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Highlights:

(1). Urinary incontinence has a negative impact on the quality of life of the elderly. (2). The psychological and social dimensions are the most affected. (3). Importance of qualified listening to increase the visibility of the problem.

PRE-PROOF

(as accepted)

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ABSTRACT

The objective is to understand the impact of urinary incontinence on the quality of life of older adults. This is a qualitative, descriptive-exploratory study conducted with eleven older adults affected by UI, belonging to the Family Health Strategy of a municipality located in the far west region of Santa Catarina. Data collection took place in August 2021 through individual semistructured interviews. Data analysis was performed using thematic content analysis. From the analysis, one thematic category emerged: Discourses and experiences of older adults with urinary incontinence and its impact on their quality of life. It is evident that urinary incontinence negatively affects the quality of life of older adults, mainly in the psychological and social domains. The triggered feelings are verbalized as shame due to odor, frustration at the risk of being seen in public with wet clothes, fear, anxiety, insecurity, and sadness. When compounded, such sensations increase the likelihood of psychological disorders, which are responsible for the development of depressive conditions, low self-esteem, withdrawal from leisure activities, and, overall, contribute to social isolation. Based on the study, it is clear that there is a need to increase the visibility of the problem, highlighting the influence of qualified listening that can bring improvements not only to the physical problems arising from urinary incontinence, but also – and especially – to the biopsychosocial and spiritual dimensions of the individual.

Keywords: Urinary Incontinence; Aged; Quality of Life; Nursing; Qualitative Research.

INTRODUCTION

Urinary incontinence (UI) stands out as a Public Health problem, defined as the involuntary loss of any amount of urine. Although it can occur at any age, UI is more prevalent in the older population¹⁻². Until the late 1990s, UI was considered a symptom of aging; however, it is currently recognized as a geriatric syndrome, included in the *International Classification of Diseases (ICD-10)².

Worldwide, approximately 423 million individuals presented some symptom of UI in 2018, with this number projected to progressively increase in the coming years. The prevalence of this syndrome rises with advancing age³. It is estimated that approximately 30% to 50% of older adults experience some type of incontinence⁴.

The diagnosis of UI affects both sexes; however, women are disproportionately affected due to the anatomy of the pelvic floor, urethral length, effects of pregnancy, previous deliveries, loss of muscle mass, and hormonal changes, making them more prone to impairments in their quality of life^{3,5}.

An individual's quality of life is conceptualized as the relationship between self-esteem and personal well-being. To achieve this, it is necessary to consider numerous aspects such as socioeconomic status, social and family interactions, self-care, religious, ethical, and behavioral values. UI is a significant trigger of impairments in quality of life, affecting various personal dimensions such as social, economic, psychological, and physical domains, thereby increasing the likelihood of developing or worsening pre-existing conditions⁶.

As this condition involves various stigmas, fears, and insecurities, some individuals experiencing the problem conceal it during nursing and medical consultations, only confiding when they find no alternative or when it begins to generate greater impacts in their lives – such as withdrawal from leisure activities, embarrassment due to episodes of involuntary urine loss, and difficulties in sexual life – thus making them more susceptible to depressive symptoms⁷.

Based on these assumptions, the study seeks to address the following guiding question: "What are the impacts of UI on the quality of life of older adults?" From this question, the objective of the study is to understand the impact of UI on the quality of life of older adults.

METHODOLOGY

This is a descriptive-exploratory study based on a qualitative approach, conducted with older adults affected by UI, belonging to the Family Health Strategy (FHS) of a municipality located in the far west region of Santa Catarina. The inclusion criteria were: being 60 years of age or older, regardless of sex, residing in the coverage area of the FHS unit where the study was conducted, and having a diagnosis of UI, including stress UI, urgency UI, or mixed UI. Older adults with UI secondary to degenerative diseases were excluded from the study.

Data collection was carried out in August 2021 through individual semi-structured interviews, conducted in a private setting to ensure participant confidentiality. The process followed the criterion of thematic saturation, whereby the inclusion of new participants was discontinued once the data obtained began to show redundancy or repetition, and no additional information was considered relevant, according to the researchers' evaluation⁸. The interviews were digitally recorded, with participants' consent, to fully capture their speech and ensure authentic material for analysis.

The study did not focus on sample size, given its qualitative approach. In this type of study, the researcher's primary concern is not the generalization of findings, but rather their depth, breadth, and diversity in the process of understanding the phenomenon. Therefore, the criterion is not numerical. An ideal qualitative sample is one that reflects the entirety of the multiple dimensions of the object under study⁸.

After the interviews, the data were transcribed verbatim from the recordings into a text editor, constituting the research corpus. Data were analyzed using thematic content analysis⁸, operationalized in three stages: pre-analysis, material exploration, and treatment of results with data interpretation. In the pre-analysis, the transcribed material was reviewed through exhaustive reading to ensure immersion in the information. During exploration, the data were categorized by organizing the recording units according to thematic affinities. Finally, interpretation sought to understand and explain the data in light of the theoretical framework⁸. To preserve participants' anonymity, their names were replaced by the abbreviation "I." (Interviewee), followed by an ordinal number.

Participants signed the Free and Informed Consent Form (FICF), and the research project was approved by the Research Ethics Committee of the Universidade do Oeste de Santa Catarina (UNOESC), under protocol number 4.780.357. The study complied with the ethical principles in health research established by Resolution 466/2012 of the National Health Council/Ministry of Health⁹.

RESULTS

A total of eleven older adults with UI participated in the study, all female, aged between 63 and 76 years. There was a predominance of participants with low educational attainment, retirees, married, and with an average of three children. After data analysis, one thematic category emerged, discussed below.

Discourses and experiences of older adults with urinary incontinence and its impact on their quality of life

UI can present in various forms. Although the final outcome is urine leakage, the mechanisms leading to this may differ for each individual, as it is directly related to the physiological pathway in which UI is classified. Thus, it is possible to observe how each person experiences UI in an individualized way.

"If I lift something heavy and it's almost time to go to the bathroom [...] also when coughing." (I2)

"[...] when sneezing or coughing, it can happen, especially if the bladder is full." (I8)

"First when coughing, we cough and suddenly, without expecting it - 'Paf' - it leaks. Another thing is when you go a long time without going to the bathroom [...], when you're doing something and keep holding it [...]." (I9)

"[...] When I coughed or strained, there was urine leakage, also when the bladder was too full or when lifting something heavy." (I11)

The process of living with UI involves multiple aspects beyond the physical, as it generates psychological and emotional repercussions that directly impact the daily life and individuality of the person affected. These emotional and psychological impacts encompass a series of stigmas, fears, and insecurities that may be explicitly verbalized, subtly implied, or left unsaid when participants are questioned about the subject.

"It affects a lot, it takes away quality (of life) [...] I don't like to leave the house anymore because of this problem [...] I feel it's something bad [...]." (I1)

"It affects a lot, I think especially psychologically, it leaves us afraid. I take a (medication) to ease the anxiety [...] I used to be afraid [...] I felt sad, disappointed." (I4)

"[...] I feel very frustrated [...] it's embarrassing, we feel somewhat ashamed [...] I feel insecure when I go out [...] when we travel too, we're always sharing a room with more people [...]." (I5)

"We could maybe talk to another colleague of the same age, but I don't open up, I don't open up, I keep it to myself, I don't even tell my children [...]." (I9)

"[...] I wish I didn't have it, to have a better life, it's sad like this. I have to go to (another municipality) for an exam where I need to drink water, my God! [...] how am I going to manage (to hold my urine), I'm already afraid of going." (I10)

During social interactions and leisure moments, those with UI are unable to mentally detach from their condition, as they are constantly afraid of urine loss, exercising caution in their actions, as reflected in the following statement:

[...] when we're in a group of people and want to smile or laugh, you have to hold back, you can't laugh freely, you have to go slowly [...]. (I1)

Thus, it is evident that UI generates a variety of discomforts, with repercussions manifesting in several areas of daily life. A striking feature emphasized by participants was the odor of urine, a circumstance that causes embarrassment and concern.

Bad smell, you always have to change clothes [...]. (I7)

Oh, it's very bad, you know, you're always thinking: '- Oh, am I smelling? Are other people noticing it?' That's the only worry we have [...]. (I8)

As previously mentioned, this syndrome presents several facets that directly interfere with the daily lives of those affected, who must deal with (re)adjustments in personal, social, and occupational spheres – such as performing household chores, socializing, and working – without letting the problem bring excessive insecurity, as illustrated by the following testimonies:

To clean the house, to do activities and go out [...] maybe it even affected my marital life. (I4)

[...] there's always that concern, since I have my job, I'm very close to people, so I'm always afraid: '- Am I smelling?' even if I've just showered [...]. (I8)

Maybe unconsciously, for example: '- Oh, I could go there, but what if it happens (urine leakage).' It stays in your mind [...]. (I9)

When staying overnight somewhere else, there were times I didn't go because I need to get up at night, I don't know where the bathroom is, and I don't want to disturb people in the house. I end up not doing certain things. (I10)

It is well known that sleep quality is an essential factor for carrying out daily activities, which include not only household tasks but also maintaining health, as rest is fundamental for physiological functions such as metabolism regulation, tissue repair, and energy restoration, among others. In contrast, the testimonies show that UI, especially when associated with nocturia, is a barrier to achieving restorative sleep.

- [...] it interferes with sleep. I get up quite often, three or four times [...] I go to the bathroom and change my pad [...] lie down again and wake up wet again, and that's how I spend the night. (I5)
- [...] at night I get up about three, even four times; sometimes it happened while sleeping and the urine leaked without me noticing. (I6)
- [...] I get up at night two or three times [...] it affects sleep quality. (I7)

Living with UI requires a series of strategies to manage situations where the individual may experience leakage. Coping strategies are adopted in various ways, most notably the use of pads and sanitary protectors, so that in case of involuntary losses, the discomfort caused by UI can be immediately minimized.

- [...] we already put on a pad, and that's it, you feel safer [...]. (I8)
- [...] I prepare myself. When I go out, I already put on a pad, because if by chance it happens [...] at least I can make it to the bathroom in time [...]. (I9)

When I go out, I take care not to drink (liquids) [...]. If I go out, I always bring a pad.. (I10)

When seeking health care, participants most often encounter professionals who are sensitive to their problem and provide guidance on the most appropriate measures to better adapt to the condition.

Yes, I went for a consultation one day, and she (the doctor) said: '- My God! You can't stay like this, it's impossible, no human being should live this way at all' [...]. (I4)

[...] I went to a doctor, and he referred me to physiotherapy [...]. (I10)

DISCUSSION

UI is defined as the involuntary loss of any volume of urine and can be classified into three different types, depending on its physiological mechanism: stress UI, urgency UI, and mixed UI¹⁰. Stress Urinary Incontinence (SUI) occurs when there is no detrusor muscle contraction and intra-abdominal pressure exceeds urethral pressure. The combination of these actions triggers involuntary urine loss during activities that increase abdominal muscle tension, such as coughing, sneezing, lifting heavy objects, walking, or laughing¹¹.

Urgency Urinary Incontinence (UUI), in turn, is triggered by detrusor muscle overactivity, which overrides the sphincter's ability to remain contracted, producing an overwhelming urge to urinate and causing urine leakage before reaching the bathroom. This overactivity may result from sensory etiologies and/or inflammation of the bladder's smooth muscle. When both pathophysiological mechanisms are present – elevated intra-abdominal pressure surpassing urethral pressure combined with sphincteric closure failure and detrusor overactivity – Mixed Urinary Incontinence (MUI) occurs¹².

A study conducted in Teresina, Piauí, found that the main causes of urine loss were episodes triggered by coughing, sneezing, laughing, and physical exertion, symptoms more closely related to SUI, corroborating the findings of the present study¹³.

Other studies available in the literature are consistent with these results, showing that UI predisposes individuals to frailty syndromes that compromise the aging process by reducing functional capacity, social participation, and quality of life. These factors are directly linked to the perceived threat of involuntary urine loss, increasing the likelihood of social isolation, low self-esteem, and depression, which undermine leisure activities, social relationships, and self-perceived health^{2,14-16}. Without adequate care, such conditions may exacerbate self-imposed limitations and intensify anxiety symptoms².

Overall, UI is regarded as a negative and distressing experience that impairs quality of life. In addition, this condition brings feelings of shame, loss of control over one's own body, guilt, discomfort, and a range of associated emotions that foster low self-esteem and insecurity¹⁷.

Fear is another feeling reported by participants, primarily due to the exposure to an unfamiliar and rarely discussed problem, which requires a degree of adaptation to minimize the perceived threat and embarrassment associated with urine leakage¹⁸. Individuals with UI also suffer from frustration, worry, apprehension, helplessness, discomfort, and embarrassment in the face of situations encountered in their daily lives, as evidenced in this study.

In addition to the imposition of negative emotions and psychological impacts, UI restricts and compromises social relationships and leisure activities due to the need for constant personal precautions. Any lapse in this management may result in what individuals with UI fear most: involuntary urine loss during moments of urgency, triggering the anguish of being seen wet in public¹⁸.

The fear of urine odor is one of the main concerns among individuals with UI, further contributing to negative psychological repercussions. This concern is deeply rooted in their subconscious and generates considerable tension¹⁹. The odor associated with urine leakage evokes childhood experiences and reinforces the loss of bodily control, further substantiating

an image of helplessness that affects not only social life but also intimate and marital relationships²⁰.

Concerns about foul odor are constant and frequently lead to worries about access to restrooms for hygiene purposes, due to feelings of dirtiness and odor, as well as attempts to manage the situation through the use of pads or cloths. However, these methods may be harmful, predisposing individuals to recurrent urinary tract infections, ammonia dermatitis, and skin lesions, which in turn increase vulnerability to other illnesses²¹.

This dysfunction encompasses a set of circumstances directly linked to quality of life. Its repercussions are interpreted and experienced differently by each individual, leading to body denial, increased stress due to concerns about urine odor, sexual restrictions due to the shame of unexpected urine loss during intercourse, and even absenteeism from work due to the need to remain close to restrooms^{17,22}.

Many individuals suffer from low self-esteem that leads to social isolation, not only due to the embarrassment of urine leakage but also because they feel more comfortable in domestic environments, where bathrooms are readily available and intimate hygiene can be performed at any time. Thus, individuals with UI refrain from certain activities due to fear of feeling vulnerable²³.

It is important to highlight that professional performance requires commitment, regularity, and proactivity, all of which are related to occupational fulfillment. When these conditions are disrupted or linked to health issues, dissatisfaction may arise. In the case of UI, this may bring feelings of dirtiness or unsuitability for work, undermining the professional image they strive to maintain²¹.

The Health, Well-being and Aging (SABE) cohort study, conducted in São Paulo, identified an association between UI and sleep disorders²⁴. Sleep quality is compromised in individuals with

UI due to the need to wake several times during the night to urinate or change clothes and sheets as a result of leakage. These challenges can lead to fatigue, loss of energy, impairments in daily life, reduced task performance, and increased risk of falls and fractures due to nighttime bathroom visits, with significant consequences for older adults.

Nocturia is considered the main cause of sleep disorders in older adults, affecting approximately 70% of this population. This disturbance impacts not only sleep quality but also cognitive functions, memory, reasoning, concentration, and motor abilities. Together, these factors become potential triggers of domestic and occupational accidents and also impair performance in leisure activities and interpersonal relationships²⁵.

Studies show a negative impact on the self-esteem of women with UI, many of whom must continuously use pads, which hinders activities of daily living, reduces quality of life, and subjects them to embarrassing situations in society²⁶⁻²⁸.

Actions adopted by individuals with UI, including the use of pads and protectors, provide a sense of comfort and security by preventing possible embarrassment, focusing solely on hygiene and symptom management. However, these measures do not aim for cure. Moreover, studies report that continuous use of pads may damage skin integrity in the perianal region, requiring additional care, complicating treatment and management of UI, and increasing the risk of fungal infections and recurrent urinary tract infections²⁸.

This study shows that most individuals with UI omit the signs and symptoms of this syndrome during routine medical visits, believing it to be inherent to aging. This finding is consistent with the literature, which reports participants' embarrassment when discussing the issue, leading one in three individuals with UI not to seek health services for this reason. As a result, people often live with the condition for many years, perceiving it as normal¹⁸.

To develop quality care for individuals with UI that addresses their particularities in a holistic manner, it is necessary to involve a multidisciplinary team supported by methods and policies that promote healthy aging and, in this case, health recovery through actions that reinforce not only physical care but also emotional support, avoiding barriers or stereotypes²⁹.

Given that working with individuals with UI is a sensitive task, it is essential that healthcare professionals provide assistance with empathy, sensitivity, and respect, using appropriate communication to create and maintain a bond of trust between professional and patient. They must be able to act in relevant moments to investigate cases when symptoms are minimized or omitted during nursing or medical consultations, in order to provide an early diagnosis and expedite treatment, thus preventing further complications in a fluid and straightforward manner⁷.

FINAL CONSIDERATIONS

Throughout this research, it was possible to understand and conclude that UI has a negative impact on the quality of life of older adults, especially regarding the psychological domain. The feelings triggered by living with UI are verbalized as shame due to odor, frustration at the risk of being seen in public with wet clothes, fear, anxiety, insecurity, and sadness. When compounded, such sensations increase the likelihood of psychological disorders, which in turn are responsible for the development of depressive conditions, low self-esteem, withdrawal from leisure activities, and, overall, contribute to social isolation.

UI, in all its facets and regardless of its etiology, can be regarded as a syndrome that significantly interferes with the quality of life of those affected. Thus, this study aims to contribute to expanding the visibility of the problem, highlighting the importance of qualified listening that can bring improvements not only to the physical problems arising from this condition, but also – above all – to the biopsychosocial and spiritual dimensions of the individual. In this context, it is essential that healthcare professionals be scientifically grounded to address syndromes associated with aging, particularly UI, as this has become a frequent manifestation that often goes unnoticed during consultations.

It should be noted that this study had some limitations, including the composition of the sample, which consisted exclusively of women, although the initial proposal was to include both sexes. However, male individuals who met the inclusion criteria did not express interest in participating. Therefore, future studies are recommended to include both sexes and to expand the sample size, in order to allow for greater generalization of the findings, for example through a quantitative study.

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