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QUALITY OF LIFE FROM THE PERSPECTIVE OF ELDERLY WOMEN WITH URINARY INCONTINENCE

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ABSTRACT

Background: Urinary incontinence (UI) is a common clinical condition among elderly people and may interfere with quality of life (QOL). For this reason, assessing its repercussions becomes important. Objective: To ascertain how elderly women undergoing physical therapy for UI perceived their current QOL. Method: This was a qualitative study that investigated QOL from the perspective of twelve elderly women aged 60 years and over, by means of individual semistructured interviews. The sample size was determined by saturation. The interviews were recorded, transcribed and then analyzed using the content analysis technique. Results: QOL was correlated with health, autonomy, personal relationships, financial stability and active life. Psychological impairment was associated with concern and disgust regarding urine loss and fear that this might occur in inappropriate places. Embarrassment because other people had noticed the smell of urine, and previous experience of similar embarrassing situations, was associated with social impairment. Conclusion: Content analysis on the interviews allowed the conclusion that, even though UI was present in these elderly women's lives and caused psychological and social harm, they had a positive perception of their QOL.

Key words: quality of life; elderly women; urinary incontinence; physical therapy.

RESUMO

Qualidade de vida na perspectiva de idosas com incontinência urinária

contextualização: A incontinência urinária (IU), condição clínica comum entre idosos, pode comprometer a qualidade de vida (QV) e, por esta razão, avaliar as repercussões sobre a mesma torna-se relevante. Objetivo: Desvendar como idosas submetidas a tratamento fisioterapêutico para IU percebem sua QV atual. Metodologia: Este foi um estudo qualitativo que, por meio de entrevistas individuais semi-estruturadas, pesquisou a QV na perspectiva de doze idosas com 60 anos e mais. O tamanho da amostra foi determinado por meio de saturação. As entrevistas foram gravadas, transcritas e posteriormente analisadas pela técnica da análise de conteúdo. Resultados: A QV vinculou-se à saúde, autonomia, relacionamentos pessoais, estabilidade financeira e vida ativa. O comprometimento psicológico vinculou-se à preocupação e desagrado diante das perdas urinárias e receio de elas ocorrerem em locais não apropriados. O constrangimento de outras pessoas perceberem o odor de urina e a vivência prévia de situações também constrangedoras vincularam-se ao comprometimento social. Conclusões: A análise do conteúdo das entrevistas permitiu concluir que, apesar de a IU estar presente na vida das idosas, trazendo prejuízos psicológicos e sociais, a QV foi positivamente percebida.

Palavras-chave: qualidade de vida; idosas; incontinência urinária; fisioterapia.

INTRODUCTION

Quality of life (QoL) can be understood as a social construct made relative by cultural factors[1], with subjective, two-directional, multidimensional[2], and mutable characteristics[3]. It was first introduced into the area of health[3] to assess objective outcomes[4,5]. Later, the need arose to assess quality of life based on personal opinion[3], which highlighted the subjectivity of the construct[3,6].

It is necessary to distinguish QoL from health-related quality of life (HRQoL). The former has a more comprehensive conception and can be illustrated by the concept proposed by the World Health Organization (WHO)[6], according to which QoL is *"an 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"*. HRQoL, on the other hand, is influenced by the concept of health proposed by WHO and designates a series of conceptual models that define the construct through domains of life and individual perceptions of health. From this perspective, it is understood that physical and emotional functioning have a direct influence on QoL, while biological abnormalities have an indirect influence on QoL because of its causal relationship with illness and physical incapacity[7].

However, it is understood that all of these aspects related to health cannot be separated from other domains of life, such as social roles and interactions, economic, cultural, political and spiritual relationships. These domains, when linked with the domains of life directly related to health, comprise what is called general quality of life, a broader construct that includes factors that interfere in individual and collective life[7].

The aging process, though physiological, is permeated with greater vulnerability to illness, which can interfere with autonomy[8,9], mobility, manual dexterity, lucidity[10] and with the functional capacity of the lower urinary tract and the bladder, favoring urinary incontinence (UI). The latter is defined as "any leakage of urine (involuntary release)"[12], and is very common among the elderly. Its true prevalence is imprecise, most likely due to the different samples and types of UI studied[13], to the research method used[10] and data underestimation[14,15].

UI is associated with physical and psychosocial impairment[16]. There is evidence that incontinent individuals experience feelings of loneliness, sorrow and depression more intensely than continent individuals[13] and that the influence of UI on HRQoL varies according to the type of incontinence and to how the individual perceives the problem[2,13].

Coyne et al.[16] studied the impact of three types of UI on HRQoL and concluded that the worst HRQoL was observed in patients with mixed urinary incontinence, especially due to the micturition urgency component which is typical of this kind of UI. Ko et al.[13] investigated the impact of UI on the QoL of the elderly and concluded that the incontinent individuals proved to be more depressed and perceived their QoL as being worse than that of the continent individuals.

The impact of UI and of interventions associated with it on HRQoL can be assessed objectively or subjectively[2,13] by means of specific questionnaires[2,17] or interviews in which the incontinent individual evaluates the impact of urinary leakage on their life[18]. The investigation of how each incontinent person perceives the repercussions of UI allows the professional to adjust their procedure in order to meet individual needs and expectations, which favors the patient's adherence to and the success of the therapeutic intervention.

In view of the negative influence of UI on QoL[13,16] and in light of the lack of qualitative studies on the QoL of incontinent elderly women based on individual perception, this study set out to explore the matter, seeking to discover how incontinent elderly women submitted to UI physical therapy perceive their current QoL.

METHODS

The present study was exploratory and descriptive in nature and based on the experimental study by Souza[17], which assessed the amount of urine leakage and the QoL of thirty-seven female patients aged 50 and over. The statistically significant results confirmed the benefits of conservative physical therapy treatment and its effect on QoL improvement. More information is available in Souza's dissertation[17].

Approximately eighteen months after the end of the abovementioned study, we decided to ascertain how the same elderly women perceived their current QoL. In order to achieve that, we opted for a qualitative investigation, better suited to answer the questions of the study.

Sample selection, instruments and data collection

From Souza's sample[17], the women aged 60 and over were selected and the sampling criterion was determined by the order of names on the contact list. The type of UI (stress, urge or mixed) was not considered in the selection of the elderly women; they only needed to have participated in Souza's study[17]. Twenty-five elderly women comprised the total of the investigation. After being contacted, twenty-two agreed to participate in the study, and one refused. Two could not be contacted because their phone number had changed.

For data collection, an interview script was created (Appendix 1), with questions based on clinical observations and the theoretical assumptions available in literature[3,16].

In order to safeguard the identity of the interviewees, their real names were replaced with fictitious names.

This research was evaluated and approved by the Ethics in Research Committee of Universidade Federal de Minas Gerais, ETIC Approval nº 116/05.

Pilot study

A pilot interview was conducted to test the questionnaire and it revealed the need for adaptations. After the alterations to the questionnaire were implemented, the data collection process was initiated.

The interviews

The interviewer contacted the elderly women over the phone. At the time, they all received a brief explanation about the study and were asked if they had any interest in participating in it. Twenty-two agreed to participate. The interviews took place at the interviewees' homes and lasted 75 minutes on average. Each elderly woman received a single visit from the interviewer and signed written informed consent before the interview.

Twelve interviews were conducted. The data collection was interrupted when recurring points were observed in the reports and once the appearance of new data became rare[19]. The interviews were recorded on cassette tapes, with the participants' prior authorization, transcribed and forwarded to the women for content confirmation. Throughout the interviewing process, a field journal was used in order to supplement the record of events.

Result analysis and interpretation

The transcribed interviews were submitted to a preliminary reading in order to increase the contact of the researcher with the material to be analyzed. This was followed by the actual scrutiny of the material through content analysis. The transcribed material was exhaustively studied in order to find recurrences in the discourses, which functioned as indicators for grouping answers into thematic categories. Researchers focused on each part of the text, analyzing the collected data paragraph by paragraph and highlighting the key words that seemed to represent the meaning of the participants' experience. These text units were analyzed and grouped into thematic categories, through which the analyzed material[19] was classified. These thematic categories allowed the comprehension and organization of data to better present them and therefore favored the final interpretations, which were also supported by the information contained in the field journal.

For the final presentation of the results, we used the information pertaining to the social and psychological domains of the QoL construct.

RESULTS AND DISCUSSION

Sample description

Twelve elderly women participated in this study, aged 61 to 83 and who had undergone UI physical therapy treatment at the time of Souza's study[17]. Six women fit the 60 to 70 age group; five, the 71 to 80 age group; and one was over 80 years old.

All elderly women are considered incontinent[12], although the amount of urine leakage and the frequency of leakage are below those observed in Souza's study[17]. None of the women were under medical or physical therapy treatment for the urinary leakage reported in the interviews.

In the group studied, five women were widows, four were married, two were divorced and one was single.

The information on education revealed that three of the elderly women had completed their tertiary education and three had technical qualification. Two elderly women had primary teaching certificates and two had a high school diploma. The lowest educational level was elementary education, completed by two elderly women.

As to professional activity, nine were homemakers and three worked outside the home. One elderly woman, besides homemaking activities, volunteered at a religious institution. Therefore, most of the interviewees did not have regular employment.

In the present study, all interviewees claimed to be affiliated with a religious denomination, the predominant one being the Roman Catholic.

How the elderly women perceived quality of life

The starting point of the present study was to reveal the factors pertaining to QoL according to the elderly women's perception. The answers were classified into two main groups: autonomy and health.

Accounts such as, *"(...) Quality of life is when the person can do what they want with full use of their physical, mental and psychological faculties (...)"* (Ubaldina, age 61) and, *"(...)Doing whatever you want (...)"* (Martha, age 64) lead us to autonomy. It is known that the QoL of the elderly is connected to the ability to maintain autonomy and independence[8]. While the latter refers to the ability to perform activities of daily life so as to live with little or no outside help[3,8], the former is characterized by the ability to establish and follow one's own rules[3,8,9].

Some of the elderly women referred to health or to healthy living as a prerequisite to QoL. *"(...) Good health (...) Because a person full of pain and problems doesn't have quality of life (...)"* (Diomar, age 62); *"(...) Having a healthy life. (...) Of course, family is important, friends too, but without health it is a bit hard (...)* (Carmelita, age 74). In this sense, the result of the present

study may be compared to that of Vecchia et al.[20] These authors, who aimed to discover the elderly's definition of QoL, found that health and healthy habits were points considered important in the construction of the concept. For Xavier et al.[21], the health aspect was a good indicator for negative QoL, because the elderly who claimed to have poor health referred to their QoL as negative, while those who perceived their health as good did not classify it as a major factor in their notion of the construct. This result disagrees with the one found by Xavier et al.[21] inasmuch as even the elderly women who considered their QoL positive indicated health as an important factor in their notion of the construct. Such disagreement may be explained by sample differences, because Xavier et al.[21] studied elderly people of both genders over 80 years of age, while the present study was limited to elderly women, of which only one was over 80. Furthermore, this sample population was considerably smaller than that of the aforementioned study. Moraes and Souza[9] maintain that health is a necessary condition to successful aging because, in their own study, they found that elderly people who perceived their health as good or very good were five times more likely to be classified as successful in terms of aging.

Self-reported quality of life

Paschoal[3] states that conclusions on QoL, from the standpoint of personal evaluation, involve a complex process in which individuals take stock of their life on the basis of values, principles and criteria assimilated throughout the years. The final purpose of this inventory is to determine their degree of satisfaction, something that is not always detected by the standard devices[3]. When elderly people are the focus of the study, QoL relates to the conservation of interpersonal relationships, health, emotional balance, financial stability, work and spirituality, among others[3,20-22]. In their personal QoL evaluation, two elderly women classified it as "not so good", while the others rated it as positive.

The elements emphasized by the elderly women who referred positively to their QoL were personal relationships, including family and friends, financial stability and an active lifestyle.

The relevance of personal relationships was observed in accounts such as *"(...) I think they* [her sons] *are the ones who give me this good quality of life. (...)"* (Sonia, age 83); *"(...) Because what I appreciate the most is being with others (...) I live very well with my family, my friends (...) We have a very strong connection, very caring (...)"* (Elizabethe, age 76); and *"(...) Everyone in my family is very nice, (...) they are very close and that gives us good quality of life (...)"* (Roseli, age 80). These observations are in accordance with the results reported by Vecchia and Bowling. Vecchia et al.[20] found that 49% of the interviewees considered interpersonal relationships to be important, while Bowling et al.[22] concluded that 81% of the interviewees made reference to the importance of social relationships for a positive QoL. According to WHO, adequate social support for the elderly is connected to the reduction of morbidity and mortality and psychological disorders, as well as an increment in general health and wellbeing[8]. Moraes and Souza[9] suggest that psychosocial support is one of the significant and independent variables for successful aging.

The financial aspect was another factor pointed out as important to QoL. In Moraes and Souza's study[9], material comfort was one of the predictors for successful aging among elderly women, a premise corroborated by the present study. *"(...) Money isn't everything, but money helps a lot. (...) I'm not putting money ahead of anything, but for me it was a relief* [to receive her ex-husband's pension] *and it improved my quality of life (...)"* (Ana, age 67). Acquiring material goods during life can indicate more peace of mind in old age, as money can contribute to meeting the needs of the elderly and their family members, such as food, transportation, clothing, medical assistance and medication[8,20,22]. Insufficient financial resources, on the other hand, can cause stress and worry. *"(...) At the moment, I am very worried because I'm not working. I retired, I have been retired for twenty years (...) So, since I am in good health, I keep working. But there comes a point when we get tired. (...)"* (Regina, age 71). Regina's account records a reality that is shared by other elderly people: the need to stay in the job market. Many of them, even after retiring, continue to provide important financial resources to their family, be it through regular or temporary jobs or in unpaid homemaking roles[8]. WHO clarifies that, in countries like Brazil, the participation of the elderly in the economically active population is frequently due to financial need. Many take over homemaking and child-rearing responsibilities so that the younger family members can work[8].

Besides the personal relationships and the financial aspect, an active lifestyle was indicated as being important to the QoL, according to what can be seen in the accounts that follow. *"(...) I go out, I do the things I have to do, I teach piano lessons, I play my keyboard, every now and then I travel (...)"* (Martha, age 64); *"(...) I (...) have a business where I can work, develop my creativity, I like going out, traveling, having moments of tenderness, of love, (...) just like when I was young, there is no difference (...) I think that gives you good quality of life (...)"* (Luíza, age 64); *"(...) I do everything I want to and get everything I want. (...) Goals are very important in our lives (...)"* (Vera, age 68); *"(...) I go to the bank, I pay the bills for my daughters… (...) So my head is working!*

I go on my own. So I even know the PIN numbers (...) the account numbers by heart. If I were sitting around doing nothing, just watching TV or knitting, you know, it would be worse. The mind would be idle (...)" (Cecília, age 77). Staying active is so relevant that WHO has been striving to propagate "active aging", which is defined as the process of optimizing health opportunities, participation and safety, aiming at improving QoL as individuals get older[8].

There are elderly people who occupy themselves with volunteer work, which benefits them because it contributes to the broadening of social contact and of psychological well-being[8]. In the present study, Roseli was the only one who reported participation in voluntary activity: *"(...) I have been doing* [voluntary] *work there for 30 years. A simple job, but for me it is very important (...)"* (Roseli, age 80). In the study by Vecchia et al.[20], charity stood out as relevant to QoL because it gave the elderly a feeling of satisfaction from being solidary.

The two elderly women who considered their QoL to be "not so good" linked precarious QoL to health problems. *"(...) I have a not so good* [quality of life]. *(...) I have problems with this urinary incontinence, which is very unpleasant, I have a problem with my bowel movements, which are too frequent, I have back problems. So, that gets in the way of my quality of life (...)"* (Diomar, age 62); *"(...) Not so good. (...) I have nocturnal urinary incontinence. (...) These problems of mine* [arthrosis of the knees, urinary and fecal incontinence, visual impairment, depression] *are restricting me, limiting me (...) My quality of life, if it depends on health, it won't do for me. (...)"* (Carmelita, age 74). Diomar and Carmelita made reference to health problems, including UI, as compromising to their QoL. This view corroborates studies in which deficient health is reflected in lower QoL[20,21] or unsuccessful aging[9]. UI, the common disorder among the participants of this study, is the source of restrictions in the physical, psychological and social domains[13,16,23-25]. There is evidence that, when compared to other health conditions, UI has more significant impact on the social and psychological domains of QoL[13]. In this sense, emphasis lies on HRQoL, which is related to QoL through life's domains and the personal perception of health[7]. It allows us to see how far individuals' expectations are from their reality in terms of health; the greater the distance, the lower the QoL tends to be[1].

Repercussions of urinary incontinence in quality of life

In the women's speeches, there are references to restrictions to social interaction. *"(...) I felt rather isolated (...) I didn't even bother going out because of this problem* [urinary incontinence] *(...)"* (Martha, age 64); *"(...) There are many times when I give up doing things (...)"* (Elizabethe, age 76); *"(...) I was afraid of going to work, I was afraid that sometimes I wouldn't have time to get to work or get home… So it was very disconcerting for me (...)"* (Regina, age 71). Literature makes reference to the tendency of incontinent individuals toward social isolation[16,24,25], and there is evidence that they feel lonelier than their continent counterparts[24]. Although the majority (63.9%) of participants in the study by Locher et al[25] mentioned they did not experience restrictions in their activities because of urine leakage, 36.1% made reference to partial or total restriction to activities. The high rate of participants who experienced no restriction in activities in Locher et al.[25] can be explained by using self-care strategies, as indicated by some of the elderly women in the present study: *"(...) I took precautions, prepared myself beforehand. Then I'd go out with no concerns (...)."* (Roseli, age 80); *"(...) I'll go out even if I'm worried, but I never stopped going out. Because if we do that, it begins to cancel out our life (...)."* (Ana, age 67). The preparation and use of different self-care strategies aim at solving the inconveniences of urine leakage and, consequently, allowing one to maintain their social routine[15,23,25].

Some elderly women, including those who reported using self-care strategies, mentioned the fear that other people would notice the distinct smell of urine. *"(...) At times I think, 'ah, I think I stink of urine' (...) I think, 'oh my God, can anybody smell that?' So that's really cumbersome and I think that urinary incontinence is really sad (...)"* (Diomar, age 62); *"(...) that bad smell clings to the clothes (...) and I'm afraid other people will notice it. I get really scared that they'll smell that unpleasant odor (...)"* (Carmelita, age 74). *"(...) I lose confidence. I am ashamed somebody will see something, notice the smell. (...)"* (Regina, age 71). Indeed, although no accounts were found in literature to corroborate or refute the premise that incontinent individuals fear the possibility of others noticing the smell of urine, in clinical practice, it is a common reality for this population and it was observed among the elderly women of this study.

The following accounts denote embarrassing experiences which can result in trauma and, consequently, favor social isolation. *"(...) Like at my cousin's son's wedding (...) I had taken two pads and had already run out. When I got up, my cousin said, 'goodness, you're completely soaked'. (...) Then I had to turn my skirt backward so it wouldn't show so much, but I got home drenched. That (...) for me was the worst part. (...)"* (Martha, age 64); *"(...) There was this time when I felt really embarrassed when I took the bus, but I was wearing dark pants and nobody noticed. But it's very sad, I cried (...)"* (Regina, age 71); *"(...) I went out, and it was a charity event. (...) I couldn't hold it and I was wearing light-colored clothing and it got all wet. (...)*

I stayed in my seat the whole time, (...) giving the excuse that I had wet the edge of the toilet seat. But it wasn't that. I never really got over it. (...)" (Ubaldina, age 61). Such reports express embarrassment that is frequently reflected in restriction of activities and social isolation, which varies greatly. Fultz and Herzog[24], for instance, found that 81% of the interviewees do not restrict their social activities, while 7% reported important restriction of the same activities. They also reported a moderately strong positive association between restriction of social activities and psychological impact[24]. Locher et al.[25], in turn, found that approximately 36% of participants reported partial or total restriction of activities. These same authors concluded that the perception of restriction that UI conferred to activities was the strongest predictor of the use of self-care strategies by women[25]. In this context, the results of this study showed there was little evidence of social isolation because many of the elderly women reported the use of self-care strategies, such as sanitary pads and prior search for lavatories in order to maintain their social routine.

The elderly women's discourses proved how difficult it is to live with urinary leakage. This difficulty pertains to the fear of leakage in inappropriate places, and can frequently cause stress. *"(...) Many times I'm somewhere like at a shopping mall, and I have to hurry home (...) That is making me rather upset (...)"* (Carmelita, age 74); *"(...) I think it's depressing that I look young but have to wear a diaper because I have urinary incontinence (...)"* (Diomar, age 62). The same woman continues to report, *"(...) Now I wake up drenched, losing urine without knowing it... It's horrible! (...) Sometimes in the middle of sexual intercourse I urinate on the bed (...)"* (Diomar, age 62). In these discourses, there is a constant worry with regard to urinary leakage and feelings of discontent resulting from the unpredictability and/or inevitability of these leakages, which can have a psychological impact[13,23-25]. However, the studies are controversial. Fultz and Herzog[24], for instance, showed that most of the interviewees stated they did not perceive a negative impact on their wellbeing, and that their emotional condition was the most compromised aspect. Locher et al.[25], on the other hand, wrote that less than half of the participants reported feeling extremely disturbed with their UI.

CONCLUSIONS

The content analysis of the discourses allowed us to conclude that health and autonomy were linked to the concept of QoL, and that even the incontinent elderly women perceived their QoL in a positive way. The elderly women who perceived their QoL as "not so good" associated it with precarious health. It was also evident that the QoL was connected to personal relationships, financial stability and an active lifestyle.

In this study, psychological damage was linked to worry or unhappiness due to urinary leakage and the fear that it might happen in inappropriate places, while social restrictions, previous embarrassing experiences and the dread that others might notice the smell of urine were linked to social damage. QoL, however, was perceived as positive, which suggests that other aspects outweigh the psychosocial damage caused by UI.

The lack of qualitative studies concerning the perception of urinary leakage and its implication for QoL made the discussion of results difficult. Therefore, we suggest that methodologically similar studies be conducted to a better understanding of the data obtained. In order to detect more subtle differences concerning the impact of UI on the psychological and social domains, we suggest that qualitative studies involving the impact of UI on the QoL of elderly women take into account the different types of UI, the different age groups and levels of education.

Although the information collected has restricted support in scientific literature, given its scarcity, it contributes to increment the body of scientific evidence pertaining to UI and the QoL of elderly women, and favors a better understanding of the psychosocial impact of UI.

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APPENDIX 1

SEMI-STRUCTURE INTERVIEW SCRIPT

A. PERSONAL DATA

Name:

Address:

DOB: Age:

Profession:

Education:

Religion:

B. OPEN QUESTIONS

1- What does it mean to have quality of life in your opinion?

2- Do you have quality of life?

2.1. How would you describe your current quality of life?

2.2. What is good currently in your life?

2.3. What is not good currently in your life?

2.4. What could happen to make your life better?

2.5. What could happen that would make your life worse?

C. DOMAIN

C.1 - Physical Domain

1- Have you been having urine leakage recently?

( ) yes ( ) no

2. How often do you have urinary incontinence, unintentional loss of urine?

( ) seldom ( ) always

3. In these situations, the amount of urine lost is:

( ) small ( ) medium ( ) great

4. Do you use any kind of pad to protect you from the urine loss?

( ) never ( ) sometimes ( ) always

C.1 - Psychological Domain

1- What is it like to live with urine incontinence in your daily life?

2- Do you fear leaving the house and having urge incontinence?

C.2 - Social Domain

1- Do you avoid doing anything because of your urinary incontinence?