

Impact of urinary incontinence on women's quality of life: an integrative literature review

Impacto da incontinência urinária na qualidade de vida de mulheres: revisão integrativa da literatura

Impacto de la incontinencia urinaria en la calidad de vida de las mujeres: una revisión bibliográfica integradora

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ABSTRACT

Objective: to verify the impact of urinary incontinence on women's quality of life. **Method:** integrative review conducted in CAPES, LILACS and PubMed electronic sources. For inclusion, articles had to be available in full electronically and address the subject; search duplicates were excluded. Twelve articles were selected. **Results:** these studies, nine cross-sectional, were published from 2015 to 2019. Four thematic categories were identified: women's perception of UI; impact of UI on women's QOL; UI type with greatest impact on QOL; and importance of assessing incontinent women's QOL. **Conclusion:** UI had adverse impact on QOL of women, because of physical, sexual, occupational, and social limitations, as well as feelings of shame, lack of control, discomfort, insecurity, suffering and guilt.

Descriptors: Women's; Women Health; Urinary Incontinence; Quality of Life.

RESUMO

Objetivo: verificar o impacto da incontinência urinária na qualidade de vida das mulheres. **Método:** revisão integrativa realizada em fontes eletrônicas da CAPES, LILACS e PubMed. Utilizou-se como critério de inclusão, os artigos disponíveis eletronicamente na íntegra e que dissertaram sobre a temática, e de exclusão os que apresentaram duplicidade na busca. Foram selecionados doze artigos. **Resultados:** os estudos analisados foram publicados no período de 2015 a 2019, sendo nove estudos do tipo transversal. Identificaram-se quatro categorias temáticas: percepção das mulheres sobre a IU; impacto da IU na QV de mulheres; tipo de IU de maior influência sobre a QV; e importância da avaliação da QV de mulheres incontinentes. **Conclusão:** evidenciou-se o impacto negativo da IU na QV de mulheres, devido a limitações físicas, sexuais, ocupacionais e sociais, e sentimentos como vergonha, falta de controle, mal-estar, insegurança, sofrimento e culpa.

Descritores: Mulheres; Saúde da Mulher; Incontinência Urinária; Qualidade de Vida.

RESUMEN

Objetivo: verificar el impacto de la incontinencia urinaria en la calidad de vida de las mujeres. **Método:** revisión integradora realizada en fuentes electrónicas CAPES, LILACS y PubMed. Para su inclusión, los artículos debían estar disponibles en su totalidad en formato electrónico y abordar el tema; Se excluyeron los duplicados de búsqueda. Se seleccionaron doce artículos.

Resultados: estos estudios, nueve transversales, se publicaron entre 2015 y 2019. Se identificaron cuatro categorías temáticas: percepción de las mujeres sobre la IU; impacto de la IU en la calidad de vida de las mujeres; Tipo de IU con mayor impacto en la calidad de vida; e importancia de evaluar la calidad de vida de las mujeres con incontinencia. **Conclusión:** la IU tuvo un impacto adverso en la calidad de vida de las mujeres, debido a limitaciones físicas, sexuales, ocupacionales y sociales, así como sentimientos de vergüenza, descontrol, malestar, inseguridad, sufrimiento y culpa.

Descriptores: Mujeres; Salud de la Mujer Incontinencia Urinaria; Calidad de Vida.

INTRODUCTION

Urinary Incontinence (UI) is defined by the International Continence Society (ICS) as any involuntary urine leakage and is considered a disease in the International Classification of Diseases (ICD-10/WHO)^{1,2}. Thought as a public health problem, this pathology affects more than 200 million people worldwide, and has a high prevalence rate among women, which increases with the aging³.

Seen as a high-incidence dysfunction in modern society, nearly 20% to 50% of the adult women can present UI at some stage of life, and for each man, two women are incontinent^{4,5}. In Brazil, approximately 30% to 43% of the women suffer from involuntary urine leakage at some point in their lives; however, these rates can be below reality, as this pathology remains underdiagnosed and undertreated^{3,4}.

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UI can be classified according to its etiology and symptomatology, the most common types being: stress urinary incontinence (SUI), characterized as the urine leakage due to effort, which causes an increase in intra-abdominal pressure, such as coughing, sneezing and physical activity; urge urinary incontinence (UUI), which is urine leakage associated with a strong sense of urgency to urinate; and mixed urinary incontinence (MUI), with urine leakage related to urgency and pressure^{6,7}.

Despite having a multi-factorial origin, female UI has some specific risk factors, such as: pregnancy, type of childbirth, menopause, hysterectomy, vaginal episiotomy and body mass index⁸. Involuntary urine leakage is a condition capable of causing physical, social, occupational, domestic and sexual limitations, compromising biopsychosocial aspects and having a great impact on women's Quality of Life (QoL)⁹.

The term QoL has two concepts in the health area according to the World Health Organization. In its most generic concept, it is defined as the "individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns"; and, in its most specific concept, health-related quality of life (HRQoL) is associated with the "aspects of a person's life that present changes in their health state, significant to impact on their quality of life", thus presenting a direct relationship with diseases and health interventions¹⁰.

Assessing the impact of UI on the HRQoL of incontinent women becomes a significant strategy to profile this pathology not only from the clinical point of view, but also from the patient's perspective. Therefore, it enables the development of an efficient therapeutic process, in search of the recovery of patients' continence and QoL¹¹. To perform this assessment, specific, valid and reliable questionnaires can be used, which measure the severity and impact of the UI symptoms on QoL, such as: the International Consultation on Incontinence Questionnaire-Short Form (ICIQ-SF), the Incontinence-Specific Quality of Life Instrument (I-QOL) and the King's Health Questionnaire (KHQ)^{12,13}.

The ICIQ-SF questionnaire is considered simple, brief and self-administered, through which the frequency, severity and impact of UI on the QoL of men and women are assessed through four questions. It also has a set of eight items of self-diagnosis, related to the causes or situations experienced by the patients. Therefore, it is an instrument that can be used in scientific research and clinical practice, serving to track and qualify urinary leakage¹⁴.

I-QOL assesses the impact of SUI on the QoL of patients of both genders through 22 questions that are divided into three domains (limitation of behavior, psychosocial impact, and social embarrassment). Like the ICIQ-SF, this questionnaire can also be used both in scientific research and in daily clinical practice, and can be conducted in face-to-face or telephone interviews¹⁵.

The KHQ validated in Brazil in 2003 is the most used questionnaire in studies on QoL and UI. Its objective is to assess the perception of the impact of UI on women's QoL through 22 questions and eight domains (general health perception, impact of UI, limitations in daily activities, physical limitations, social limitations, personal relationships, emotions, sleep and energy). The scores obtained in each domain will determine the impact of UI on QoL, that is, higher scores indicate greater impact¹³.

Given the above and the relevance of the theme, the study had the following as guiding question: What is the impact of urinary incontinence on the quality of life of incontinent women? To answer this question, the objective was to verify the impact of urinary incontinence on women's quality of life through an integrative literature review, providing fundamental knowledge of this theme in view of the published literature.

METHOD

This is an integrative literature review, a scientific method that seeks to assess and synthesize results of previous research studies, presenting conclusions of the literary corpus on a given phenomenon in a systematic, orderly and comprehensive manner¹⁶.

For the review, the following steps of the method were used: identification of the theme and selection of the research question; establishment of the inclusion and exclusion criteria; definition of the information to be extracted from the selected studies; assessment of the studies included in the integrative review; interpretation of the results; and presentation of the knowledge review¹⁷.

Data collection occurred from February to March 2020, through the CAPES Journals portal, LILACS and PubMed, using the combination of the following keywords recognized by the Health Sciences Descriptors (*Descritores em Ciências de Saúde*, DeCS): *Incontinência Urinária* (Urinary Incontinence); *Qualidade de Vida* (Quality of Life); and *Saúde da Mulher* (Women's Health). These terms were searched in the databases using the Boolean logical operator *AND*, and crossed-examined as descriptors, title words and abstract.

For the refinement of the research and definition of the sample, the following inclusion criteria were considered: full articles indexed on the CAPES Journals portal, LILACS and PubMed, published between 2015 and March 2020, electronically available in full in Portuguese, English or Spanish, that directly addressed the research object and answered the guiding question. Articles that were duplicated in the search or that did not meet the inclusion criteria defined were excluded.

Initially for this review, 86 articles were found indexed in the CAPES Journals portal, 150 in PubMed and two in LILACS, totaling 238 articles. Of these, after the search process with the application of the inclusion and exclusion criteria, it was possible to select 86 scientific articles for an exploratory pre-reading of the titles and abstracts. By means of this eligibility, 21 articles were chosen, which were read in full, checking whether they met the inclusion criteria and answered the guiding question of this review.

Upon assessment and characterization as to title, authorship, journal, year of publication, method and main results, in order to organize and tabulate the information of the selected studies, nine articles were excluded as they did not present a direct approach to the theme and did not answer the guiding question. Therefore, as provided in the Flowchart of Figure 1, 12 publications were selected for the analysis, by means of a pertinent and critical reading, in order to extract information to achieve the objective of this study.

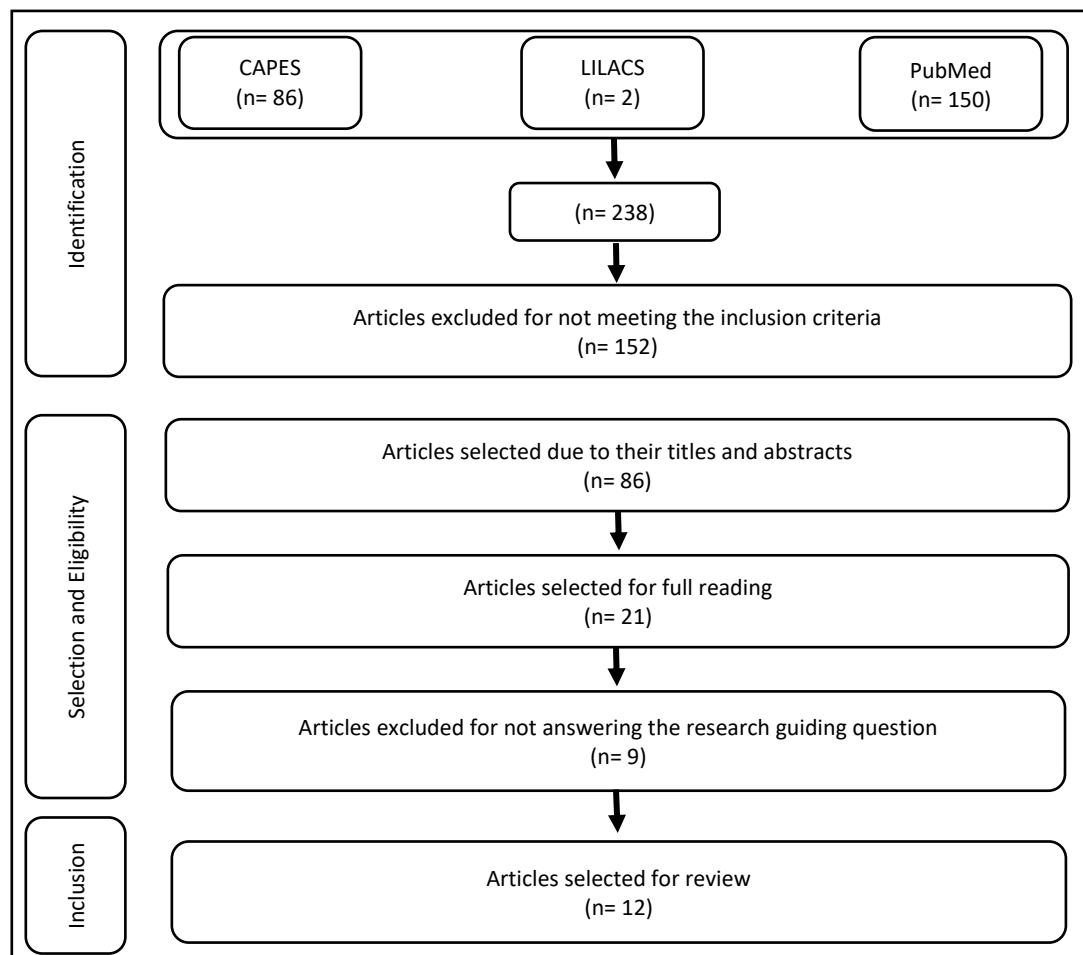


FIGURE 1: Explanatory flowchart on the stage of searching for articles on the CAPES Journals portal, LILACS and PubMed. Juiz de Fora, MG, Brazil, 2020.

After the analysis, similar contents were grouped, in which the following themes emerged: women's perception of UI; impact of UI on women's QoL; type of UI with the greatest influence on QoL; and the importance of assessing QoL among incontinent women.

RESULTS AND DISCUSSION

The 12 scientific articles selected to compose this study were categorized and exposed in Figure 2.

Title/Year	Journal/Database	Method	Main Results
<i>Perfil e qualidade de vida de mulheres em reabilitação do assoalho pélvico, 2018</i> ¹²	REBEn CAPES	Cross-sectional study	The change in sexual activity and some types of UI affected HRQoL.
Living with UI: potential risks of women's health? A qualitative study on the perspectives of female patients seeking care for the first time in a specialized center, 2019 ¹⁸	Int. J. Environ. Res. Public Health PubMed	Qualitative and exploratory study	UI was defined as something unpleasant, stressful and traumatic, leading to feelings of shame, insecurity, suffering and guilt. Thus, it was determined as a negative experience.
<i>O impacto da IU sobre a qualidade de vida e sua relação com a sintomatologia depressiva e ansiedade em mulheres, 2019</i> ¹⁹	Rev. Salud Pública CAPES	Cross-sectional study	There was high prevalence of depression and anxiety, associated with the worst impact on the QoL of incontinent women.
UI among urban and rural community dwelling older women: prevalence, risk factors and quality of life, 2019 ²⁰	BMC Public Health PubMed	Data analysis	Women in rural areas who presented UI experienced greater physical, social and emotional limitations and sleep disorders compared to their urban peers.
<i>Investigação da qualidade de vida de mulheres com IU, 2018</i> ²¹	Arq. Ciênc. Saúde UNIPAR LILACS	Cross-sectional study	The ICQ-SF and KHQ instruments showed a negative impact of UI on women's QoL.
Female urinary incontinence: quality of life comparison on reproductive age and postmenopausal period, 2016 ²²	Fisioter Mov. CAPES	Descriptive-Retrospective study	In the sample studied, UI negatively affected QoL but there was a significantly greater impact of the pathology on women in the post-menopausal period.
<i>O impacto da IU feminina na qualidade de vida, 2016</i> ²⁴	Educação e Ciência para a Cidadania Global CAPES	Cross-sectional study	The results showed that the QoL of women with UI is negatively affected, causing feelings of low self-esteem, interfering with daily activities and restricting social contact.
<i>Impacto do tipo de IU sobre a qualidade de vida de usuárias do SUS no Sudeste do Brasil, 2015</i> ²⁵	Rev. Bras. Ginecol Obstet. CAPES	Cross-sectional study	It was possible to observe in this study that women with MUI presented worse scores on the KHQ assessment questionnaire and had their QoL compromised in a moderate/severe way.
Quality of life of women with urinary incontinence in rehabilitation treatment, 2016 ²⁶	Journal of Health Psychology PubMed	Cross-sectional study	It was identified that sexual satisfaction, severity, suffering and the impact of UI predict QoL.
<i>Impacto dos tipos de IU na qualidade de vida de mulheres, 2017</i> ²⁷	Rev. Esc. Enferm. PHU CAPES	Cross-sectional study	All types of UI affect both general and specific QoL, but women with MUI are the most affected.
<i>Qualidade de vida em mulheres com IU, 2015</i> ²⁸	Revista de Enfermagem Referência CAPES	Cross-sectional study	UI moderately influences women's QoL, with SUI having the worst impact.
Urinary incontinence and quality of life of women living in nursing homes in the Mediterranean region of Turkey, 2017 ²⁹	PSYCHOGERIATRICS PubMed	Cross-sectional study	It was verified that the QoL of women who did not consider UI as a health problem was significantly higher than that of those who did so. MUI was the most common subtype and was identified as the one that most affects QoL.

FIGURE 2: Distribution of the articles selected according to title, reference, author, journal/year, method, and main results. Juiz de Fora, MG, Brazil, 2020.

Of the selected studies, six were published in 2016 and 2019, three in each year; and, in 2015, 2017 and 2018, two articles were published each year. Regarding the language, five publications were in English, and seven were in Portuguese. It is noteworthy that all the articles are original, with nine cross-sectional studies, and published in different journals related to the health sector.

All the studies aimed to analyze, evaluate or investigate the impact/influence of UI on women's QoL. As information collection instrument for assessing this QoL, nine used the King's Health Questionnaire (KHQ), two chose more specific measurement questionnaires (PRAFAB-questionnaire and Incontinence-Specific Quality of Life Instrument), and one used the semi-structured interview as method. Four articles that applied the KHQ as a questionnaire also used other questionnaires, such as the ICIQ-SF and the I-QOL, in order to compare data and offer more accurate information about the impact of UI on the QoL of incontinent women.

The sample analyzed in this review addressed some similar aspects, such as: the impact of UI on the QoL of women; the perception of the QoL of women with UI; the influence of specific types of UI on QoL; the influence of variables such as sociodemographic, obstetric, gynecological and clinical on UI and, consequently, on QoL; and the importance of assessing QoL among incontinent women. They resulted in the following thematic categories: *Women's perception of UI*, *Impact of UI on women's QoL*, *Type of UI with the greatest influence on QoL* and *Importance of assessing QoL among incontinent women*, which present the synthesis of knowledge contemplated in the literature.

Women's perceptions of UI

The symptoms caused by UI can adversely affect the woman's routine. The perspectives and narratives about the impact of this pathology are essential for its understanding, mainly considering the view of incontinent patients¹⁸.

Women perceive UI as a negative, unpleasant and stressful experience, which causes feelings of shame, lack of control, malaise, insecurity, suffering and guilt¹⁸⁻²⁰. Scholars report that women, when living with involuntary urine leakage, feel dirty and impure, describing this situation as their defect or failure, to the point of experiencing guilt for being that way¹⁸.

These feelings can result in: isolation and social exclusion, low female self-esteem, depression, anxiety and delay in seeking treatment, directly influencing the QoL of these women and forcing them to undergo changes in their daily habits. Lack of information about the pathology, false beliefs and myths can enhance the negative perception^{19,20}.

Impact of UI on women's QoL

UI influences women's QoL in several dimensions, which can cause psycho-emotional changes and limitations such as physical, social and sexual, as well as and on daily activities²¹. The researchers report that this impact is related to individual perception of the severity, type and amount of urine leakage and to the cultural context in which women are inserted²².

The physical and social limitations are related to fear or shame of leaking urine in public, which leads women to stop going out, going to parties and to the church, shopping, taking long trips and practicing physical activities for fear of appearing to have wet clothes, smelling of urine or not finding a bathroom nearby. Many of these women only leave their homes when they know they will have easy access to bathrooms when they need^{23,24}.

The limitations in sexual activity are associated with the discomfort of feeling the need to urinate or with urinary leakage during intercourse, which can cause the loss of sexual pleasure and desire. Therefore, women reduce and even avoid this activity^{23,25}.

As for daily activities, the most reported limitations are refraining from performing household chores that require physical effort or carrying weight, actions that influence the urine leakage and cause greater trips to the bathroom or leakage in the clothes. The increase in trips to the bathroom on a daily basis also causes limitations in occupational activities, which interferes with the professional performance of incontinent women, as they need to interrupt work several times. Given this factor, many feel so embarrassed that they resign from work^{23,24}. These restrictions can lead to frustration and demonstrate the influence and impact of UI on the QoL of incontinent women²³.

The studies analyzed^{12,18-22,24-29} unanimously verified that UI negatively impacted the QoL of women in a severe/very severe way. The negative effects on the general perception of health, resulting limitations and impact of UI interfere with QoL; however, the main indicator of that reduction is the level of severity of the pathology^{21,26}.

Some quantitative and qualitative variables such as gender, age, and clinical and sociodemographic conditions, can potentiate this negative impact of UI on QoL. This aspect was identified in a study²⁰, in which older adult women with UI who lived in urban areas presented higher prevalence, while women in the same condition, but who lived in rural areas, had a greater negative impact on their QoL. Some symptoms can also intensify this low QoL, as found in

another study¹⁹ in which women with UI that were characterized as depressed and anxious presented worse QoL compared to those who were only incontinent.

All the QoL domains assessed by the KHQ questionnaire can be compromised by UI, especially the general perception of health, the limitations in daily activities, personal relationships and emotions. These presented higher mean scores in the studies and reveal the negative impact of this pathology on the QoL of women^{12,24,26}.

Type of UI with the greatest influence on QoL

The domains present in the ICIQ-SF, I-QOL and KHQ questionnaires can vary in terms of their impairment according to the UI subtype, with mixed urinary incontinence (MUI) responsible for higher scores and, consequently, a lower QoL index. The studies^{19,25,27} identified that this subtype of incontinence has a greater influence on the restrictions of personal relationships and daily activities, as well as greater emotional impact. In this context, the researchers²⁵ also showed a great impact on sexual activity, as leaking urine during sexual intercourse can cause anxiety, decreased libido and conflicts in the relationship, increasing the negative effect on QoL.

MUI has the worse impact on QoL due to its greater clinical severity and, unlike other subtypes, it does not have predictable situations of urine leakage, like stress urinary incontinence (SUI), being difficult to find modalities to reduce its negative impact on daily life^{19,27}.

Importance of assessing QoL among incontinent women

Given all the impacts and circumstances that UI can cause on a woman's life, the studies^{21,22,26} demonstrate the need to consider the analysis of QoL, through specific questionnaires, during the routine assessment of a patient with incontinence. These questionnaires must be directed to UI and its impact, and more than one type can be used, making it possible to carry out a complete analysis and to identify the severity and influence of this pathology on the patients²¹.

In this way, the investigation of QoL must be considered as a central parameter in the assessment of UI, on which the actions of the health professionals during treatment planning and orientation will be focused, proving to be essential for the recovery process^{12,22,27}. Therefore, these professionals must prioritize an assistance focused on health promotion and on therapeutic processes, mainly seeking to reduce the negative aspects of UI affecting the QoL of women^{12,22,27-29}.

CONCLUSION

UI is experienced by women as something harmful, which causes great physical and emotional discomfort, in addition to significantly influencing their daily habits. Lack of information, the incontinence subtype, the severity of the symptoms and the sociodemographic and urogynecological characteristics can negatively potentiate this experience.

It is evidenced, then, the negative impact of UI on women's QoL due to psycho-emotional changes, physical, sexual, occupational and social limitations and feelings like shame, lack of control, malaise, insecurity, suffering and guilt. This impact on QoL can vary according to the UI subtype, with MUI being characterized as the one that most compromises QoL, especially regarding daily activities, emotions and personal relationships.

It was verified that the understanding and assessment of the QoL of incontinent women must be presented a central parameter of the clinical practice in order to define a complete therapy that aims at the needs of the patient and seeks to reduce the negative aspects of UI. It is necessary and important to demystify incontinence, making information available to these women about the pathology, the importance of professional help and the therapeutic strategies.

The limitations of the study include the sample and the search in the selected electronic sources, a procedure that restricted the search to three databases, and thus only the online articles available in full were included and, of these, only one study used the qualitative method.

Therefore, after reading the literature on the theme, it is recommended that the search be expanded and that new qualitative studies be produced on understanding the impact of UI on women's lives, in order to contribute to clarifying the experience of this phenomenon and the specific interventions for this population.

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