Research article

Cognitive interviewing validation of the Chinese version of the neurogenic bladder symptom score

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ABSTRACT

Background: The neurogenic bladder symptom score (NBSS) has been widely used to specifically measure symptoms and consequences of neurogenic bladder (NB). The cognitive interviewing (CI) is effective in assessing item clarity and identifying key issues related to the comprehension of the instrument. We aim to translate the NBSS into Chinese and use the CI approach to explore the thought processes of patients with NB in responding the Chinese Version of the NBSS, identify and modify the factors hinder the thought processes to enhance the face validity of the NBSS.
Methods: The translation of the NBSS into Chinese was conducted with the guidance of the recommended frameworks. Patients with NB were recruited by purpose sampling. CI with the combination of thinking aloud and verbal probing techniques were used to explore thought processes. The interviews were transcribed and analyzed based on Tourangeau four-stage response model.
Results: Two rounds of CI were carried out. The problems of comprehension, judgement and response mapping were identified in 8 items. Four items were revised based on the results of the interview. The revised items were verified and eventually integrated into the final version.
Conclusion: The Chinese Version of the NBSS was easy to comprehend and use. The use of CI methodologies can increase the comprehensibility and cultural applicability of the NBSS, providing the evidence for the development of a clearer and more appropriate questionnaire.

1. Introduction

Neurogenic bladder (NB) is a nonspecific term, that loosely refers to lower urinary tract dysfunction resulting from central or peripheral nervous system disease or damage, such as spinal cord injury (SCI), spina bifida, cerebrovascular accidents and multiple sclerosis (MS) [1,2]. NB is a lifelong and complex condition, with various symptoms and complications. NB presents with a wide variety of urological complications including urinary tract infections, calculus disease, hydronephrosis, vesicoureteral reflux, and renal failure [3]. These symptoms and complications can directly decrease health-related quality of life (HRQoL), carry social and

psychological burdens on individuals, and eventually evolve into a public health issue, seriously affecting the socio-economic field [3,4].

In recent years, patient-reported outcome measurements (PROMs) have been widely used in NB populations to measure physical and psychological symptom burden and describe HRQoL [5–7]. PROMs have several benefits, including a better understanding of patients' experiences or values, a more rounded interpretation of the treatment or intervention outcomes, and a notable role in clinical decision-making [8,9]. Welk et al. developed the Neurogenic Bladder Symptom Score (NBSS) through a literature review, semi-structured patient interviews, multidisciplinary professional opinions, and patient pretesting to specifically measure the symptoms and consequences of NB dysfunction [6,10]. The NBSS contains 24 items scored on a Likert scale. For the first item, patients are classified based on bladder or urine function management methods. The final question measures the overall quality of life by evaluating satisfaction with the current bladder working state. The remaining 22 items cover three aspects: voiding, incontinence, and consequences [11]. This instrument has been validated in populations with SCI, stroke, MS, and cerebral palsy [12,13], and has been culturally adapted in different languages, including Polish, Spanish, and Turkish [14–16]. The NBSS-short form (NBSS-SF) was created and validated in 2020 [17] and has been translated into Arabic and French [18,19]. The NBSS-SF has been shown to have excellent validity and reliability [17]. However, using the complete version of the NBSS is more appropriate if the NB symptoms or individual domains are the primary outcomes [17]. As PROMs are often self-administered questionnaires, it should be confirmed that the selected PROM is applicable and appropriate for the target population, and has been validated in their language [20].

As a commonly used qualitative research approach in the developmental process of PROMs, cognitive interviewing (CI) has been demonstrated to be useful for identifying and addressing potential issues and improving the content validity or face validity of questionnaires [21,22]. CI is a semi-structured interview process with respondent-centered techniques (e.g., thinking aloud, verbal probing) used to study how the target population understands, mentally processes, and responds to the content of the selected questionnaire [23]. In general, responding a PROM contains a series of cognitive tasks. The most widely used theory to describe these cognitive tasks is attributed to Tourangeau [24], and was further developed by Willis [25]. Theoretically, the process people undergo when responding to a question can be described by four cognitive tasks [24]. Respondents should first understand the content of the question, retrieve relevant information from the memory of the recall period, and form a mental judgment on the answer to the question. Finally, the respondents map their mental responses based on the categories (options) provided in the questionnaire [25,26].

More recently, CI has been widely used to develop PROMs and confirm the content or face validity of instruments for clinical trials [22,27]. Thus, the current study aimed to perform CI on patients with NB to evaluate whether the instructions, items, and response options in the Chinese version of the NBSS were clear, appropriate, and easy to comprehend.

2. Methods

2.1. Study population

Patients from the urology department and urogynaecology pelvic floor reconstruction unit of a tertiary hospital were eligible to participate if they (1) had an established diagnosis of NB according to the *Chinese urology and andrology disease diagnosis and treatment guidelines, 2019 edition* [28] or the disease diagnosis code N31.901 [29], (2) were ≥18 years old, and (3) were stable, conscious, participated voluntarily, and signed the informed consent form. The following patients were excluded: (1) those unwilling to cooperate, (2) those with cognitive dysfunction or without normal understanding and communication, and (3) those with a history of mental illness. The sampling was purposive, with a maximum variation strategy to ensure heterogeneity in the respondent group concerning demographic and socioeconomic characteristics, leading cause of NB, duration of NB diagnosis, and primary type of bladder management. As a classical qualitative approach, a good sample size commonly depends on theme saturation [30]. Willis et al. [25] suggested that an appropriate target number of respondents for each round is 12–15. Consequently, we stopped recruiting participants if (1) there were more than 15 respondents included in each round, and (2) saturated themes emerged, indicating that no new results or themes could be obtained.

2.2. Measures

We received authorization from the original developers to translate the NBSS items. The translation process includes five stages: forward-translation, forward-translation reconciliation, back-translation, back translation reconciliation and harmonization [31]. As recommended, two bilingual translators whose native language was Chinese completed the forward-translation, resulting in two independent translations (NBSS-translation 1 and NBSS-translation 2). Subsequently, the research team discussed integrating NBSS-translation 1 and 2 into a consensus version of the forward translation and checked this version and the original English version. The back-translation of the previous Chinese consensus version was performed by an English-speaking translator who had no knowledge of the research background and was blinded to the original version of NBSS. All translators were involved in the back-translation reconciliation to check whether the original text and the back-translated versions were translatable and similar. Finally, an expert committee consisting of a language professional, five neurogenic bladder clinical experts, and all translators discussed and proofread the final Chinese version of the NBSS to determine its clinical relevance and suitability.

2.3. Data collection

The research team had experience in performing CI in previous studies. Before conducting these interviews, the research team

reviewed the seminal literature on CI, such as journal articles, books or monographs and the interview guides, and conducted the training procedures recommended by Willis [25]. The interview group consisted of one facilitator, four researches and one observer. Prior to being involved in the interviews, interview group members had never established physician-patient or nurse-patient relationships with the respondents. Interviews were conducted by an experienced facilitator specializing in neurourological diseases and trained in qualitative research. During the interviews, the observer took notes and opportunely asked questions to clarify the issues raised.

Based on individual preferences, the respondents were interviewed in an undisturbed hospital office or via online video-recorded meetings. All interviews were audio recorded. A combination of thinking aloud and verbal probing approaches was used to concurrently elicit problems or comments when participants responded to the NBSS. The study team developed a CI guide for verbal probing based on the Tourangeau four-stage response model (comprehension, retrieval, judgement and response mapping) [24]. Examples of the CI guides are provided in Supplementary Table 1. Each interview was conducted in Mandarin Chinese and lasted for 40 min to 1 h. An incentive of ¥100 Yuan (equivalent to $14 US) was given as compensation for the respondents' time. The interviews were conducted individually using the following process.

(1) The facilitator introduced the study's purpose and interview process to the respondents.
(2) The respondent signed an informed consent form and answered the demographic questions.
(3) After the facilitator demonstrated "thinking aloud" techniques, a warm-up exercise was provided for participants to familiarize themselves with this method. The participants were provided with sample questions and asked to read them, select a numerical response on a Likert scale, and speak aloud their thought process in answering the questions.

Table 1
Participant demographic and disease characteristics of Sample in Cognitive Interviewing.

Participant characteristics	Total (n = 36)	First round (n = 20)	Second round (n = 16)
Gender, n(%)			
Female	17(47.22)	9(45)	8(50)
Male	19(52.78)	11(55)	8(50)
Age			
Mean (SD)	50.61(15.53)	48.6(14.78)	53.13(16.07)
Median (Range)	49(19,74)	45(19,74)	54(21,73)
Marital status, n(%)			
Single	6(16.67)	4(20)	2(12.5)
Married	28(77.78)	13(65)	13(81.25)
Widowed	2(5.56)	1(5)	1(6.25)
Highest level of education, n(%)			
Without education	2(5.56)	1(5)	1(6.25)
Completed primary school	6(16.67)	2(10)	4(25)
Completed middle school or equivalent	11(30.56)	6(30)	5(31.25)
Completed high school or equivalent	8(22.22)	6(30)	3(18.75)
Completed college/university or equivalent	8(22.22)	5(25)	3(18.75)
Work status, n(%)			
Student	2(5.56)	1(5)	1(6.25)
Work full-time for pay	9(25)	6(30)	3(18.75)
Work part-time for pay	4(11.11)	2(10)	2(12.5)
Not working	6(16.67)	5(25)	1(6.25)
Retired	15(41.67)	6(30)	9(56.25)
Main cause of NB, n(%)			
NA[a]	13(36.11)	7(35)	6(37.5)
SCI	8(22.22)	5(25)	3(18.75)
Radical hysterectomy	3(8.33)	2(10)	1(6.25)
Cerebrovascular accidents	2(5.56)	1(5)	1(6.25)
spinal bifida manifesta	2(5.56)	1(5)	1(6.25)
spinal bifida occulta	3(8.33)	2(10)	1(6.25)
Duration of NB diagnosis (in months)			
Mean (SD)	128.97(139.13)	130.45(167.67)	127.13(91.67)
Median (Range)	78(2612)	42(2612)	96(6288)
Main type of bladder management, n(%)			
Spontaneous voiding	9(25)	4(20)	5(31.25)
Bladder Expression	12(33.33)	7(35)	5(31.25)
IC	5(13.89)	3(15)	2(12.5)
Indwelling catheterization	7(19.44)	5(25)	2(12.5)
Urostomy	3(8.33)	1(5)	2(12.5)

Note.
[a] Main cause of neurogenic bladder has not been clearly defined or diagnosed; SCI: spinal cord injury; NB: neurogenic bladder; IC: intermittent catheter.

(4) The respondents were asked to complete the Chinese version of NBSS by expressing their thoughts while answering questions. If respondents were inactive during the "thinking aloud" process, verbal probing was used to complement the cognitive process with the CI guide (Supplementary Table 1).

(5) The research team stopped recruiting participants in each round when saturation was reached, and more than 15 respondents were included.

(6) The researchers analyzed the data, and revised the questionnaire based on the findings of a CI round. The revised questionnaire was used in the next round of interviews until no further questions arose.

2.4. Data analysis

Two trained researchers listened to and transcribed the recordings verbatim, and another researcher corrected the problems arising in the two transcripts and rechecked that all transcripts were anonymized. Two data coders blinded to the demographic details of the respondents independently coded the corrected transcripts and reached an agreement with the mediation of the facilitator. The theory-based categories of Tourangeau's model were applied as a codebook [24]. Then, the research group met to compare and aggregate each category, check for sufficient text fragments to support the categories and identify the reasons for difficulties in answering the questionnaire. After each interview round, the research group revised the scale based on the results. Data analysis was completed upon reaching data saturation.

2.5. Ethics approval

The study was approved by the Research Ethics Committee of the Second Hospital of Tianjin Medical University, with approval number KY2024K002.

3. Results

3.1. Patients

Two rounds of CI were conducted and 36 patients with NB were recruited. The first and second rounds of the CI were conducted with 20 and 16 respondents, respectively. The characteristics of the respondents are shown in Table 1.

3.2. First round of CI

Both two rounds indicated that the Chinese version of NBSS was comprehensible and easy-to-use. The identified problems were primarily relevant to comprehension, whereas a few were related to response formulation or judgement during the first round. The interview and revision records are presented in Table 2.

Table 2
Revisions made to items following the review of cognitive interviewing results.

Category of Issue	Chinese Version/English Equivalent	Related Item	Final Chinese Version	Reasons for Revision
Comprehension	使用避孕套式导尿管/ With a condom catheter.	NBSS 1	使用尿套式接尿器(男士体外导尿器)/With a condom catheter (male external catheter)	"Condom catheter" was rarely realized in China, and it was mistaken for "using condom to collect urine". The term "male external catheter" is a more common and authentic, so it is added with supplementary explanation.
	间歇导尿/intermittent catheter	NBSS 1 and10	间歇导尿/intermittent catheter	The research team reached a consensus that no modifications should be made to these medical terms, as they did not impede comprehension of the entire question or elicit inaccurate responses.
	膀胱痉挛/bladder spasm	NBSS 9	膀胱痉挛/bladder spasm	
	储尿囊/urinary reservoir	NBSS 15 and 24	储尿囊/urinary reservoir	
	造口袋/urostomy bag (stoma bag)	NBSS 1, 11, 15, 16 and 17	造口袋/urostomy bag (stoma bag)	
Judgement	垫子/Pads	NBSS 3, NBSS 4	垫子(护理垫或尿布)/pads (medical nursing pads or diapers)	The words causing extra judgment (pads) was added with supplementary explanations (medical nursing pads or diapers).
	需要2张垫子, 需要1张垫子/Requires 2 pads, requires 1 pad	NBSS 3	需要约2张垫子, 需要约1张垫子/Requires about 2 pads, requires about 1 pad	Respondents suggested the response options should be a rough estimate, since this is more in conformity with their actual situation.
Response mapping	你将感到愉悦/You would feel pleased	NBSS 24	你将感到满意/You would feel satisfied.	It is impossible that option "pleased" will be chosen. Therefore, this word is changed to "satisfied", which is in conformity with Chinese culture.

3.2.1. Comprehension

All the participants reported that the introduction was sufficiently applicable and straightforward. In addition, the item phrasing and response options were clear to the participants, and they could demonstrate this by paraphrasing or explaining items in their own words. In the first round of interviews, respondents answered to all 24 questions, 16 of which were easily comprehensible. Some participants responded negatively to the item comprehensibility of the remaining eight questions.

CI revealed that some respondents who urinate on their own felt that most questions were comprehensible, but some medical terms were unclear, including "intermittent catheter" in NBSS 1 and 10, "bladder spasm" in NBSS 9, "urinary reservoir" in NBSS 15 and 24, "urostomy/stoma bag" in NBSS1, 11, 15, 16 and 17. The root cause of all comprehension issues was the challenging nature of medical terminology interpretation. Understandably, it would be challenging for respondents who have never personally experienced specific bladder symptoms, management, or treatment to clearly explain these specific medical terms. Nevertheless, this did not impede respondents from comprehending the meaning of the entire question and providing an accurate response, as they were merely required to choose an option that matched their actual situation instead of understanding irrelevant terms.

> *"I don't understand the management method of 'condom catheter' because I haven't used it. But it doesn't matter, it's not my option. I mean, it's not my bladder management method." (Patient 3, male, 45 years old, Indwelling catheterization).*

In addition, none of the participants reported using a condom catheter as their primary method of bladder management. Although the condom catheter is considered as a safe method to manage incontinence in men, its long-term use may cause several potential complications, such as urinary tract infections, skin erosion, and pressure injury [32]. Consequently, it is unlikely to be the main long-term bladder management method for patients with NB. Two participants who had used the condom catheter perceived that the term *"condom catheter"* to be too technical and made suggestions for alternatives. "*Male external catheter*" or "*urisheath for men*" were suggested, as these terms are often used when communicating with patients. To improve comprehension and adapt to cultural specificities, the term "*condom catheter*" was revised to *"condom catheter or male external catheter"* in NBSS1 based on respondent suggestions.

> "Although I can roughly know what the term condom catheter refers to, we don't usually call it that. Like a urisheath, or a male external catheter, if you say so, everyone will know what it is." (Patient 14, male, 65 years old, urostomy).

3.2.2. Retrieval

The retrieval process is how respondents retrieve the relevant information from memory in the correct time-period [24]. The respondents declared that the retrieval process was effortless for recalling personal situations. Most respondents considered "*usual bladder function*" as easy to understand, and accurately distinguished the difference between "*usual bladder function*" and "*temporary changes to bladder function*" by citing actual examples they had experienced. Given that no retrieval-related problems arose in this round of interviews, no further modifications were made to any NBSS content.

3.2.3. Judgment

Participants reported difficulties related to their decision-making processes. NBSS3 asked about the amount of urine leakage (the number of pads). Three respondents perceived a gap between response options on the "amount of urine leakage" item, and considered it difficult to choose between "*requires 1 pad*" or "*requires 2 pads*". The respondents suggested that the response options should be rough estimates. Furthermore, regarding NBSS3 and NBSS4, another important phenomenon was that the term "pad(s)," which was explained in two different ways: diaper(s) for eight respondents, and medical nursing pad(s) for four respondents. Additionally, the respondents noted that vague and confusing term made it difficult to map the options. Overall, we modified some options of the NBSS3 into rough estimates, and added more explanations after the word "pad(s)."

> *"It's hard for me to choose an option on this question. Hmm … Urine leakage is a problem that has been with me for a long time. During the day, I may use only one diaper or may use two diapers, or occasionally more. Urine leakage is erratic and unpredictable, depending on the functional state of the bladder at that time. That there maybe should be a rough option 'about 1 pad or 2 pads' or something like that." (Patient 13, female, 57 years old, spontaneous voiding).*

3.2.4. Response mapping

All the respondents were able to respond to the questions on Likert scale. Four respondents noted that they liked the Likert scale and its qualitative descriptors for numbers in some items. The participants commented that brief introductory sentences after each option should be added to help explain overly general definitions; this would help them map their symptoms on a qualitative scale.

> "I notice that all options of this questionnaire, each number, from 0 to 3 or from 0 to 4, is given a specific qualitative definition. Compared with the abstract definition, concrete examples can make it easier for me to choose which option is closer to my actual situation. I mean … for example, if you say clothes are soaked, wet or damp, I think that's an easy question. But if haven't experienced all of that, especially extreme situations, how do you know how many points you should evaluate?" (Patient 5, male, 70 years old, indwelling catheterization)

Moreover, none of the participants chose the option of "*pleased*" in the NBSS24. Two participants expressed that the statement, "*If you had to live the rest of your life with the way your bladder currently works, you would feel pleased,*" was not meaningful, because of its extreme language expression. Within the Chinese context, compared with the word "*satisfied*,", the word "*pleased*" was misunderstood

as "*very pleasant*". In addition, the participants preferred mild or less extreme responses. Therefore, the translation of the option about being "*pleased*" (feeling pleasure) was modified to "*satisfied*" (though not extremely pleased, it is acceptable as expected.). For clarity, it was changed to "*If you had to live the rest of your life with the way your bladder currently works, you would feel satisfied.*"

> "Living with the way my bladder currently works is the one problem that bother me. Um, you know though it was not a huge health problem, but it would still plague all aspects of my life … I mean, it is always a trouble, and it never make anyone feels pleased, Isn't it?" (Patient 17, female, 45 years old, indwelling catheterization).

3.3. Second round of CI

The revised questionnaire from the first round of interviews was verified in the second round. Based on the results of the first round of interviews, twenty items were unchanged, and the remaining four items were modified to ensure they were easier to comprehend or judge. The revision records are shown in Table 2. The second round of interviews indicated that no more substantial changes were needed, and face and content validity were considered good. In general, participants evaluated the scale as applicable, straightforward, comprehensible, and easy to use.

4. Discussion

To our knowledge, this is the first study to use a qualitative method to confirm the content validity of NBSS items in Chinese patients with NB. Qualitative analysis is one of the main approaches for developing PROMs, which is a continual process [33]. Thus, a growing body of research has verified, culturally adapted, and modified questionnaires using CI methodologies. Previous evidence suggests that structural validity demonstrates poor model fit if content validity is inadequate [21]. A possible explanation is that items with poor clarity can cause random errors and make detecting actual changes (i.e. responsiveness) or real relationships between variables (i.e. construct validity) more difficult. Therefore, content validity is fundamental and should be regarded as an essential prerequisite for validating psychometric properties.

In past studies, the content validity of the NBSS was determined by considering expert suggestions, calculating the content validity ratio or index, or asking for opinions from the pre-patient group [12,16,34]. However, as previous evidence supports, it is impossible for experts or health care professionals to accurately predict how respondents will comprehend and explain the questions [35]. Participant-driven pre-testing is an essential form of validation [35]. Until now, qualitative methods have not been adequately described, and patients have not been sufficiently involved in many studies. This study utilized CI to verify whether the existing instrument for patients with NB could apply to this population. Conducting CI with thinking aloud and verbal probing techniques is crucial for exploring how respondents interpret questions in their own words, thereby facilitating item revisions and improving the final questionnaire [36].

As previously mentioned, respondents undergo four thought processes when answering questions. Respondents must understand the content of the question, retrieve the relevant information needed to answer the question from memory, judge the response, and map the response to the corresponding option. It is well-recognized that thinking aloud and verbal probing are the two most commonly used key techniques in CI. The thinking-aloud methodology is valuable, as respondents can freely and openly verbalize their thoughts [36]. It was shown that the thought processes of respondents can be captured clearly with this technology [37], More specifically, many respondents can describe the process that leads them to find an appropriate answer to a question in thinking-aloud interviews [27]. Given that thinking-aloud approach was intended to elicit thought processes and might be limited in capturing comprehension or judgment problems [25], Willis et al. suggested that thinking aloud and verbal probing techniques should be used complementarily in practice [38].

This qualitative study of 36 patients showed that it is difficult to achieve optimal semantic and item equivalence by translation alone, and that CI methods can provide additional insights. Responses to the first round were positive, with most participants reporting an understanding of all but eight items. Although most items exhibited good comprehension and acceptability, this CI emphasized potential equivalence gaps, including those overlooked by translators. We identified obscure terminologies, inappropriate translation wordings and vague expressions that prevented a clearer understanding, better judgment, and more accurate response mapping of items. The respondents in this study stated that some items in the questionnaire contained specific medical wording that can be difficult to understand or create confusion. The most likely cause of this phenomenon is that different experiences are unique to specific types of bladder management. In addition, CI indicated that some wording was not self-explanatory and should be revised to supplement broader information. Specifically, adding supplementary wordings (e.g., male external catheter in NBSS1) to items can promote comprehension of the entire question among respondents, which is consistent with previous studies [39]. This finding suggests that it will be easier to understand and answer questions about which expressions are more applicable and suitable for the daily life of the respondents. Unexpectedly, some wording was somewhat ambiguous, such as pad(s), which could refer to medical nursing pad(s) and diaper(s). Although developers may intentionally use generalized wording to allow definitions depending on personal preferences and real situations, it would become problematic if the respondent struggles with the judgment, thereby distracting from the core question. Furthermore, our results indicated that the participants were satisfied with the qualitative description of the response options. The brief introductory sentences following each option are beneficial for participants in mapping their responses, which makes the scale seem less "clinical" and more user-friendly.

One final, notable finding in this study was that CI, expert committee review, and quantitative methods did not conflict with each other; instead, they were mutually complementary. Experts familiar with research on the targeted subjects play a vital role in judging

whether the pre-translation is equivalent to the original version [40]. In this study, researchers and experts rigorously translated the NBSS, confirmed its face validity, and achieved cross-cultural equivalence. After careful consideration, the expert committee comprised a group of clinical experts with extensive experience in the diagnosis, treatment, and health care of NB, and basic theoretical psychometric knowledge. During this stage, a few minor linguistic issues were identified, and the text was slightly changed. These results provided a basis for subsequent CI.

This study has several limitations. First, our sample primarily included patients whose primary language was Mandarin Chinese. However, it remains undetermined whether individuals from other linguistic or cultural backgrounds would have interpreted the items similarly. Further research should be conducted on a larger, more linguistically and culturally diverse sample to provide a broader and deeper understanding of the meaning and context of the instrument. Additionally, all participants in our sample had good cognitive abilities. In other words, we excluded patients with cognitive dysfunction, such as those with cerebral palsy and dementia. Although excluding participants with cognitive dysfunction is normal in social psychology research, it is clear that cerebral palsy is a typical subgroup of NB. Thus, a future goal is to evaluate and possibly refine the NBSS to ensure its use by all patients, irrespective of minor cognitive disorder.

5. Conclusions

The respondents deemed the NBSS to be easy to comprehend and use. Minor textual changes were made based on the results. Instrument development is a continuous process. Using CI methodologies can increase the comprehensibility and cultural applicability of the NBSS, thus providing evidence for developing of a clearer and more appropriate questionnaire. Our results further revealed that difficulties in understanding the scale were mainly related to differences in the participants' bladder treatments or management. The findings from this study emphasize the importance of CI and contribute valuable insights into measuring HRQoL in patients with NB.

Data availability statement

Data will be made available on request.

CRediT authorship contribution statement

Xue Wang: Writing – review & editing, Writing – original draft, Data curation. **Shen Gao:** Writing – review & editing, Writing – original draft, Data curation. **Ting Wang:** Writing – review & editing, Project administration, Conceptualization. **Jun Xue:** Writing – review & editing, Data curation. **Yixuan Yang:** Data curation. **Lu Han:** Data curation. **Yuanjie Niu:** Writing – review & editing, Project administration. **Li Fu:** Writing – review & editing, Project administration, Methodology, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.heliyon.2024.e37435.

References

[1] J.N. Panicker, Neurogenic bladder: epidemiology, diagnosis, and management, Semin. Neurol. 40 (5) (2020) 569–579, https://doi.org/10.1055/s-0040-1713876.
[2] J.B. Gajewski, et al., An International Continence Society (ICS) report on the terminology for adult neurogenic lower urinary tract dysfunction (ANLUTD), Neurourol. Urodyn. 37 (3) (2018) 1152–1161, https://doi.org/10.1002/nau.23397.
[3] U. Nseyo, Y. Santiago-Lastra, Long-term complications of the neurogenic bladder, Urol. Clin. 44 (3) (2017) 355–366, https://doi.org/10.1016/j.ucl.2017.04.003.
[4] A. Dinh, et al., Urinary tract infections in patients with neurogenic bladder, Med. Maladies Infect. 49 (7) (2019) 495–504, https://doi.org/10.1016/j.medmal.2019.02.006.
[5] O. Moghalu, et al., Time-related changes in patient reported bladder symptoms and satisfaction after spinal cord injury, J. Urol. 207 (2) (2022) 392–399, https://doi.org/10.1097/ju.0000000000002228.
[6] R. Clark, B. Welk, Patient reported outcome measures in neurogenic bladder, Transl. Androl. Urol. 5 (1) (2016) 22–30, https://doi.org/10.3978/j.issn.2223-4683.2015.12.05.
[7] B. Welk, Quality of life in neurourology patients, Eur Urol Focus 6 (3) (2020) 531–533, https://doi.org/10.1016/j.euf.2019.09.001.
[8] C.J. Loftus, et al., Bladder management is the top health concern among adults with a spinal cord injury, Neurourol. Urodyn. 43 (2) (2023), https://doi.org/10.1002/nau.25369.
[9] R.G. McGee, How to include patient-reported outcome measures in clinical trials, Curr. Osteoporos. Rep. 18 (5) (2020) 480–485, https://doi.org/10.1007/s11914-020-00611-5.
[10] B. Welk, et al., The conceptualization and development of a patient-reported neurogenic bladder symptom score, Res. Rep. Urol. 5 (10) (2013) 129–137, https://doi.org/10.2147/rru.S51020.

[11] B. Welk, et al., The validity and reliability of the neurogenic bladder symptom score, J. Urol. 192 (2) (2014) 452–457, https://doi.org/10.1016/j.juro.2014.01.027.

[12] M. Talebi, et al., Psychometric properties of the Persian version of neurogenic bladder symptom score questionnaire: a methodological study on patients with multiple sclerosis and stroke, Neurourol. Urodyn. 41 (8) (2022) 1817–1823, https://doi.org/10.1002/nau.25029.

[13] J.J. Pariser, et al., Reliability and validity of the neurogenic bladder symptom score in adults with cerebral palsy, Urology 128 (2019) 107–111, https://doi.org/10.1016/j.urology.2019.02.033.

[14] M. Przydacz, et al., Neurogenic bladder symptom score: Polish translation, adaptation and validation of urinary disorder-specific instrument for patients with neurogenic lower urinary tract dysfunction, Int. J. Clin. Pract. 74 (10) (2020) e13582, https://doi.org/10.1111/ijcp.13582.

[15] J. Moreno-Palacios, et al., Cross-cultural adaptation and validation of the neurogenic bladder symptom score for Spanish speakers, Neurourol. Urodyn. 40 (8) (2021) 1939–1944, https://doi.org/10.1002/nau.24768.

[16] M.A. Guler, D. Doğan, E. Yilmaz Yalcinkaya, Validity and reliability of the Turkish version of the neurogenic bladder symptom score, Disabil. Rehabil. 44 (12) (2022) 2889–2895, https://doi.org/10.1080/09638288.2020.1846216.

[17] B. Welk, et al., The creation and validation of a short form of the Neurogenic Bladder Symptom Score, Neurourol. Urodyn. 39 (4) (2020) 1162–1169, https://doi.org/10.1002/nau.24336.

[18] Y.A. Khadour, M. Zheng, F.A. Khadour, The validity and reliability of the Arabic version of the short form of neurogenic bladder symptoms score in patients with spinal cord injury, J. Orthop. Surg. Res. 18 (1) (2023) 464, https://doi.org/10.1186/s13018-023-03956-6.

[19] S. Berradja, et al., French version of the short form of the Neurogenic Bladder Symptom Score: cross-cultural adaptation and validation, Can Urol Assoc J 16 (9) (2022) E468–e472, https://doi.org/10.5489/cuaj.7709.

[20] L. van Stiphout, et al., Development and content validity of the bilateral vestibulopathy questionnaire, Front. Neurol. 13 (2022) 852048, https://doi.org/10.3389/fneur.2022.852048.

[21] J.C. MacDermid, ICF linking and cognitive interviewing are complementary methods for optimizing content validity of outcome measures: an integrated methods review, Front Rehabil Sci 2 (2021) 702596, https://doi.org/10.3389/fresc.2021.702596.

[22] S. Izumi, R. Vandermause, S. Benavides-Vaello, Adapting cognitive interviewing for nursing research, Res. Nurs. Health 36 (6) (2013) 623–633, https://doi.org/10.1002/nur.21567.

[23] N. Ahmed, et al., The use of cognitive interviewing methodology in the design and testing of a screening tool for supportive and palliative care needs, Support. Care Cancer 17 (6) (2009) 665–673, https://doi.org/10.1007/s00520-008-0521-2.

[24] W.L. Schaible, et al., Cognitive aspects of survey methodology: building a bridge between disciplines, J. Am. Stat. Assoc. 82 (397) (1987) 351, https://doi.org/10.2307/2289187.

[25] G.B. Willis, Cognitive interviewing revisited: a useful technique, in theory?, in: Methods for Testing and Evaluating Survey Questionnaires Wiley, New York, 2004.

[26] M. Murphy, S. Hollinghurst, C. Salisbury, Patient understanding of two commonly used patient reported outcome measures for primary care: a cognitive interview study, BMC Fam. Pract. 19 (1) (2018) 162, https://doi.org/10.1186/s12875-018-0850-2.

[27] A. Egger-Rainer, Enhancing validity through cognitive interviewing. A methodological example using the Epilepsy Monitoring Unit Comfort Questionnaire, J. Adv. Nurs. 75 (1) (2019) 224–233, https://doi.org/10.1111/jan.13867.

[28] J. Huang, Chinese Urology and Andrology Disease Diagnosis and Treatment Guidelines, 2019 edition., Science Press, Beijing, 2020.

[29] G. Amarenco, et al., Diagnosis and clinical evaluation of neurogenic bladder, Eur. J. Phys. Rehabil. Med. 53 (6) (2017) 975–980, https://doi.org/10.23736/s1973-9087.17.04992-9.

[30] K. Meadows, Cognitive interviewing methodologies, Clin. Nurs. Res. 30 (4) (2021) 375–379, https://doi.org/10.1177/10547738211014099.

[31] D.E. Beaton, et al., Guidelines for the process of cross-cultural adaptation of self-report measures, Spine 25 (24) (2000) 3186–3191, https://doi.org/10.1097/00007632-200012150-00014.

[32] A.K. Sinha, et al., Condom catheter induced penile skin erosion, J. Surg. Case Rep. 2018 (10) (2018) rjy275, https://doi.org/10.1093/jscr/rjy275.

[33] H. Coats, et al., Using cognitive interviews to improve a Psychological-Social-Spiritual Healing instrument: voices of aging African Americans with serious illness, Appl. Nurs. Res. 39 (2018) 109–114, https://doi.org/10.1016/j.apnr.2017.11.019.

[34] L.K.L. Cintra, et al., Cross-cultural adaptation and validation of the neurogenic bladder symptom score questionnaire for Brazilian Portuguese, Int. Braz J. Urol. 45 (3) (2019) 605–614, https://doi.org/10.1590/s1677-5538.Ibju.2018.0335.

[35] K. Scott, O. Ummer, A.E. LeFevre, The devil is in the detail: reflections on the value and application of cognitive interviewing to strengthen quantitative surveys in global health, Health Pol. Plann. 36 (6) (2021) 982–995, https://doi.org/10.1093/heapol/czab048.

[36] J. Kedroske, et al., Development of a national caregiver health survey for hematopoietic stem cell transplant: qualitative study of cognitive interviews and verbal probing, JMIR Form Res 4 (1) (2020) e17077, https://doi.org/10.2196/17077.

[37] C. Nehlin, M. Wennberg, C. Öster, How do people with mood and anxiety disorders perceive and interpret the Drinking Motives Questionnaire? A think-aloud study in a clinical setting, Addiction Sci. Clin. Pract. 13 (1) (2018) 7, https://doi.org/10.1186/s13722-018-0109-1.

[38] G.B. Willis, A.R. Artino Jr., What do our respondents think we're asking? Using cognitive interviewing to improve medical education surveys, J Grad Med Educ 5 (3) (2013) 353–356, https://doi.org/10.4300/jgme-d-13-00154.1.

[39] W.L. Lee, et al., Utility of equivalence and cognition models in enhancing validity of translated questionnaires: a methodological example using the heart quality-of-life questionnaire, J. Nurs. Res. 29 (1) (2020) e136, https://doi.org/10.1097/jnr.0000000000000414.

[40] M. Jia, et al., Translation and cross-cultural adaptation of post-stroke checklist into Mandarin: a cognitive interview study, Neuropsychiatric Dis. Treat. 18 (2022) 87–95, https://doi.org/10.2147/ndt.S342464.