



# Measuring the impact of managing incontinence on people with dementia and informal caregivers: Cognitive debriefing interviews of 'ICIQ-Cog' (English translation)

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## ABSTRACT

**Aim:** The ICIQ-Cog questionnaire was developed in German to measure the impact of incontinence and/or toilet use problems on people living with dementia and their paid carers and unpaid caregivers; it has been translated into English. This study aimed to (1) examine the linguistic validity of the ICIQ-Cog English translation and (2) determine whether it addresses what is important to unpaid caregivers.

**Methods:** Cognitive debriefing interviews were conducted with 13 unpaid caregivers of people with dementia and problems with incontinence or toilet use recruited via Joint Dementia Research. Interviews were conducted across 3 rounds and transcribed then thematically analysed based on the questionnaire framework.

**Results:** All participants were unpaid caregivers; they highlighted the need for the questionnaire. Changes were made to the title and response options were added to 10 of 12 questions; wording changes were made to 5 questions. One of the questions was deemed difficult to answer as an unpaid caregiver due to the need for more general caring experience; another used phraseology potentially more understandable by professional carers. Several participants emphasised missing questions (such as cost of buying continence aids and extra washing). The interviews were halted because the questionnaire did not fully meet unpaid caregivers needs.

**Conclusion:** This linguistic validation of the ICIQ-Cog questionnaire identified that it is not appropriate for use among unpaid caregivers. A questionnaire to assess impact of managing incontinence designed purposefully for unpaid caregivers of a person with dementia is needed. Further work is required to finalise the English translation for paid carers.

## 1. Introduction

Over 50 million people across the world live with dementia with this number expected to triple by 2050 [1]. People living with dementia are at considerably higher risk of developing incontinence than those without dementia (adjusted rate ratio: urinary incontinence 3.2 in men and 2.7 in women, faecal incontinence 6.0 for men and 4.5 for women) [2]. Incontinence can cause substantial harm to health and be hugely distressing not just for the person living with dementia, but also their carers [3,4].

Many people with dementia want to live at home as long as possible, supported by family, friends and care services [5]. They are cared for

by unpaid caregivers or paid carers or both [6]. The term 'unpaid caregiver' refers to carers, whether family, friends or neighbours, who are not paid for providing support, whereas 'paid carers' are people in formal employment, sometimes from a professional background [7]. There is high burden on unpaid caregivers [8]. Caregivers rate independent toilet-use as the most important activity of daily living for the person living with dementia (PLWD) to preserve [9]. They also equate issues with managing incontinence as one of the main reasons a PLWD moves into a care home [10]. A valid and reliable tool is important to understand the impact of managing incontinence and to measure the impact of any new interventions for people with dementia and their caregivers.

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## **International Consultation on Incontinence Questionnaire-Cognitively Impaired Elderly (ICIQ-Cog)**

The ICIQ-Cog was developed in German, using ICIQ methodology [11,12] to assess the impact of managing incontinence and toilet-use problems on the person with cognitive impairment and their carers. The ICIQ-Cog was originally developed with both paid carers and unpaid caregivers, but the validation work was completed mainly with paid carers from nursing homes in Germany. The development and validation process involved 4 stages; interviews with paid carers and unpaid caregivers, expert urologist analysis, a blank paper session and test-retest. The blank paper session included a group of 12 people working in the field of continence care or caring for a relative or friend with dementia and incontinence. The participants were asked what question they would want to be asked to evaluate incontinence and its impact on the person affected and their own work. The responses were compared to existing scale items (from the interviews and expert analysis) and those best corresponding to the items from the blank paper exercise were selected [12]. The test-retest then followed.

The psychometric testing of the ICIQ-Cog was conducted according to the ICIQ guidelines. Detailed descriptive statistical analysis was used to assess frequency distribution of item responses, internal and re-test reliability, validity and exploratory and confirmatory factor analysis. An item response theory approach that used the Rasch model was applied [12]. The final validated questionnaire was divided into 2 main sections: the 'ICIQ disease-specific bother scale' (ICIQ-Cog-P) (8 questions) and the 'ICIQ care efforts scale' (ICIQ-Cog-C) (4 questions).

The aim of this study was (1) to examine the linguistic validity (reliability, conceptual equivalence and content validity) of the ICIQ-Cog English translation with paid carers and unpaid caregivers and (2) to consider whether it addresses what is important to unpaid caregivers.

## **2. Methods**

### *2.1. Linguistic validation*

The ICIQ group recommend 4 steps to validate a translation of an ICIQ tool, to ensure a high level of linguistic validity [13]. The initial 2 steps, translation and back translation by native and fluent speakers in both the original and target languages respectively, have been completed. Ordinarily, the 3rd step involves review of the back translation by the ICIQ team, however as the origin language was German this was not possible. Harmonisation with the original version was therefore conducted by the translation developer. The final stage, reported in this paper, involves cognitive debriefing interviews with the target population (English speaking) to assess content validity.

### *2.2. Study approval*

A cognitive debriefing semi-structured interview study was conducted to assess the linguistic validity of the previously translated version of the ICIQ-Cog from German into English. The study was approved by the University of Southampton Ethics Committee.

### *2.3. Participant recruitment*

Participants were recruited via Join Dementia Research (JDR) between September 2023 and April 2024. JDR is a UK-wide service which enables people with dementia, caregivers and healthy volunteers to register their interest in taking part in research.

Both paid carers and unpaid caregivers, over 18 years old, able to read and communicate in English, representing the target population for the ICIQ-Cog were invited to take part in the study. Eligible potential participants were sent the participant information sheet and consent form by post, with a copy of the appropriate version of the ICIQ-Cog depending on interview round (Supplementary table 1). Written informed consent was received prior to interview.

### *2.4. Study setting*

The cognitive debriefing interviews were conducted by telephone or Microsoft Teams using a method involving unprobed self-administration, followed by a debriefing session [14,15]. Initially, participants completed the ICIQ-Cog and time taken was recorded. An interview schedule was used for the debriefing session. They were asked about their understanding of the title, instructions, questions, and response options. The interviews lasted 30–60 min; the interviews were recorded, and field notes were taken.

Interviews were conducted across 3 rounds. Following the first round, the interviewer summarised field notes and consulted with the study team, the ICIQ and questionnaire development teams to identify necessary modifications to improve the translation. Further modifications were made after round 2, and the final interviews took place in round 3.

### *2.5. Saturation*

The interviews were intended to continue until the objectives of the study were met and no new major modifications were identified.

### *2.6. Data analysis*

The data analysis was completed using Microsoft Excel including within interview and across interview analysis [14]. The notes for each interview were tabulated by questionnaire section, then aggregated across interviews to check for clarity and consistent interpretation of questions, and to confirm comprehension or highlight areas of mis-interpretation, lack of clarity or possible solutions or improvements. Observed patterns were discussed within the study team and potential modifications were actioned (Tables 3 and 4, Supplementary table 1). This process was completed at the end of each interview round.

Interview recordings were transcribed verbatim and analysed thematically on a per question basis, based on the Braun and Clark method [16]. The analysis focused on the clarity of the English translation, problems with questions and solutions.

## **3. Results**

A total of 13 participants were recruited across three rounds of interviews: round one (n = 5), round two (n = 5) and round three (n = 3). After 13 interviews, and a review of the findings, the decision was made by the study team that the needs of unpaid caregivers could not be fully addressed by the questionnaire, so recruitment was ended.

### *3.1. Participant characteristics*

Participant characteristics are shown in Table 1. There were 11 females and 2 male participants, mean age 63.5 years. Although both paid carers and unpaid caregivers were invited to take part, we were only able to recruit unpaid caregivers (with one having some experience of paid caring in the past). All participants were White British, Irish, or European and had experience as an unpaid caregiver for someone with dementia and urinary and/or faecal incontinence. Most were former caregivers (n = 10). The participants were caregivers for an average of 4.8 years.

The time taken to complete the ICIQ-Cog questionnaire (English translation) was recorded at the start of the interview. The mean time taken (excluding one participant who had already completed it) was 2 min 42 s (range: 50 s–9 min 54 s).

**Table 1**  
Participant characteristics.

Participants	Round 1	Round 2	Round 3	Overall
Number	<i>n</i> = 5	<i>n</i> = 5	<i>n</i> = 3	<i>N</i> = 13
Background characteristics				
Age (years) [mean ±SD]	60.4 (14.8)	66.8 (7.7)	63.3 (9.3)	63.5 (10.7)
Sex (male)	1	1	0	2
Sex (female)	4	4	3	11
Ethnic group (White British, Irish, or European)	5	5	3	13
Carer information				
Unpaid caregiver experience	5	4	3	12
Both paid carer and unpaid caregiver experience	0	1	0	1
Current caregiver	2	1	0	3
Former caregiver	3	4	3	10
Length of time a caregiver (current) (yrs) [mean]	3.8	1.5	N/A	3
Length of time a caregiver (former) (yrs) [mean]	4.5	4.7	7.0	5.3

**Table 2**  
Participant quotes for importance and ease of completion of the ICIQ-Cog.

Participant quotes
<b>Area: Importance and need for the questionnaire</b>
'Well first of all I had never seen anything like it before. Secondly it is a very big issue so I'm glad that it's being addressed..... I think one of the things that it does is acknowledge how much it impacts people and the people that, certainly people with dementia but definitely the people who look after them as well.' (FP)
'The only thing is really personally I think it's very good that something like this has been created because incontinence is quite a big issue with someone who is sadly suffering with dementia particularly further along in the latter stage of the disease.' (FP)
<b>Area: Ease of completion</b>
'They were really succinct. .... I think this is easy, .....It flowed well, and it made sense and it all makes sense to people looking after them. You just want an easy, you don't really want to think too hard.' (FP)
'No easy to complete because it's quite straightforward. It's nothing too, that would need looking up what the definition of the words are.' (FP)
'I found the majority of the questions easy but there were several that I felt were harder to answer accurately or there needed to be another option or that I didn't feel I fitted an option well (MP).'

FP=female participant, MP=male participant.

### 3.2. Need for, ease of completion, and clarity of the ICIQ-Cog (English translation)

The need for and importance of the ICIQ-Cog questionnaire was emphasised by several participants. Overall, the majority of participants found most of the questionnaire easy to complete. It was described as 'really succinct' and 'quite straightforward' with nothing 'scary' in the language used (Table 2). Others found some questions more difficult to answer accurately and some of the words used overly complicated.

The ICIQ-Cog question items were generally well understood and appeared to be consistently interpreted by the participants. Some highlighted how the examples in brackets for ICIQ-Cog-P questions 1, 2 and 4 helped their understanding.

### 3.3. Amendments made to the ICIQ-Cog

The data from interviews was heterogeneous with some participants having directly opposing points of view. For example, some participants found the statement 'my daily routines are dictated by the person's incontinence' (ICIQ-Cog-C Q2) clear and understandable, whereas others really did not like the word dictated and wanted this to be changed. Where this happened, modification decisions were made based on the cognitive debriefing interview data and expert opinion. Some comments were considered to be personal preference, but for others there were patterns within or across interview rounds.

#### Title and instructions

Several participants did not like the phrase 'cognitively impaired elderly' in the questionnaire title. This was modified to 'adult' after the round 1 interviews. Several participants in rounds 1 and 2 preferred a change to the word 'burden' in the questionnaire instructions; this was discussed within the study team and modified to 'impact'.

### Questions

Over the 3 rounds of interviews, participants raised issues or showed uncertainty related to the wording, the interpretation or the structure of some questions. Modifications were made to the wording of 5 of the 12 questions (Table 3).

### Response options

The response option definitions table was positioned at the start of the questionnaire. Some participants forgot these definitions and applied their own understanding. After the round 1 interviews, the response option definitions box was repeated on the second page as a reminder.

The response options for most questions did not cover all necessary scenarios. Changes were made to response options in 10 of the 12 questions (Table 4). As advised by the ICIQ team, 'seldom' was changed to 'rarely' for all ICIQ-Cog-P questions for consistency across ICIQ questionnaires. The option 'never' was also added to all ICIQ-Cog-P questions. Some participants described how questions, such as 'impact on eating and drinking' were 'never' an issue; others described how 'never' was needed for all questions and varies depending on the stage of dementia.

The response option 'not applicable' was added to 4 questions and 'I don't know' was added to 2 questions. Some participants expressed difficulty in answering ICIQ-Cog-P Q7 where they did not sleep in the same room as the person. The statement 'people with dementia require significantly more help to manage incontinence than people without dementia' (ICIQ-Cog-C Q3) was difficult to answer for some unpaid caregivers. Many had only experience of caring for the one relative and so could not answer this.

**Table 3**  
ICIQ-Cog Question modifications.

Question No.	Question	Comments	Modifications
ICIQ-Cog-P Q3	How often did the person show negative emotions such as anger or disgust during or after an incontinent episode?	The phrase 'incontinent episode' not considered 'good English'	Changed 'incontinent episode' to 'episode of incontinence'
ICIQ-Cog-P Q4	How often did personal care, change of continence aids, or help with toileting provoke negative reactions in the person (e.g., verbal comments, defensive movements)?	Complicated 3-part question	Simplified the question
ICIQ-Cog-P Q6	How often was the person's ability to participate in social activities strongly affected by their incontinence?	Difficulty with the word 'strongly'	Changed 'strongly' to 'significantly'
ICIQ-Cog-P Q7	How often was the person's sleep interrupted by their incontinence?	Different interpretations of whether avoiding incontinence is included in interrupted sleep	Changed 'by their incontinence' to 'due to an episode of incontinence'
ICIQ-Cog-P Q8	How often did incontinent episodes negatively impact on the person's mood?	The phrase 'incontinent episodes' not considered 'good English'	Changed 'incontinent episodes' to 'an episode of incontinence'

**Table 4**  
Response option modifications.

Question No.	Question	Response options	Modifications to response options
ICIQ-Cog-P Q1	How often was the person unable to indicate verbally or non-verbally (through specific actions or gestures) that they have experienced an episode of incontinence?	very often; often; sometimes; seldom	Change seldom to rarely Add never Add not applicable
ICIQ-Cog-P Q2	How often did incontinence have a negative impact on the person's eating and drinking (avoiding fluid intake)?	very often; often; sometimes; seldom	Change seldom to rarely Add never Add not applicable
ICIQ-Cog-P Q3	How often did the person show negative emotions such as anger or disgust during or after an incontinent episode?	very often; often; sometimes; seldom	Change seldom to rarely Add never
ICIQ-Cog-P Q4	How often did personal care, change of continence aids, or help with toileting provoke negative reactions in the person (e.g., verbal comments, defensive movements)?	very often; often; sometimes; seldom	Change seldom to rarely Add never
ICIQ-Cog-P Q5	How often did incontinence limit the mobility of the person in their daily activities?	very often; often; sometimes; seldom	Change seldom to rarely Add never
ICIQ-Cog-P Q6	How often was the person's ability to participate in social activities strongly affected by their incontinence?	very often; often; sometimes; seldom	Change seldom to rarely Add never Add not applicable
ICIQ-Cog-P Q7	How often was the person's sleep interrupted by their incontinence?	very often; often; sometimes; seldom	Change seldom to rarely Add never Add I don't know
ICIQ-Cog-P Q8	How often did incontinent episodes negatively impact on the person's mood?	very often; often; sometimes; seldom	Change seldom to rarely Add never
ICIQ-Cog-C Q2	My daily routines are dictated by the person's incontinence.	strongly agree; moderately agree; disagree; strongly disagree	Add not applicable
ICIQ-Cog-C Q3	People with dementia require significantly more help to manage incontinence than people without dementia.	strongly agree; moderately agree; disagree; strongly disagree	Add I don't know

### 3.4. Other issues raised

Other issues related to ease of understanding of the wording used, difficulty in answering 'by proxy' and specific issues for unpaid caregivers.

#### *Simplifying English throughout the survey*

Through the 3 rounds of interviews, participants highlighted difficult words in some questions and suggested alternatives. For example, modifying the word provoke to 'cause' or participate to 'take part in' or episode to 'period' or 'event'. Some viewed the words 'taboo' and 'dictated' as overly complicated. Several did not understand what the word 'mobility' meant in the context of impact on daily activities in ICIQ-Cog-P Q5.

#### *Negative phrasing of first question*

Through all 3 interview rounds, participants raised the issue of the negatively phrased first question, emphasising a preference for describing how the person was 'able' rather than 'unable' to do certain things.

#### *Difficulty in answering questions 'by proxy'*

The difficulty of answering some of the questions as a proxy was highlighted, for example, one participant could not be sure whether changes to eating and drinking related to incontinence or how much the lack of social participation was related to incontinence for the person with dementia.

### **Potentially related to being an unpaid carer**

Some of the issues raised with the questions relate to the specific needs of the unpaid caregivers. There was variation in understanding of the phrase 'daily activities' in ICIQ-Cog-P Q5, which is a term like 'activities of daily living' commonly used by healthcare professionals.

The first question of ICIQ-Cog-C asks about 'caregiving responsibilities'; one participant was uncertain about the use of the word 'responsibility'. They described the difference between a professional carer who has a 'duty of care' to a person to that of an unpaid spousal caregiver who loves the person and wants the best for them. For some there was also difficulty in answering ICIQ-Cog-C (Q2) 'my daily routines are dictated by the person's incontinence', and a dislike of the word 'dictate' in this question. Others emphasised the potential difference in response to this question between paid and unpaid caregivers; or unpaid caregivers who did not live with the person.

Another participant raised the difference between unpaid caregivers and paid carers more generally. They described the shock and worry for the unpaid caregiver of caring for the person compared with that of a paid carer for whom it was part of their job, routine, nothing to worry about and a 'completely different scenario.' In the ICIQ-COG-C, question 3 relating to the difference in managing incontinence in a person with or without dementia remained a difficult one to answer.

### **3.5. New emerging question areas**

During the interviews, participants raised question areas they considered important, but not included in the ICIQ-Cog questionnaire, mostly related to the needs of unpaid caregivers. The financial burden for the PLWD and their caregiver and the costs associated with caring for the person was raised by 3 participants as important and one that can cause stress (Supplementary table 3). Other new emerging question areas were difficulty in sourcing suitable absorbent products and the embarrassment of having to collect and dispose of products.

## **4. Discussion**

In this paper, we present the findings from a series of cognitive debriefing interviews evaluating the linguistic validity of the English translation of the ICIQ-Cog questionnaire, originally developed in German. Participants were all unpaid caregivers; the interview findings revealed that the English translation of the ICIQ-Cog did not fully meet the needs of this caregiver group. A questionnaire in English that purposefully explores the impact of managing incontinence for unpaid caregivers of a PLWD is needed; the importance of such a tool was highlighted. This need is reflected in the literature where the value of validated patient/carer reported outcome measures to support both dementia-focused clinical care and research has been widely reported [17,18]. We did not test the ICIQ-Cog with paid carers and this work still needs to be done.

In its current form, the ICIQ-Cog does not translate well into English as a validated tool to be used in practice. The ICIQ-Cog was quick to complete, and some question items were described as clear, covering relevant areas. However, the interviews revealed key areas where modifications were needed to improve clarity and to ensure all the necessary response options were available. Simplification of some of the phraseology and English wording, which targets a more formal caring relationship by comparison with the roles undertaken by unpaid carers, is needed. Interview analysis showed heterogeneous data, with participants sometimes having opposing points of view about certain questions or wording. Although outliers are expected due to individual perspectives, ultimately, the aim is that most people should be able to complete the questionnaire without significant categories of differences of opinion.

Whilst the ICIQ-Cog was developed for use by both paid carers and unpaid caregivers, it may be difficult to fully meet the needs of both groups in one overarching questionnaire. The fact that this

questionnaire was predominantly developed within a group of paid carers, means that the issues and wording may not have been explored to saturation among unpaid caregivers. For example, there were some questions that some respondents could not answer due to lack of experience of looking after people without dementia. Again, paid carers may well have the knowledge and experience to answer this question. Furthermore, new themes emerging from the interview analysis centred on the relationship an unpaid caregiver may have with the PLWD. When exploring the impact of intimate continence care on the dyad relationship (caregiver and PLWD), Cole et al. (2022) [19] found that although difficult, being involved in intimate continence care sometimes made the family dyad relationship stronger. The importance of the quality of the family dyad caring relationship has been highlighted previously [20].

Some key question areas were identified as important but missing from the ICIQ-Cog. The additional burden and impact on the caregiver when the person they care for tried to manage themselves was considered important; this has been raised in previous studies [3]. Caregivers described the additional impact of managing inappropriate disposal of soiled clothing or urine and faeces [3]. Other key issues relate to finances and cost (e.g., continence products and washing) and the difficulties around finding and choosing the best continence aids for the person they care for. In a qualitative interview study to establish views from caregivers and the PLWD on continence service provision, product provision was a key issue with most caregivers having to self-purchase some or all the continence aids they used [21]. The lack of advice and support to informal caregivers around choice of appropriate aids has been highlighted [4,21]. The embarrassment of having to collect and dispose of continence products is also an unpaid caregiver issue and not something that would impact a paid carer.

The study has several limitations. Firstly, the linguistic validation process undertaken here was stopped before recruitment had reached the intended target, as it became clear through the rounds of interviews that the ICIQ-Cog did not fully meet the needs of unpaid caregivers. Secondly, the study is limited by the fact that no paid carers were recruited. Further investigation of its appropriateness for paid carers is warranted. Thirdly, the sample recruited could be described as 'super competent' participants [22]. Several described their interest in the English language, linguistics and learning other languages as motivation to take part. They had an understanding of words and phraseology which may not have been representative of the wider unpaid caregiver population. Finally, although both female and male caregivers were included, they were predominantly female, and all participants described themselves as White British, Irish, or European. There was no representation from ethnic minority groups.

## **5. Conclusion**

This linguistic validation of the ICIQ-Cog questionnaire identified that it is not appropriate for use among unpaid caregivers. A questionnaire to assess the impact of managing incontinence designed purposefully for unpaid caregivers of a PLWD is needed to be able to evaluate the quality of care and to measure the health benefits of assistive technology or new interventions for this carer group. Further work is needed to finalise the English translation for paid carers.

### **Declaration of competing interest**

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Dr Miriam Avery reports financial support was provided by National Institute for Health and Care Research. Professor Cathy Murphy reports financial support was provided by National Institute for Health and Care Research. Professor Mandy Fader reports financial support was provided by National Institute for Health and Care Research. If there are other authors, they declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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## Appendix A. Supplementary data

Supplementary material related to this article can be found online at <https://doi.org/10.1016/j.cont.2024.101739>.

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