# Cogitare Enfermagem

ORIGINAL ARTICLE

# ADHERENCE TO SELF-CARE IN PATIENTS WITH NEUROGENIC LOWER URINARY TRACT DYSFUNCTION: INSTRUMENT VALIDATION

**HIGHLIGHTS**

1. The nurse is fundamental in education and adherence to self-catheterization.
2. Functional capacity can impair patient compliance.
3. The instrument helps in the care practice of health professionals.

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**ABSTRACT**

**Objective:** To build and validate the content of the instrument for adherence to self-care for patients with Neurogenic Lower Urinary Tract Dysfunction who perform intermittent self-catheterization as to appearance and content. **Method:** Methodological study of instrument content validation, composed of three stages: literature review, instrument construction and instrument validation, respectively. The analysis was performed using the Agree model, and by calculating the content validation index, between 2020 and 2021. **Results:** Agree II, showed a result of 85.6% and 84.5% for validation of the scope and purpose and stakeholder domains. In content validation, the family history item was removed from the instrument with a content vanity index of 0.77. **Conclusion:** The instrument will contribute to offering subsidies for professional practice and to patients with the dysfunction.

**DESCRIPTORS:** Urinary Bladder, Neurogenic; Intermittent Urethral Catheterization; Self-care; Cooperation and Adherence to Treatment; Nursing Theory.

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# INTRODUCTION

Neurogenic Lower Urinary Tract Dysfunction (NLUTD), formerly known as neurogenic bladder, is a disorder that affects the storage and emptying capacity of the bladder, caused by alterations in the central or peripheral nervous system, which can be caused by trauma, disease, or injury, bringing about micturition, bladder emptying, and filling alterations.[1] An alternative for the treatment of NLUTD is intermittent catheterization.

Clean Intermittent Bladder Catheterization (CIC) is considered the gold standard in the treatment of NLUTD; it consists of the insertion of a catheter through the urethra into the bladder, with the objective of generating bladder emptying and maintaining the integrity of the urinary tract and can be performed by the user or his/her caregiver, temporarily or permanently. Despite the benefits, when performed over the long term it may cause complications such as urethral injury, recurrent urinary tract infections, false pathway, and urethral stenosis.[1,2]

Research conducted with patients who use intermittent bladder catheterization, states that some barriers prevent the continuity of self-catheterization, which are characterized by cognitive deficit, motor disorders, gender (female), obese, as well as psychological factors.[3] Thus, the management of self-catheterization is a challenge for patients and the nurse should motivate them to continue catheterization, favoring the reduction of complications and more favorable results in adherence. Adherence to self-care in patients with NLUTD provides higher quality of life, and improved bladder and kidney health, but when performed over the long term, adherence rates may decrease for various causes.[4]

Self-care can be defined as the practice of activities that favor the improvement and maturity of the people who initiate and develop it within specific time frames, whose goals are the preservation of life and personal well-being.[5] Thus, Dorothea Orem was chosen as the theorist to guide this study regarding adherence to self-care in patients with neurogenic dysfunction, based on the Theory of Self-Care; Theory of Self-Care Deficit and the Theory of Nursing Systems.

Given this, this study aims to construct and validate the content of the self-care adherence instrument for patients with Neurogenic Lower Urinary Tract Dysfunction who perform intermittent self-catheterization as to appearance and content.

# METHOD

This is a methodological study of instrument content validation. The validation study consists of three stages: literature review, instrument construction, and instrument validation, respectively.

In the first stage, to construct the search strategy, an adaptation of the PICO strategy (P = Patient, I = Intervention, C = Comparison, and O = Outcome/Outcome) was used to guide the elaboration of the research question and the bibliographic search, and also allows the professional or researcher to accurately locate the best scientific information available: What has been studied about factors that influence adherence to self-care in patients with Neurogenic Lower Urinary Tract Dysfunction?

The bibliographical survey was conducted virtually, through the databases available at the Regional Virtual Health Library Portal, accessed in the period from March to April 2021. As a search strategy, the Health Descriptors (DeCS) "Neurogenic Urinary Bladder", "Cooperation and Adherence to Treatment", "Self-Care", and "Intermittent Urethral Catheterization" were used. To determine the sample, simple search filters were used,

using the Boolean operator, "AND" associating the descriptors one by one alternately, totaling six combinations. The inclusion criteria for the articles were: full texts in Portuguese, English, and Spanish, and a publication year interval of the last five years (2015-2020); and as exclusion criteria: systematic review articles, case reports, duplicate articles, and articles not related to the theme.

The search strategy allowed 1,377 articles to be retrieved; after applying the inclusion criteria, 372 articles were selected; after inserting the exclusion criteria, 293 remained; finally, after reading and analyzing the 293 titles and abstracts to select the articles pertinent to the study, 79 articles were eligible, 26 of which in Latin American and Caribbean Health Sciences Literature, 15 in the Nursing Database, while 12 of these associated with LILACS, and 50 articles integrated to the Medical Literature Analysis and Retrieval System Online. Figure 1 represents the flow of the analyses.
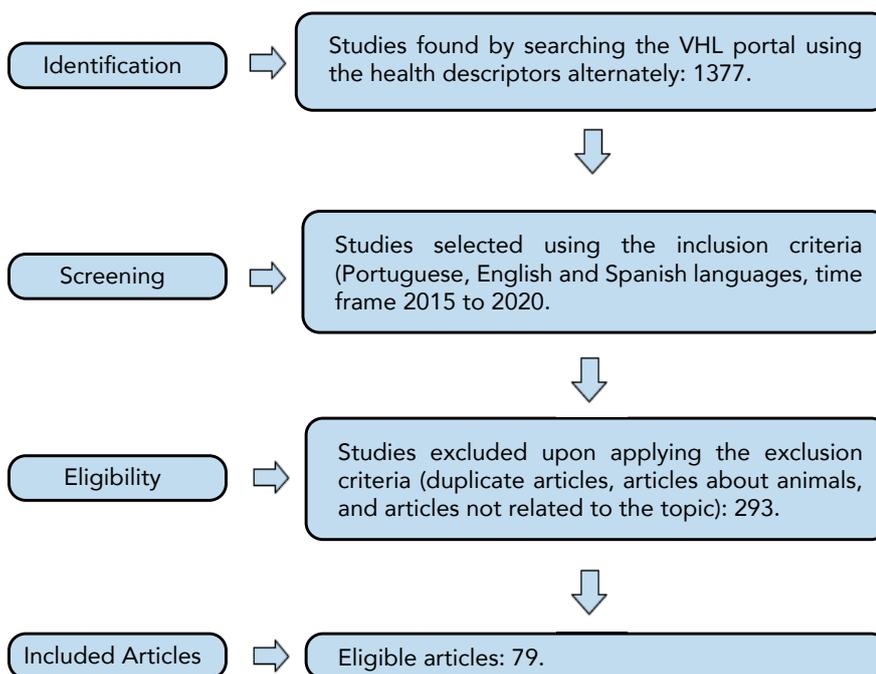
| Identification | ⇨ | Studies found by searching the VHL portal using the health descriptors alternately: 1377. |
|---|---|---|

⇩

| Screening | ⇨ | Studies selected using the inclusion criteria (Portuguese, English and Spanish languages, time frame 2015 to 2020. |
|---|---|---|

⇩

| Eligibility | ⇨ | Studies excluded upon applying the exclusion criteria (duplicate articles, articles about animals, and articles not related to the topic): 293. |
|---|---|---|

⇩

| Included Articles | ⇨ | Eligible articles: 79. |
|---|---|---|

**Figure 1** - Flowchart of database search analysis. Rio de Janeiro, RJ, Brazil, 2021
Source: The authors (2021).

In the second stage, the construction of the instrument was developed from the reading of articles and selected materials. It also counted on the collaboration of medical professionals specialized in the area, in addition to nursing, to add content to the instrument and allow its use by all health professionals working in the care of patients with NLUTD Orem's Theory served as a framework for the construction of the instrument, helping to identify the main deficits in the health of the individual with NLUTD and the main needs of health care to promote better adherence to treatment and quality of life.

The instrument created presents 65 items subdivided into domains (D), being scope and purpose (D1) and stakeholder involvement (D2) referring to the validation model or Agree II, and as to the content of the instrument identification data (D3), past pathological history (D4) history of current disease (mainly related to NLUTD) (D5), family history (D6), lifestyle habits/relevant information on systems affecting NLUTD (D7), functional assessment scale (D8), therapeutic adherence scale (D9), and technical assessment of self-catheterization (D10).

In the third stage of the validation process, the instrument was sent via electronic mail using an online form, along with the Informed Consent Form (ICF) and the invitation letter, within 15 days to receive a response, with a reminder sent to the evaluators every four days. The search and selection of experts through the Lattes' platform was not possible during the period due to the unavailability of the platform, being a limitation of this study.

For the selection of expert experts, the Fehring[6] model with adaptations was used as selection criteria (Chart 1); health professionals with university ties and experience in the care of patients with NLUTD and who perform intermittent bladder catheterization were selected.

The initial sample included 21 experts selected as specialists in the area. After sending the invitations, the experts who agreed to participate in the content validation process signed the Free and Informed Consent Form, totaling nine experts.

**Chart 1** - Specialist expert selection based on Fehring's model.

| Specialist expert selection criteria: adapted Fehring model[6]. |
| --- |
| Have a recent clinical practice of at least one year with patients with Neurogenic Lower Urinary Tract Dysfunction or who perform intermittent catheterization. |
| Author or study leader in the areas of Neurogenic Lower Urinary Tract Dysfunction or intermittent catheterization. |
| In teaching, he teaches/taught a subject that involves/involved the subject Neurogenic Lower Urinary Tract Dysfunction or intermittent catheterization. |
| Participates/participated in a research group/project that involves/involved the topic of Lower Urinary Tract Neurogenic Dysfunction and intermittent catheterization. |

Source: The authors (2021).

The form for completing and evaluating the expert experts was based on the AGREE II model (Appraisal of Guidelines for Research & Evaluation) with adaptations, which aims to evaluate the methodological rigor and quality of clinical guidelines.

The validation of this model is performed from six domains(D) of evaluation, totaling 23 questions, whose scores range from one to seven, being one totally disagree, used when there is little relevant information on the subject and/or not informed, and the item seven totally agree, applied to information content considered excellent. And the scores between two and six are applied to the content when it does not meet all the criteria proposed by the domain (considering: two = I partially disagree, three = I disagree, four = indifferent, five = I agree and six = I partially agree)[7]. However, only the domains of scope and purpose (D1) and stakeholder involvement (D2) of the AGREE II model were selected for content validation in this instrument, in addition to the overall assessment topic of the instrument.

Furthermore, the instrument was evaluated by the experts according to the Pasquali[8] model, covering the aspects of clarity, accuracy and relevance, based on the Likert scale[9] with adaptations, which could be scored from one to seven as to the degree of agreement of the expert with each question of the instrument, except for domains eight and nine, composed of the assessment scales of the activities of daily living and Morisky's therapeutic adherence scale[10, 11], because they are already validated instruments. Below each evaluation

question, the expert could add comments and suggestions regarding the instrument.

After the evaluation of the instrument by the expert specialists, the data analysis was elaborated in stages. The domains scope and purpose, and stakeholder involvement were obtained from the Agree II model, with a result of 85.8% and 84.5% respectively, where the validation calculation occurs by domains independently, through the sum of the evaluators' score of each item and relating the total to a percentage of the maximum possible score in each domain. The formula is

$$\frac{score\ obtained\ -\ minimum\ score}{maximum\ score\ -\ minimum\ score}\qquad 7$$

The second stage of data analysis, through the experts' evaluation, counted on a quantitative approach through the Content Validity Index (CVI), this method measures the agreement of experts on certain aspects of the instrument, based on a Likert scale with scores from one to four (one=item not equivalent, two =item needs revision to assess equivalence; three = item needs few revisions, and four = equivalent item) [12]. In this case, the CVI method was used in Pasquali's criteria, considering the accuracy, relevance, and clarity of each content. Considering that the assessment instrument was developed based on a Likert scale from one to seven, it was necessary to make adaptations to the CVI method: with answers one, two of the Likert scale corresponding to CVI scale one and two; and answers five, six, and seven corresponding to CVI scale three and four. Answer four of the scale proposed in the instrument was not considered because it represented indifference in the experts' opinion about the item.

From this, we have the formula:

$$\frac{no.of\ answers\ 3\ or\ 4}{total\ no.of\ participating\ experts}\qquad 12$$

Considering the need to adapt the instrument's scale to the CVI scale, from the validation obtained by the judges, a calculation was performed, according to the following formula IVC =

$$\frac{no.of\ responses\ 5,6\ or\ 7}{total\ no.of\ responses}$$

This study is part of a project entitled "Systematization of Nursing Care in the perspective of technological innovation in the Health Units of the UERJ: Clinical Research of broad scope", approved by the Ethics Committee of the State University of Rio de Janeiro, with opinion number: 3,443,800. To guarantee anonymity, the expert judges were identified with the letters A to I, considering the participation of 09 judges.

## RESULTS

The construction of this instrument is based on Dorothea Orem's Theory of Self-Care and its purpose is to be used by health professionals who work with patients with NLUTD, entitled "Instrument for the assessment of adherence to self-care in patients with neurogenic lower urinary tract dysfunction who undergo clean intermittent catheterization". Initially, the bibliographic survey was carried out to include in the instrument items necessary for the assessment of adherence to self-care in patients with NLUTD, described in Chart 2. The instrument was sent in full along with the evaluation form to the participating judges.

**Chart 2** - Development of the instrument to assess adherence to self-care in patients with NLUTD who perform CIC. Rio de Janeiro, RJ, Brazil, 2021

| Domains that compose the instrument of adherence to self-care in patients with NLUTD. | |
|---|---|
| Domain Three: Identification Data | Name, social name; CPF; date of birth; address; occupation; self-reported color; education; family income; employment relationship. |
| Domain Four: Previous Pathological History | SAH; DM; stroke; CHF; asthma; COPD; AC; spinal cord injury; Parkinson's disease; myelomeningocele; spina bifida; multiple sclerosis; HTLV; Abdominoperineal amputation. |
| Domain Five: History of Current Illness | Diagnosis of the associated disease; diagnosis of the NLUTD; start of outpatient follow-up and start of CIC training; Need for further training after reassessment; caliber of catheter used; date of last hospitalization; urinary complaints; frequency of consultations and performance of tests. |
| Domain Six: Family History | Systemic Arterial Hypertension; Diabetes Mellitus; Stroke; Acute Myocardial Infarction; Cancer, and degree of kinship affected by the disease. |
| Domain Seven: Lifestyle habits/relevant information about the systems | Alcoholism, smoking, and use of illicit drugs; habits related to food and number of meals per day; physical activity; sleep pattern; speech and/or communication impairment; amount of fluid ingested per day; elimination pattern (urinary, bowel, difficult elimination, use of laxatives); level of consciousness; spiritual support. |
| Domain Eight: Functional Assessment Scale | Katz Assessment Form for Activities of Daily Living. |
| Domain Nine: Therapeutic Adherence Scale | Morisky's Therapeutic Adherence Scale. |
| Domain ten: Technical evaluation of clean intermittent catheterization | Patient privacy; number of times performing CIC per day; hygiene (hand and genital hygiene); use of lubricants or hydrophilic catheters; difficulty in performing the procedure in public restrooms; use of appropriate materials when leaving home; interference in social and work activities; complications associated with CIC; perceived difficulties in performing the procedure; psychological factors influencing non-adherence to CIC; need for further CIC training. |

Source: The authors (2021).

Among the participating experts, seven experts (77.7%) were female. About four experts (44.4%) had a doctoral degree in their area of expertise, while three (33.3%) had a master's degree and two (22.2%) were specialists. According to the professional category informed, five (55.5%) are stomal therapists, one being a specialist around family health and one with a master's degree in education in the health professions; and they have professional experience between nine and 40 years.

Regarding the characterization of the judges based on Fehring's criteria[6], among the nine participants, three (33.33%) reported having a recent clinical practice of at least one year with patients with neurogenic lower urinary tract dysfunction or intermittent catheterization, three (33, 33%) were authors or study mentors around NLUTD or intermittent catheterization, two (22.22%) had experience in all the options presented, and one (11.11%) participates/participated in research groups/projects involving/involving the themes NLUTD or intermittent catheterization.

In the instrument validation process, based on the domain (D1) scope and purpose, which covers the general objective of the instrument and the definition of the population and target audience[7], in the question: "Is the general objective specifically described?", eight (88.8%) answered that they agree, partially agree, or strongly agree with the description of the general objective.

In the question "Are the health issue(s) covered by the study specifically described?", eight (88.8%) responded that they agree, partially agree, or completely agree with the description of the health issues covered. In the third question of this same domain "Is the population (patients, audience, etc.) for whom the instrument is intended specifically described?", eight experts (88.8%) responded that they agree, partially agree, or completely agree with the description of the target audience. The result of the nine evaluators' assessment regarding the scope and purpose of the instrument was: 85.8% approval of the instrument's quality.

In the validation of the stakeholder involvement domain (D two), which highlights the way in which the instrument was designed regarding stakeholders and intended users[7], the fourth question entitled "Does the instrument development team include individuals from all relevant professional groups?", seven (77.7%) of the raters responded that they agree, partially agree, or fully agree with the involvement of relevant professionals in the development.

In the fifth question called "Did we try to know the opinions and preferences of the target population (patients, public, etc.)?", nine (100%) raters responded that they agree, partially agree, or strongly agree about knowing the opinions and preferences of the target population. And, in the last question of the domain described as "Are the target users of the instrument clearly defined?", eight (88.8%) agree, partially agree, or strongly agree about defining the target users.

The result of the nine evaluators regarding the involvement of the parties in the instrument was 84.5% approval of the instrument's quality. Table 1 presents the quantitative analysis of the experts' opinion, regarding the concept measured in the items of the instrument.

**Table 1**- Content validity index (CVI) of the instrument to assess adherence to self-care in patients with NLUTD. Rio de Janeiro, RJ, Brazil, 2021

| Item | CVI - CONTENT VALIDITY INDEX | | | |
|---|---|---|---|---|
| | Validation of the item | Clarity | Accuracy | Relevance |
| Domain three | 1.00 | 1.00 | 1.00 | 1.00 |
| Domain four | 1.00 | 0.88 | 0.88 | 1.00 |
| Domain five | 1.00 | 1.00 | 1.00 | 1.00 |
| Domain six | 0.77 | 0.88 | 0.88 | 0.77 |
| Domain seven | 1.00 | 1.00 | 1.00 | 1.00 |
| Domain eight | 1.00 | - | - | - |
| Domain nine | 1.00 | - | - | - |

| | | | | |
|---|---|---|---|---|
| Domain ten | 1.00 | 1.00 | 1.00 | 1.00 |

Source: The authors (2021).

Regarding the experts' assessment of the validation of each item of the adherence instrument, all domains, from D3 to D10, obtained a CVI score of one, except D6, which showed a CVI of 0.77, below the minimum limit of 0.80. The D6 concerns family history and showed the same CVI value when the relevance of the domain for the experts was evaluated. This was the only domain excluded from the instrument since the experts did not find the item relevant to composing the instrument.

In the evaluation of the clarity and precision of domain four, which concerns prior pathological history, the experts' assessment led to a CVI value of 0.88, above the minimum limit of 0.80. Thus, the items were not excluded, and the experts' observations were taken into consideration for adjustments of the instrument.

In the pre-existing scales for the assessment of self-care and therapeutic adherence, entitled Katz's Basic Activities of Daily Living Assessment Form and Morisky's Therapeutic Assessment Scale, the assessments based on the CVI criteria were not included, since they are scales that have already been validated and used by health professionals, and the experts have judged their pertinence in the instrument.

## DISCUSSION

The criterion for the choice of health professional judges was based on the need for multi-professional monitoring in patients with NLUTD, since the dysfunction is caused in a secondary way to a certain disease, requiring various types of care for rehabilitation and disease control. In this study, the nurse specialists in stoma therapy stand out.

Some studies show the nurse with a key role in patients who undergo intermittent catheterization as a form of treatment, being the professional trained to implement care and guidance on the procedure, preparation of training for CIC, helping in the maintenance of self-care and in the practice of continuing education for these patients and caregivers, and risk stratification, promoting better quality of life.[13, 14, 15] These studies reflect the prevalence of nursing professionals in relation to other health professionals who are experts in the evaluation of the instrument.

The result of the instrument validation proposed by the Agree II model[7] was approved according to the result obtained in the two domains evaluated, since the percentage value exceeded more than half of the proposed value. In the validation process regarding the steps of the instrument, based on Pasquali's validation criteria[8], the content of the instrument was validated regarding clarity, precision, and relevance. The instrument's domains five and seven, referring to the history of the current disease and life habits/system information, respectively, had suggestions for adaptations and reformulations. In the CVI analysis of the domains referring to identification data (D3), History of Current Illness (D5), Life Habits (D7), Assessment of CIC Technique (D10), the criteria of clarity, precision, and relevance obtained maximum scores, as well as in item validation.

Regarding the items of Past Pathological History (D4), in the analysis through the CVI, the item reached the highest score in validation and relevance. In this topic, besides the main chronic diseases that affect the population[16], the main diseases and disorders that affect the NLUTD are addressed, such as spinal cord injury, Parkinson's disease, multiple sclerosis, HTLV, diabetes, and spinal cord dysraphism.[17]

Domain five obtained the maximum score in all items in the CVI analysis; however, some experts provided suggestions to the domain. Expert C suggested removing vesicoureteral reflux from the complaints box, justifying that it is not a complaint that the patient can report for not knowing how to identify it; expert D suggested including the type of catheter used and the interval/frequency between each procedure; while expert G suggested changing the items of frequency of appointments and performance of routine exams separately, so that the patient can attend the appointments and not necessarily perform the requested exams. And two experts suggested separating the item frequency in consultations and performance of the requested exams because the user may attend the consultations and not necessarily perform the requested exams.

In the item related to lifestyle habits and relevant information about the systems (D7), in the question about bowel elimination, expert G suggested the removal of the term neurogenic bowel because it can be characterized by constipation and fecal incontinence, items that are already included in the instrument. However, the neurogenic bowel, also affected in people with NLUTD, is composed of several signs and symptoms in addition to those already exposed, such as abdominal pain, hemorrhoids, anal pain, and fissures, being essential to highlight which signs and symptoms of neurogenic bowel the patient was affected. These factors have a direct impact on the patient's social life and quality of life and may affect the patient since childhood in cases of bladder and bowel dysfunction.[18] In addition, the inclusion of the Bristol scale was suggested to assess the appearance of the stool.

The scales of therapeutic adherence and functional assessment acquired maximum score in the validation of the item, but they were not evaluated according to Pasquali's criteria[8] because they are already validated scales. The application of the scales in the instrument becomes necessary because, in the hypothesis of the patient having difficulty in performing daily life activities, it can impair adherence to self-catheterization, since this form of treatment can be hindered by extrinsic and intrinsic factors such as, for instance, difficulties in mobilization, need for caregiver assistance and lack of infrastructure to perform the procedure.[11]

One of the factors that most influence adherence to self-catheterization is the choice of catheter and the nurse's guidance on the procedure, considering the comfort of handling, transport and disposal of the material and the aesthetic aspect of the catheter.[3] In view of this, Dorothea Orem's Theory of Self-Care Deficit reflects the non-adherence to self-care, requiring assessment of treatment continuity and health maintenance. Care planning prepared by nurses and health education practices are necessary to help patients with dysfunction to follow up on treatment, as it is a prolonged therapy in many cases.[19]

In the analysis of the CIC Technique Evaluation domain (D10), expert B suggested the inclusion of the item "review of the steps of clean intermittent catheterization", composed of the organization of the necessary materials until the completion of the technique. Considering that this item may help the dysfunction patient to perform all the steps correctly.

The performance of health professionals as a multidisciplinary team is essential in the rehabilitation process of patients with lower urinary tract neurogenic dysfunction. The content validation of this instrument aimed to provide methods for the assistance of health professionals, noting the nurse as a highlight during the literature review and the validation process, where most judges were composed of nurses. The nursing professional has a key role in adherence to self-care during treatment with self-catheterization, enabling the identification of physical, structural, and psychological barriers that may interfere with adherence, stimulating health promotion and developing health education.

Therefore, the instrument aimed at the needs of adherence to self-care was built for these patients, seeking to provide adherence to self-care, the main factor for the maintenance of voiding dysfunction, since it reduces the risks of complications that can develop during the process of dysfunction and treatment. This may provide a better quality

of life and the management of care planning aimed at patients with chronic diseases [16].

Among the limitations of this study was the unavailability of the Lattes' platform during the period of selection of the experts that evaluated the instrument. The verification of the applicability of the validated instrument will be carried out in further studies.

## CONCLUSION

The research could contribute to the development of an instrument for the assessment of adherence to self-care for the care of patients with NLUTD, listing the main contents and resources needed to assist health professionals working in the area. After the process of content validation, the experts' assessment indicates that the instrument brings together relevant content regarding adherence to self-care and updated regarding clinical issues of patients with NLUTD, being considered a promising instrument for the practice of health care professionals in the area.

It is concluded that in addition to adherence to self-care for NLUTD, it is also necessary to adhere to self-care and treatment of the underlying disease, which can affect the dysfunction. The material will contribute to promoting benefits and adherence to treatment for patients with the dysfunction, since there are several barriers that affect the continuity of clean intermittent catheterization or performing it improperly.

The study will contribute to offering subsidies for the organization of health care, highlighting the nursing professionals and their professional practice, to patients affected by NLUTD; patient orientation regarding the dysfunction, promoting self-care and improving adherence; as well as contributing to the research, since little literature was found that portrays the adherence to self-catheterization in patients with NLUTD.

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Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work - **Candido CF, Silva FH da, Mello LF de, Moraes ACB, Peres EM, Nunes AS**; Drafting the work or revising it critically for important intellectual content - **Candido CF, Silva FH da, Mello LF de, Moraes ACB, Peres EM, Nunes AS**; Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved - **Candido CF, Silva FH da, Mello LF de, Moraes ACB, Peres EM, Nunes AS**. All authors approved the final version of the text.