; psychological analysis	Age range Cultural-religious	Journal of Advanced Nursing	1993
3. General practitioners and women with urinary incontinence	Qualitative study; semi-structured interview; thematic analysis; purposeful sampling.	Self-care	British Journal of General Practice	1998
4. Response to urinary incontinence by older persons living in the community	Qualitative study; semi-structured interview; thematic analysis; ethnographic software.	Self-care	Journal of Wound Ostomy and Continence Nursing	1998
5. Barriers to help seeking in people with urinary symptoms	Qualitative study; semi-structured interview; thematic analysis; random sample.	Age range Cultural-religious Self-care	Family Practice	2001
6. Pakistani women's perceptions and experiences of incontinence	Qualitative study; semi-structured interview; content analysis	Cultural-religious Self-care	Nursing Standard	2001
7. What prevents older people from seeking treatment for urinary incontinence? A qualitative exploration of barriers to the use of community continence services.	Qualitative study; semi-structured interview; content analysis; purposeful sampling.	Self-care	Family Practice	2004
8. Developing a cultural model for long-term female urinary incontinence	Qualitative study; semi-structured interview; cultural model analysis	Age range Cultural-religious Self-care	Social Science & Medicine	2006
9. Do nurses promote urinary continence in hospitalized older people? An exploratory study	Qualitative study; focus group; content analysis; purposeful sampling.	Cultural-religious	Journal of Clinical Nursing	2006
10. Female urinary incontinence in China: experiences and perspectives	Qualitative study; semi-structured interview; interpretative phenomenological analysis.	Cultural-religious Self-care	Health Care for Women International	2006
11. Urinary incontinence restrictions in women's life	Quantitative study; structured interview; descriptive analysis.	Age range Self-care	Revista da Escola de Enfermagem da USP	2006
12. Urinary incontinence in Moroccan and Turkish women: a qualitative study on impact and preferences for treatment	Qualitative study; semi-structured interview; thematic analysis; sampling by saturation.	Cultural-religious Self-care	British Journal of General Practice	2006
13. Chinese women's experiences in coping with urinary incontinence	Qualitative study; semi-structured interview; content analysis; purposeful sampling.	Cultural-religious	Journal of Clinical Nursing	2007
14. Coping with stress incontinence: women's experiences of everyday incontinences	Qualitative study; semi-structured interview; content analysis; purposeful sampling.	Self-care	International Journal of Urological Nursing	2007
15. Culturally sensitive continence care: a qualitative study among South Asian Indian women in Leicester.	Qualitative study; focus group; systematic and iterative analysis; purposeful sampling.	Cultural-religious Self-care	Family Practice	2007
16. Fear of humiliation inhibits women's care-seeking behavior for long-term urinary incontinence	Qualitative study; phenomenological hermeneutics; semi-structured interview; psychosocial analysis; purposeful sampling.	Age range Self-care	Scandinavian Journal Caring Science	2007
17. Silent no more: elderly women's stories of live with urinary incontinence in long-term care	Qualitative study; semi-structured interview; thematic analysis;	Self-care	Journal Gerontology Nursing	2007
18. The impact of urinary incontinence on female nursing personnel	Quantitative study; structured interview; descriptive analysis; purposeful sampling.	Age range Self-care	Revista Brasileira de Enfermagem	2007
19. The meaning of women's experience of living with long-term urinary incontinence is powerlessness.	Qualitative study; phenomenological hermeneutics; semi-structured interview; psychosocial analysis; purposeful sampling.	Cultural-religious	Journal of Clinical Nursing	2007

## EXPERIENCES ACCORDING TO AGE RANGE

Nowadays, the UI experiences of older women are investigated more often, probably due to its high

prevalence after the menopause, although psychosocial alterations seem to be expressive in all age ranges. The symbolic aspects, however, are shown to be different according to the age range and particularities of UI.

For women over 60 years old, the feelings of urinary loss come about built and "negotiated" as a result of individual and shared experiences<sup>(8)</sup>; they are associated with the idea that this is an inevitable phenomenon, a consequence of advancing age and an implication of the amount of children delivered. The women describe incontinence as a *degenerative* process<sup>(9)</sup>, and a condition inherent to their life history<sup>(8)</sup>.

Among young and middle-aged women (under 50 years old), the problem is perceived as a *personal dysfunction*, with a loss of the healthy properties of the body, thus facing a significant difficulty in coping with the disease. Because they consider UI a taboo, they see this phenomenon as unacceptable for social life and feel socially despised and guilty in the face of a consequent repulsive reaction from the group and abandonment by a part of society<sup>(10)</sup>.

Elderly women explained that accidents or other problems related to UI were a threat to their self-esteem, with this threat encouraging them to develop efficient systems of care for continence, which helped to protect their self-esteem. If they succeeded, they could possibly accept UI and lead a "normal" lifestyle<sup>(11)</sup>.

Some of the younger women reported experiencing the characteristic feelings of the urinary symptoms with indifference, or even underestimating them. It is remarkable that they are able to keep *normality*, since there seem to be negative defensive responses, because it involves a large adjustment of efforts with behaviors that are characteristic of continent people, and they frequently do not follow the rational pathways to cope with the problem<sup>(10)</sup>.

The lack of control over UI during social activities is shown to be present, with evidence of psychological implications in leisure, professional and family life. Women mention the fear of losing their jobs or changing their work functions because of labor restrictions, causing limitations in activities that demand physical effort, and constant interruptions to go to the restroom because of higher micturition frequency<sup>(4-5)</sup>. For elderly women, the fear of the odor was shown to have a high impact on social restrictions, with the most affected practices being going to places where there is no restroom and taking longer trips<sup>(5)</sup>. Among the younger women, besides the aforementioned complaints, they report shame when this "disgrace" happens in public, especially in social events with friends and during sports practice<sup>(4-5)</sup>.

Since beauty care is applied to the body in the frequent idolatry of physical shape, added to the fact that women usually tend to desire with their *whole bodies*, with sexuality distributed across the whole body and not centered only in the genital organs<sup>(12)</sup>, urinary loss restricts sexual interaction, since they imagine themselves as unattractive. For young women, this would point to an "early old age", which they normally tend to abhor, feeling shame in the face of clear evidence of loss of self-esteem, highlighted by the fear of rejection in sexual activity due to incontinence, guilt about not feeling desire or pleasure and about losing urine during the orgasm<sup>(5)</sup>. The impact of UI was felt in intimate relationships: sexual life was inhibited due to its lack of spontaneity, needing to be planned, interfering in the sexuality of the women and their partners<sup>(13)</sup>.

The several aspects mentioned by the women are related to the psychodynamic and cultural meanings attributed to the body. Body-related meanings change with age, since elderly women saw UI as a natural condition of aging. Among the younger women, it seems to mean *loss of control* over the body. Feelings, statements and practices were observed to be associated to the body, embedded in interpersonal relations that alter the emotional aspects of incontinent women.

## CULTURAL-RELIGIOUS EXPERIENCES

Literature points more frequently to studies performed with western women, especially in the United States and Europe. Among those who studied women from Morocco, Turkey, Pakistan and India, the population was constituted by immigrants living in European countries<sup>(14-16)</sup>. There seem to be similarities in the psychological meanings of UI for women living in different cultures, ethnic groups and social conditions; however, regarding religious practices, the experiences of incontinent women can interfere with following some religions<sup>(15-16)</sup>.

When searching for studies about reports of eastern women experiencing UI, the psychosocial aspects indicated that cultural differences do not change the meanings of urinary loss, since there were similarities between narratives of western and eastern women. Like women from American and European countries<sup>(7-11)</sup>, the body was experienced as being uncontrolled; insecurity, despair and powerlessness

were experienced when the women could not control the accidents, leading to feelings of helplessness and anguish<sup>(17)</sup>.

Chinese women reported feelings of guilt, loneliness and emotional isolation<sup>(18)</sup>, described a personal loss of control every time they wetted themselves with urine, felt stressed when it occurred in public, and in front of friends. The feeling of shame and humiliation was higher than fear<sup>(19)</sup>. For the Indian women living in Leicester, UK, it is possible that social stigmas from the southern Asian population contribute to the difficulty they may have to discuss continence-related care with other people<sup>(14)</sup>.

In the subgroup where the religious identity was analyzed, such as Islamic or Jewish, urinary loss becomes a problem in the following of religious precepts<sup>(15)</sup>. For some Muslim women, being a UI sufferer means having to be reserved, isolated and with feelings of low self-esteem<sup>(16)</sup>. Similar to what happens to Jewish women, incontinence for the Muslim women led to the limitation of religious life, related to the need of cleanliness for the practice of prayer<sup>(15-16)</sup>.

However, Muslim women resort to prayers to minimize their anguish, but this comfort may be denied due to being unclean, therefore increasing their stress<sup>(16)</sup>. Losing urine would represent a sinful and unclean phenomenon, experiencing personal cleanliness as a heavy burden, since they feel physically dirty when urinary loss occurs, and the ritual of cleaning is needed more frequently so that they can keep themselves clean<sup>(15)</sup>. Experiencing incontinence during the cleansing ceremony makes them feel filthy and impure because, after the body cleaning, it becomes indispensable to repeat prayers before restarting the cleansing rituals<sup>(15-16)</sup>.

## EXPERIENCES REGARDING SELF-CARE

Women frequently disregard symptoms when the disturbances caused by incontinence are small; they feel ashamed when they have to report their problem to a professional, omit the fact in family life and generally suffer in silence<sup>(4)</sup>.

For some women, the meaning of valuating a body that is strong and healthy induces a certain resistance to pain, and it frequently becomes a determining factor for not seeking a medical appointment. Often, they expect the disease to reach such an intensity that it would impede the normal use

of the body, to the extent that the problem is disregarded due to the difficulties that they face when exposing and describing the symptoms to the physician<sup>(20)</sup>.

Embarrassment and shame, associated to the lack of knowledge and understanding about incontinence as a disease, and experiencing different meanings or urinary loss for each person generate multiple ways of self-care, disregarding the help of a healthcare professional. Elderly people, even those who regularly see healthcare professionals, rarely speak about their urinary loss, probably due to shame or to the erroneous conception that it is not a health problem<sup>(8,18)</sup>. Among those who believe that UI is an irreversible problem and a consequence of aging, there seems to be a better acceptance of the symptoms. Although there are social and psychological costs, sometimes even for their own physical health, success in strategies utilized to minimize incontinence also contributes to make them not reveal the problem to others<sup>(21)</sup>.

The interferences of UI in the restriction of younger women's everyday activities do not seem to have an expressive meaning in the search for self-care to solve the problem<sup>(13)</sup>, with the psychological factors drawing attention when they react to urinary loss with apathy or when they abstain from rectifying actions<sup>(9)</sup>. Others experience urinary loss as a taboo, try to manipulate incontinence in different ways, recover the power over their uncontrolled body and continue living normally<sup>(17)</sup>.

For the immigrant Muslim women living in European countries, inhibitions and limitations of language prevent them from clearly reporting their condition to the healthcare professionals and completely understanding the orientations they receive, which suggests that inadequate care may be adopted<sup>(14-16)</sup>. The inhibitions may be reduced when treated by a female healthcare professional. These women cope with urinary loss by sharing the problem with other women, and then develop strategies to live with incontinence, such as trying to reduce the incidence by managing the episodes<sup>(16,18)</sup>. Deficiencies in seeking help also seem to be related to a lack of knowledge about their own anatomy, physiology and available treatments<sup>(15)</sup>.

On the other hand, the attitude of some healthcare professionals may cause inhibition and prevent the woman from expressing her complaints during an appointment, in the same way that it is necessary to understand the cultural and religious



identities of the population receiving care. The attitudes and practices of these professionals are strong barriers for people to seek counseling or help. If the professionals asked the women about their urinary symptoms regularly, they would probably verbalize them and seek help more often<sup>(21-22)</sup>.

Elderly women with UI living in long-term stay institutions reported common concerns in their experiences with urinary loss, and they report that the institutional culture can influence changes in nursing practice related to individual care, suggesting opportunities to provide health education measures related to quality of life<sup>(23)</sup>.

People who seek the help of healthcare professionals desire more information about the causes, treatments and mechanisms to deal with the problem. Women request better interaction with these professionals, and the need for discussion and further knowledge about the topic was identified<sup>(24)</sup>. The way of performing this communication is reported as a priority for the diagnosis and establishment of bonds and empathy to seek and determine the most appropriate educational method to facilitate comprehension, and thus compliance with the treatment<sup>(25)</sup>.

It is necessary, especially for healthcare professionals, to make more efforts in order to know what each person feels about her condition, how she deals with the problem in her day-to-day activities and how she is ruled by the symbolic meanings of this phenomenon.

The personal and healthcare professionals' barriers women faced when they sought help encourage the improvisation of means for the adaptation of urinary loss, often inadequate or even inefficient. Women adopt self-care measures as a way

to minimize urinary loss, although they acknowledge that many are harmful to their health, such as the continuous usage of absorbent pads and hydric restriction, which may trigger dermatologic problems and urinary infections<sup>(4,5,21)</sup>.

## FINAL CONSIDERATIONS

An important result in the healthcare and biomedical literature review was the evidence that the studies published about urinary incontinence, in general, offer few references to reports collected with women about how distressing this disease is and the many consequent psychosocial problems, since wetting oneself with urine is a very embarrassing personal experience.

The studies considered here reveal that the degree of distress experienced and the range of difficulties are not only related to age, ethnicity or religion, but also with the responses of each person and *how* each individual perceives her incontinence, since the meanings given to healthcare problems structure our lives. It is known that responses with different degrees of emotional disorders in the face of this urinary problem can shatter the confidence and respect one has for oneself, and prevent them from seeking help.

Regarding the implications for nursing practice, these results can be used as a guideline for procedures that will lower or eliminate the barriers perceived in self-care maintenance, facilitate the execution of interventions to reduce urinary loss and promote continence, with the necessary educational focus that favors open discussions, during which women can report and share their experiences and feelings.

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