

Validating the EQ-HWB-9 in long-term care recipients and carers: a qualitative study from Slovenia

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Abstract

Background The EQ Health and Wellbeing 9 (EQ-HWB-9) is the short form of an experimental generic measure developed to extend preference-based measurement beyond health-related quality of life, for use in economic evaluation across health care, social care, long-term care and public health. Evidence on its content validity among long-term care recipients with complex needs and carers remains limited. This study examined the content validity of the Slovenian EQ-HWB-9 among long-term care recipients with complex needs and carers and explored preferences for selected modifications between the original ('experimental' v1.1, 2022) and modified ('experimental modified' v1.2, 2024) versions.

Methods One-to-one cognitive interviews using verbal probing were conducted in Central Slovenia from June to August 2025 with long-term care recipients and carers acting as proxies. Participants reviewed the Slovenian modified EQ-HWB-9 (self-complete [care recipients] or proxy 1 version [carers]) and were probed on comprehensibility, relevance, and comprehensiveness. Selected items and questionnaire design features were compared between the original and modified versions, including control and mobility wording, response scale labels, item order, and item stem format.

Results The final sample comprised 27 participants (14 care recipients and 13 carers), including 11 dyads and five individual participants. The EQ-HWB-9 was considered relevant, acceptable in length and sufficiently comprehensive. Activities, mobility, exhaustion, loneliness, sad or depressed, and pain items were generally well understood, while concentrating or thinking clearly, anxiety, and control were more difficult to interpret, particularly for care recipients. Participants preferred placing activities before mobility, while no clear overall preferences emerged for control or mobility wording. Preferences for response scale labels and item stem format were mixed.

Conclusions The Slovenian modified EQ-HWB-9 was generally considered relevant and acceptable by long-term care recipients with complex needs and carers. Several items may require clearer wording to improve comprehension among care recipients. Findings on the proposed modifications were mixed, with the clearest support for placing activities before mobility. Some difficulties may also reflect the demands of cognitive interviewing in populations with complex long-term care needs. The findings support further refinement of the EQ-HWB-9.

Keywords EQ-HWB-9 · Content validity · Long-term care · Slovenia · Modifications · Proxy

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Background

The EQ Health and Wellbeing (EQ-HWB) is a generic, experimental measurement instrument from the Euro-Qol Group to capture outcomes relevant across health care, social care, long-term care and public health. It was developed to extend preference-based measurement beyond health-related quality of life, so that quality-adjusted life-years can be estimated on a common basis across these sectors [1]. Its content was derived from a review of qualitative evidence on the domains of quality of life that patients, social care users and informal carers identify as important [2]. The instrument is available as a long form profile measure and a 9-item short form (EQ-HWB-9) [1]. To support its use across different settings and populations, the EQ-HWB has recently been translated from English into several other languages. Several qualitative studies have examined the content validity and performance of the EQ-HWB or EQ-HWB-9 across multiple countries. These studies have included patients and social care recipients with long-term conditions [3–5], as well as informal carers and parental carers of children facing adverse life events [4, 6]. More recently, qualitative work has begun to examine the EQ-HWB-9 specifically when completed by carers as proxies for older people and people living with dementia, including how proxies interpret the recall period and the response options [7, 8].

Since publication, several modifications have been proposed to improve the EQ-HWB-9, including changes to item wording, response options, item order and layout and instructions (see Additional file 1). As the EQ-HWB-9 remains an experimental instrument, empirical evidence on how such refinements perform across populations, languages and contexts is needed to inform decisions about the final version of the instrument. However, qualitative evidence remains limited with respect to long-term care recipients with complex care needs and carers often acting as proxies. Previous qualitative studies have examined the EQ-HWB among informal carers completing the instrument for themselves [4], family members and care staff completing the proxy-person (Proxy 2) version for residents in aged care [9], and older adults in residential care completing it as self-report [10]. Evidence on the modified EQ-HWB-9 remains limited in long-term care populations with complex care needs, and particularly scarce for family carers completing the Proxy 1 (proxy-proxy) version.

These considerations are particularly relevant in the context of population ageing. As populations age and life expectancy increases, long-term care has become increasingly important in supporting older people with functional limitations and complex care needs [11, 12]. In Slovenia, as in many European countries, long-term care relies heavily on care provided by family members or close relatives [13, 14]. Long-term care recipients with complex needs may be unable to complete self-reported outcome measures because of cognitive, physical or health-related limitations. Proxy reporting may therefore be required in some cases, most often by carers, who are involved in the care recipient's daily life. Given the intended use of the EQ-HWB-9 across social and long-term care contexts, content validity should be examined from both self-complete and proxy perspectives.

Content validity concerns whether an instrument adequately reflects the construct it aims to measure in a given population and context of use [15]. Qualitative methods examining respondents' understanding and response processes are particularly suited to assessing comprehensibility, relevance and comprehensiveness, and to establishing whether proposed modifications work as intended, especially when instruments are translated and applied in older populations with complex care needs [16–19].

In the context of long-term care recipients and carers, wellbeing is shaped not only by health status, but also by functional limitations, autonomy, emotional and social experiences, as well as reliance on care and support. Accordingly, these factors may influence how items are interpreted, whether they are perceived as relevant, and whether important aspects of quality of life are considered missing, corresponding to the COSMIN dimensions of comprehensibility, relevance and comprehensiveness [15].

Against this background, the aim of this study is to qualitatively examine the content validity of the Slovenian modified EQ-HWB-9, from both self-complete and proxy perspectives, among long-term care recipients with complex care needs (hereafter referred to as care recipients or CRs) and carers completing the Proxy 1 version (proxy-proxy perspective), and to explore the preferences for selected modifications between the original and

modified versions of the instrument. Under Slovenian law [20], long-term care refers to assistance needed for at least three months or permanently due to illness, age-related frailty, injury, disability, or loss of intellectual abilities. In this study, complex care needs were operationalised as either eligibility for care by a family-member carer¹, or, where such formal eligibility was absent, a need for at least four hours of care and support per day. All carers were family carers rather than professional care workers; those with and without formal family-member carer status are referred to collectively as carers (CAs) throughout the manuscript.

Methods

Study design and data collection process

Data were collected through one-to-one, semi-structured interviews conducted in person in the Central Slovenia region from June to August 2025. All interviews took place in participants' homes and followed a standardised topic guide developed by EuroQol, building on COSMIN recommendations and using verbal probing to assess the comprehensibility, relevance and comprehensiveness of the modified EQ-HWB-9. All interviews were conducted by K. Z., MSc, a qualitative researcher with formal training and experience in interviewing people with disabilities, mental health conditions, and long-term care needs. She had no prior relationship with the participants and had not been involved in the development of the EQ-HWB-9. Interview conduct and emerging issues were regularly discussed within the research team to support high data quality.

At the start of each interview, participants were informed about the role of the researcher in the research team, study purpose, audio recording, and their right to skip questions or terminate the interview at any time. Written informed consent was obtained before participation. Interviews began with a brief introductory discussion on participants' understanding of health and wellbeing and the role of health or caregiving in their daily lives. Participants were presented with the modified EQ-HWB-9 in a paper-based format but were not asked to complete it. Care recipients reviewed the self-complete version, while carers reviewed the proxy 1 version and answered based on their own assessment of the care recipient's health and wellbeing. When both members participated, interviews were conducted consecutively on the same day. Only the interviewer and the participant were present during the interviews.

Participants discussed the questionnaire using verbal probing and were asked to explain how they understood each item and response options. For selected items and questionnaire design features, participants were asked to compare the original and modified versions and to explain which they preferred and why. Interviews lasted an average of 47 min, ranging from 29 to 83 min. Interviews were audio-recorded with consent and transcribed verbatim. Transcripts were reviewed for accuracy against the audio recordings prior to coding. All interviews were conducted in Slovenian. Quotations presented in the manuscript were translated into English for reporting purposes. Participants received a EUR 40 voucher for their time.

Reporting was guided by the Consolidated Criteria for Reporting Qualitative Research (COREQ).

Instruments

In this study, both the original ('experimental' v1.1, 2022) and a modified ('experimental modified' v1.2, 2024) versions of the EQ-HWB-9 were used. The tested modifications included changes to item wording (*control* and *mobility*), response scale labels (*some* vs. *moderate*), item order (*activities* vs. *mobility*), and item stem structure (Additional file 1).

¹ Under the Slovenian Long-Term Care Act (LTC Act-1), eligibility for care by a family-member carer is limited to persons assessed in the two highest long-term care categories, the fourth or fifth category. The family-member carer must co-reside with the care recipient and provide daily care and is entitled to compensation for loss of income. Family-member carers may also remain in half-time employment, with proportionate compensation.

The modified EQ-HWB-9 was used as the primary instrument, while selected items and questionnaire design features were examined in comparison with the original version to explore the impact of proposed refinements. As no Slovenian version of the EQ-HWB-9 was available at the time of the study, the entire long form of the instrument was translated following the EuroQol Version Management Committee translation and cognitive debriefing guidelines². The translation was undertaken by members of the research team who were also members of the EuroQol Group, under the supervision of the EuroQol Version Management Committee (VMC).

Selected additional items from the EQ-HWB long form and an experimental visual analogue scale were also tested. Findings related to these components are outside the scope of the present manuscript.

In addition to the EQ-HWB-9 (self-complete and proxy 1 versions), a short questionnaire collected demographic, health and caregiving characteristics, reported in Table 1.

Table 1 Demographic, health and care-related characteristics of care recipients, CR ($N=14$) and carers, CA ($N=13$)

	Category	CR ^a	CA ^b
Gender	Male	6 (42.9)	4 (30.8)
	Female	8 (57.1)	9 (69.2)
Age (years)	Mean (range)	82.9 (62–94)	55.3 (44–68)
	Median	86.5	54.0
Education	Primary education or less	1 (7.1)	1 (7.7)
	Lower secondary / vocational	0 (0.0)	2 (15.4)
	Upper secondary – vocational/technical	6 (42.9)	3 (23.1)
	Upper secondary – general	1 (7.1)	3 (23.1)
	Tertiary	6 (42.9)	4 (30.8)
Employment status or caregiving status	Retired	9 (64.3)	-
	Disability retired	4 (28.6)	-
	Homemaker	1 (7.1)	2 (15.4)
	Family-member carer, full-time	-	10 (76.9)
	Family-member carer with half-time employment outside the caregiving role	-	1 (7.7)
Marital status	Married	8 (57.1)	-
	Widowed	4 (28.6)	-
	Divorced / separated	2 (14.3)	-
Relationship to care recipient	Adult child, caring for a parent	-	9 (69.2)
	Spouse/partner	-	2 (15.4)
	Son-in-law/daughter-in-law	-	1 (7.7)
	Other relationship	-	1 (7.7)
Duration of caregiving by carers	Less than 1 year	-	1 (7.7)
	1–2 years	-	3 (23.1)
	3–5 years	-	4 (30.8)
	6–10 years	-	1 (7.7)
Hours of provided care by carers per week	More than 10 years	-	4 (30.8)
	Mean (range)	-	72.2 (20–168)
	Number of chronic conditions ¹	4.7 (1–8)	0.6 (0–3)
	Mean (range)		

¹ Among CRs, the most common chronic conditions were musculoskeletal diseases (8 CRs); cardiovascular diseases (7 CRs); incontinence (7 CRs); hearing impairments (6 CRs); respiratory diseases (5 CRs)

^a CR ... care recipient

^b CA ... carer

² EuroQol Research Foundation. EQ-HWB Translation Guidelines. 16 February 2022. Not publicly available.

Participants and recruitment

Participants were recruited with the support of social workers at the long-term care entry point in Ljubljana, which serves as the point of access for information, application and assessment for long-term care. Care recipients and carers were required to have lived in Slovenia for at least 10 years, be fluent in Slovenian, provide or receive care daily, and have sufficient cognitive ability to participate in an interview. Care recipients were aged ≥ 60 years and carers ≥ 18 years old.

Participants were initially approached by telephone by social workers, who briefly informed them about the study and asked whether they were willing to be contacted by the research team. For participants with formal long-term care eligibility, the level of care needs had been assessed using the adapted German assessment instrument [21, 22] as part of the Slovenian long-term care assessment process.

Purposive sampling aimed to ensure heterogeneity in age, gender, and education. All nine items were discussed across the full sample. Comprehensibility was assessed for each item, relevance only among participants who demonstrated adequate comprehension, and comprehensiveness for the instrument as a whole. The sample exceeded the COSMIN threshold of seven participants per item for a “very good” rating of sample size in qualitative content validity studies [23].

Data analysis

Interview transcripts were analysed using framework analysis [24], focusing on comprehensibility, relevance, and comprehensiveness. Participants’ interpretations were compared with the intended meanings defined by the EuroQol development team to assess participants’ understanding of the items and the reasoning underlying their responses. Three researchers coded the transcripts using structured Excel spreadsheets. They all independently coded the first five transcripts, discussed discrepancies and refined the coding framework. The remaining transcripts were divided among the coders, with regular consensus meetings, after which the first author reviewed all coding for consistency. Difficulties, which reflected the extent to which items were understood as intended (comprehensibility), were classified into three types of interpretation. *Wrong interpretation* referred to cases where respondents clearly misunderstood the intended meaning of the item, interpreted key wording incorrectly, or explicitly stated that they did not understand the question. *Narrow interpretation* referred to responses focusing on only one aspect of the intended construct while overlooking broader elements captured by the item. *Unclear interpretation* was used when respondents appeared to discuss potentially relevant concepts, but their explanations remained difficult to interpret or insufficiently clear to determine whether the intended meaning had been fully understood.

Results

Sample characteristics

The final sample comprised 27 participants: 14 care recipients and 13 carers. Dyadic participation was preferred, but individual participation was accepted when recruitment of both members was not feasible. The sample included 11 care recipient–carer dyads and five individual participants (3 CRs and 2 CAs). One additional interview was conducted with a care recipient but excluded from analysis because they were younger than 60 years. Their carer met the separate eligibility criteria for carers, and their Proxy 1 interview was retained in the analysis, with the carer counted among the five individual participants. In the remaining individual cases, only one member of the dyad was willing to participate.

Demographic and care-related characteristics of care recipients and carers are presented in Table 1.

Table 2 Comprehensibility and relevance of EQ-HWB-9 items (Total: $N=27$; CR: $N=14$; CA: $N=13$)

Item	Comprehensibility – Yes	Comprehensibility ^a – No (CR / CA ^c)	Relevance ^b – Yes	Relevance ^b – No (CR / CA)
Activities	25	2 (2 / 0): 1x (CR) unclear 1x (CR) narrow interpretation	25	0 (0 / 0)
Mobility	25	2 (1 / 1) 1x (CR) unclear 1x (CA) wrong interpretation	23	2 (0 / 2)
Exhaustion	23	4 (3 / 1) 2x (CR, CA) narrow interpretation 1x (CR) unclear 1x (CR) wrong interpretation	23	0 (0 / 0)
Loneliness	25	2 (1 / 1) 2x (CR, CA) unclear	22	3 (3 / 0)
Concentrating or thinking clearly	16	11 (9 / 2) 2x (2xCR) narrow interpretation 1x (CR) unclear 8x (6xCR, 2xCA) wrong interpretation	16	0 (0 / 0)
Anxious	19	8 (5 / 3) 3x (1xCR, 2xCA) unclear 5x (4xCR, 1xCA) wrong interpretation	16	3 (2 / 1)
Sad or depressed	26	1 (1 / 0) 1x (CR) unclear	24	2 (2 / 0)
Control	15	12 (8 / 4) 4x (CR) unclear 8x (4xCR, 4xCA) wrong interpretation	13	2 (1 / 1)
Pain	24	3 (2 / 1) 3x (2xCR, 1xCA) unclear	24	0 (0 / 0)

^a Wrong interpretation was coded when respondents clearly misunderstood the intended meaning of the item, interpreted key wording incorrectly, or explicitly stated that they did not understand the question. Narrow interpretation was coded when respondents focused on only one aspect of the intended construct, while overlooking broader elements captured by the item. Unclear interpretation was used in cases where respondents attempted to explain the item and discussed potentially relevant concepts, but their responses remained difficult to interpret or insufficiently clear to determine whether the intended meaning had been fully understood

^b Relevance was assessed only among participants who demonstrated adequate comprehension of the item

^c CR ... care recipient; CA ... carer

Content validity of the slovenian EQ-HWB-9

Item-level findings on comprehensibility and relevance are summarised in Table 2. Additional illustrative quotations are provided in Additional file 2.

Comprehensibility of items

Across the nine items, at least some degree of misunderstanding or uncertainty was observed for each item. Adequate comprehension was observed for *activities*, *mobility*, *exhaustion*, *loneliness*, *sad or depressed*, and *pain*. Across these items, most identified comprehension difficulties were coded as unclear interpretations that were difficult to interpret with certainty or narrow interpretations. Wrong interpretations for these items, indicating clear misunderstanding of the intended constructs or wording, were uncommon and identified in only two cases overall: one for *mobility* and one for *exhaustion*.

Lower and more problematic comprehensibility was identified for items *concentrating or thinking clearly*, *anxious*, and *control* with difficulties occurring more frequently among care recipients than carers.

The *control* item showed the highest number of difficulties. Twelve of 27 participants showed wrong (4 CRs, 4 CAs) or unclear (4 CRs, 0 CAs) understanding. Some participants also found the item difficult to answer or elaborate on, even when they considered the wording itself clear. For example, when asked whether she could think of a situation in which someone did not have enough control over their day-to-day life, one carer responded: “*I don’t know.*” When asked whether the question itself was clear, she explained: “*It is clear, but a little difficult. I don’t know what I would say to that. These are really difficult questions*” (female, 58, CA).

For *concentrating or thinking clearly*, 11 participants demonstrated wrong (6 CRs, 2 CAs), narrow (2 CRs) or unclear understanding (1 CR). One care recipient explicitly stated: “*That word is not clear to me. It is the first time I have heard it.*” (male, 67, CR). Misinterpretations, for example, included limiting the concept to severe mental illness, substance misuse, or individual deficits rather than difficulties in thinking clearly. For example, one participant equated concentration problems with mental illness: “*Yes, yes, that is an illness. That can be a mental illness*” and later with alcohol misuse: “*That could also be someone who keeps drinking*” (female, 82, CR). Another linked the concept to low educational attainment: “*someone who is not sufficiently literate, not sufficiently educated*” (male, 67, CR).

For *anxiety*, difficulties were observed among eight participants (5 CRs, 3 CAs). These included lack of familiarity with the concept: “*If you ask me what anxiety is, I couldn’t really say*” (male, 90, CR) and confusion with social withdrawal or being confined indoors rather than anxiety: “*Someone who stays inside all the time and does not go among people*” (female, 82, CR). These were coded as wrong interpretations.

Relevance

Relevance was assessed only among participants who demonstrated comprehension of the item concepts. Among these participants, relevance was high across all items. *Activities*, *exhaustion*, *concentrating or thinking clearly*, and *pain* were rated as relevant by all respondents, while relevance also remained high for *mobility* (23/25), *sad or depressed* (24/26), *control* (13/15), *loneliness* (22/25), and *anxious* (16/19). When items were considered not relevant, this typically reflected participants’ assessment of their current experience rather than rejection of the construct. For example, regarding item *loneliness*: “*For me it’s not important, I don’t feel that way, I like being alone*” (female, 89, CR). This pattern was most evident for *loneliness*, *anxiety*, *sadness or depression*, and *control*, where the absence of a feeling or situation was interpreted as lack of relevance. *Mobility* reflected a distinct pattern: complete immobility was interpreted by some carers as making the item irrelevant, despite representing the most severe mobility limitation and a clear indicator of reduced health and wellbeing: “*Well, here I don’t find it meaningful at all, because he’s completely immobile*” (female, 58, CA).

Comprehensiveness

Comprehensiveness was assessed by asking participants whether any questions or concepts they considered important were missing from the questionnaire. Overall, the questionnaire was perceived as comprehensive, and most respondents, including both care recipients and carers, considered its length acceptable. Nine respondents (seven CRs and two CAs) explicitly stated that they did not perceive any missing questions or concepts. Among six carers who identified potential gaps, suggestions concerned positive affect, social relationships and participation, dignity and intimacy in care, and socio-economic circumstances. One carer suggested including a positively framed item to complement the predominantly problem-focused content: “*Yes, but it would be nice to have a question that is more positively framed. When do you feel good or happy? Then you can see the answer to feeling happy and to feeling sad and see the difference*” (female, 54, CA). Another highlighted dignity and intimacy in situations involving personal care: “*Many older people have strong issues related to their body and intimacy. It is difficult for them to accept that someone else, especially a stranger, is cleaning them. I think this is very important for the topic of this questionnaire*” (female, 53, CA). One carer suggested that the items *anxious* and

Table 3 Preferences for original vs. modified versions (CR = 14; CA = 13)

	Group ^a	Original total (weak) ^b	Modified total (weak) ^b	Unclear / Other	Missing
Control item – original vs. modified wording ¹	CR	7 (1)	4 (1)	3 unclear	0
	CA	7 (3)	5 (0)	1 unclear	0
Difficulty scale – “some” vs. “moderate”	CR	4 (1)	1 (0)	2 unclear	7
	CA	1 (0)	4 (0)	1 other preference ^c	7
Item order – activities first vs. mobility first	CR	3 (0)	7 (5)	3 no preference	1
	CA	2 (0)	10 (0)	1 no preference	0
Item stem format ²	CR	4 (2)	8 (7)	1 no preference; 1 did not understand	0
	CA	6 (0)	5 (0)	1 did not understand; 1 same	0
Mobility wording ³	CR	6 (2)	3 (3)	4 no preference; 1 did not understand	0
	CA	4 (2)	6 (0)	2 no preference; 1 other preference ^d	0

¹ For the *control* item, the two versions differed both in the item wording (“feel you had no control” vs “feel you lacked control”) and in the accompanying bracketed explanation (“had no choice to do things or have things done for you as you liked and when you wanted” vs “had no choice over what you did or how things were done for you”). Participants compared the complete items

² Two item-stem formats were compared. In the modified version, the recall period and task were combined in a single lead-in (“How much difficulty did you have in the last 7 days”), followed by domain items. In the original version, the recall period appeared once as an introductory line (“In the last 7 days:”), and each item repeated the evaluative task (“how much difficulty”)

³ The *mobility* item wording was compared as “getting around inside or outside” (modified version) versus “getting around inside and outside” (original version)

^a CR ... care recipient; CA ... carer

^b Weak preference refers to a stated preference without a clear or elaborated justification

^c One CA did not express a clear preference for either wording (“some difficulty” or “moderate difficulty”) and instead suggested that a numerical response scale (e.g. 1–5) would make it easier to judge and communicate the intensity of difficulties

^d One CA suggested using two different questions: first one measuring getting around inside, and the other getting around outside

sad or depressed may be perceived as overlapping and difficult to distinguish. Additional illustrative quotations regarding comprehensiveness are provided in Additional file 2.

Assessment of proposed EQ-HWB-9 modifications

Participants’ preferences for the tested modifications are summarised in Table 3.

Control item

No clear overall preference emerged between the versions. Although the original wording was selected more often, participants provided more explicit reasoning when supporting the modified wording. Participants noted that it was “*more understandable*” (male, 87, CR) or “*shortened and concise*” (female, 53, CA). Another explained that the original felt overly complex and potentially confusing: “*I would keep the first [modified] one. In the second question [original] it’s too elaborated and there are too many ‘or, or, or’ options and things that can confuse you. It’s better to have the first one because it’s general enough and not so complicated*” (female, 53, CA).

Mobility item

Preferences between “*inside or outside*” and “*inside and outside*” were approximately evenly distributed across care recipients and carers, although care recipients often expressed only weakly articulated preferences. The “*and*” formulation was perceived as supporting a more holistic assessment, whereas the “*or*” formulation was valued for allowing respondents to focus on the context they considered most relevant: “*The second version*

(‘inside and outside’) captures the whole picture, while the first (‘inside or outside’) allows the respondent to choose what to focus on” (female, 58, CA).

Ordering of activities and mobility items

There was a clear preference for *activities* first, expressed by both care recipients and carers, with 7 care recipients and 10 carers favouring this order. Participants who explained their preference referred to the logical sequence of daily functioning, day-to-day activities (e.g. washing, dressing, eating) were described as preceding movement within or outside the home: *“It seems to me that it starts like this. Performing everyday (activities) means the morning, getting up, the basic things, then you go shopping or to work or take care of the household; only then comes mobility. I prefer this one. If I were asked right away about mobility indoors or outdoors, I wouldn’t know what they are trying to say. Here, it places me in my day”* (female, 62, CA).

Difficulty scale: “some” vs. “moderate”

Among the participants who were asked to compare the response labels, preferences were mixed between the original (“*some difficulty*”) and modified (“*moderate difficulty*”) wording. Participants’ explanations, however, provided clearer support for retaining “*moderate difficulty*”. As one participant noted, *“I think ‘moderate difficulties’ is entirely appropriate. There are difficulties, but they do not burden or hinder you too much”* (female, 89, CR). Another added, *“In this case, I would keep ‘moderate’. ‘Mild difficulties’ and ‘some difficulties’ seem very similar to me. ‘Moderate’ feels like something in the middle, perhaps a bit more constant”* (female, 58, CA).

Item stems

Regarding item stems, participants compared a format in which the full stem (“How much difficulty did you have in the last 7 days:”) was presented once before the items (modified), with a format in which only the recall period (“In the last 7 days:”) was presented once and “how much difficulty did you have” was repeated within each item (original, see Table 3). Care recipients more often preferred the modified format, describing it as clearer and more logically connected to the task: *“I prefer the first [modified version] one. ‘In the last seven days’ on its own doesn’t say much: it’s just a calendar”* (female, 90, CR). Another care recipient noted that it felt more intuitive and easier to follow: *“For me, the first version [modified version] is clearer. You first ask how much difficulty I had, and only then about the time”* (male, 94, CR). Carers expressed more mixed views, but more frequently justified a preference for the original structure, particularly when considering very old respondents or those who might lose track of the initial instruction. They suggested that repeating “how much difficulty did you have” within each item could make the questions easier to follow: *“Imagine someone over 80 or 90; they would probably need to read it two or three times to understand. For them, the second [original] version might be better”* (female, 50, CA). Another carer similarly noted: *“Older people might forget the first part of the sentence, so it could be better if ‘how much difficulty did you have’ is repeated each time”* (male, 51, CA).

Discussion

The study examined content validity of the Slovenian EQ-HWB-9 among care recipients and carers and explored participant preferences for selected modifications between the original and modified versions of the instrument. Overall, findings from the cognitive interviews indicate that the EQ-HWB-9 was perceived as appropriate in length, while also revealing areas where item wording required clarification. Items addressing *activities*, *mobility*, *exhaustion*, *loneliness*, *sad or depressed*, and *pain* were interpreted with little difficulty. In contrast, *concentrating or thinking clearly*, *anxiety* and *control* were harder to interpret, particularly for care recipients. Existing

qualitative studies which have examined the experimental EQ-HWB or EQ-HWB-9 in carers, social care users, and older adults in residential care have similarly reported difficulties with wording, response options, and proxy reporting [4, 9, 10].

The sources of comprehension difficulty differed across items. For both *concentrating or thinking clearly* and *anxiety*, wrong interpretations predominated. These included associations with severe or clinical conditions, such as mental illness, alcohol misuse or dementia, or with educational attainment for the former, and with social withdrawal for the latter. Unclear interpretations and unfamiliarity with the terms were also reported for both items. A similar pattern was observed for *control*, with wrong interpretations predominating, followed by unclear interpretations. However, difficulties with this item may have been partly attributable to a translation issue identified during analysis. The Slovenian wording of the bracketed explanation, which provides examples intended to clarify what having control over day-to-day life means, shifted the intended meaning. While the English version referred to decision-making and agency, namely how things were done or decided for the person, the Slovenian wording was closer to how things “turned out” for the person. This may have made the item more ambiguous and less concrete, particularly for respondents with complex long-term care needs.

This pattern aligns with models of survey response processes, which conceptualise answering survey questions as involving sequential stages of comprehension, retrieval, judgement and response mapping [25]. The interpretations described above suggest that some respondents understood the items differently from their intended meaning. Unfamiliar terms or ambiguous wording may require greater cognitive processing to establish what is being asked and how it applies to their own experience. As questions become more demanding to process, respondents may be more likely to misunderstand the intended meaning or to adopt simplified response strategies [26, 27]. At the same time, these findings should be interpreted with some caution. In cognitive interviews, participants are not only asked to answer questionnaire items, but also to explain how they understood the questions and how they arrived at their answers. This task places additional demands on memory, abstraction, and language compared to standard questionnaire completion [28, 29]. Such demands may be especially challenging for older adults and people with complex long-term care needs, who may experience fatigue, difficulties with abstract concepts, or challenges putting their thoughts into words. Recent studies on cognitive interviewing with older adults have shown that difficulty answering probing questions does not necessarily mean that participants did not understand the item. In many cases, they may simply find it difficult to explain or put into words how they arrived at their answer [30, 31]. In other words, difficulty articulating one’s interpretation is not the same as failing to understand a concept. Some responses coded as unclear may therefore reflect the demands of the interview format rather than difficulties understanding the items themselves.

Since comprehension difficulties were more common among care recipients than carers, the use of proxy reporting may offer a practical option in long-term care settings where some respondents find certain items cognitively or linguistically demanding. Although self-report should remain the default and proxy assessments cannot fully substitute for it [9, 32], our findings suggest that they can be both feasible and useful in this population, particularly for the items that care recipients found most difficult to interpret. This is consistent with recent qualitative evidence supporting carer-completed proxy assessment of the EQ-HWB-9 among older people and people living with dementia, while also noting that proxies draw on their own observations and may not always remain within the intended recall period [7, 8].

Relevance was assessed only among participants who demonstrated adequate comprehension of each item. Relevance was generally high; even for *anxiety*, the item most often judged less relevant, 16 of 19 participants who understood the item considered it relevant. Participants identified relatively few potential gaps in content coverage; however, some aspects of quality of life were perceived as insufficiently captured, including social relationships, socio-economic circumstances, and dignity and intimacy in care situations. Consistent with other studies (e.g., 9), it was suggested to include more positively phrased items. The EQ-HWB was developed through a systematic, multi-stage process drawing on qualitative evidence from patients, social care users, and carers to identify domains of health, social care and carer-related quality of life relevant across these settings [1, 2]. Although not designed exclusively for long-term care settings, the instrument was deliberately developed to

capture broader quality of life and wellbeing outcomes across health care, social care and carer populations. For example, dignity may be particularly relevant for this study population as ongoing dependency can reduce choice and control [33]. The EQ-HWB-9 includes a *control* item intended to capture autonomy and choice in everyday life, but since the translation might have altered the intended meaning, this could have contributed to dignity being articulated as a distinct topic. At the same time, dependence on others for intimate bodily care places dignity at particular risk, as reliance on others can affect privacy, bodily integrity, and self-respect [33, 34]. Further cross-national research is needed to better understand how these constructs are interpreted in long-term care contexts before firm conclusions can be drawn.

The findings add to the growing international body of qualitative evidence informing the ongoing refinement of the EQ-HWB-9. As the EQ-HWB-9 remains an experimental instrument, empirical evidence on how such refinements perform across populations, languages, and contexts is essential to inform decisions about its final form. In the Slovenian context, we tested several proposed modifications. Consistent support was observed for starting the questionnaire with *activities* instead of *mobility*, similar to other studies [6, 35]. No clear quantitative preference emerged between “some difficulty” and “moderate difficulty”, as the number of respondents preferring each option was comparable. However, participants provided more compelling reasoning in favour of retaining “moderate difficulty”. For the modification to the *mobility* item, no clear overall preference emerged. Differences between care recipients and carers were most evident in preferences regarding item stem structure. Care recipients more often preferred the modified format with a single lead-in combining the recall period and response task. Carers, in contrast, more often preferred the original format, explaining their choice in terms of what they believed would be easier for very old or vulnerable respondents. Although carers were asked to consider the items from a Proxy 1 perspective, some at this point justified their preferences by speculating about how very old or vulnerable respondents might understand the items. This suggests that carers’ preferences were shaped by assumptions about respondent burden that did not always align with care recipients’ reported experiences. The mixed preferences we observed for the difficulty scale also echo cross-cultural evidence that respondents can struggle to distinguish adjacent response-scale labels, suggesting that the labelling of intermediate categories warrants further refinement [36].

This study is not without limitations. Participants were recruited purposively through the Ljubljana long-term care entry point in the Central Slovenia region. Although the sample included both urban and rural participants, it reflects a single geographical and service context, which may limit the transferability of the findings to other regions. The study deliberately focused on long-term care recipients with complex needs. The findings may therefore not apply to people with milder needs or to routine health care populations. Evidence on the response scale modification, namely “some” versus “moderate” difficulty, should also be interpreted with caution, as this comparison was introduced later in data collection and tested only in a small subsample, with many preferences remaining unclear. A translation issue identified in the bracketed explanation during analysis may have influenced participants’ understanding of the *control* item and limits the interpretation of the findings. Finally, further quantitative research is needed to examine the equivalence of proxy and self-reported responses.

Conclusions

The Slovenian modified EQ-HWB-9 was generally perceived as relevant and acceptable among care recipients and carers. Although some items posed comprehension challenges, particularly among care recipients, the findings suggest that the instrument has potential for use in long-term care settings and offer useful insights for the further refinement and cross-cultural development of the EQ-HWB-9.

Abbreviations

CA Carer

CR Care recipient
EQ-HWB-9 The EQ Health and Wellbeing-9
COSMIN Consensus-based Standards for the Selection of Health Measurement Instruments

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Data availability The qualitative datasets generated and/or analysed during the current study are not publicly available due to participant confidentiality and data protection requirements.

Declarations

Ethics approval and consent to participate The study was approved by the Commission of the Republic of Slovenia for Medical Ethics (20 February 2024; reference no. 0120–50/2024-2711-3). All procedures were conducted in accordance with national ethical standards, and written informed consent was obtained from all participants.

Consent for publication Not applicable. The manuscript contains no directly identifiable individual participant information.

Competing interests F.R. and V.P.R. are members of the EuroQol Group. F.R. is employed by the EuroQol Research Foundation. F.R. serves as co-editor-in-chief at Health and Quality of Life Outcomes and will have no involvement in the editorial or peer review process for this manuscript. The other authors declare no competing interests. The views expressed are those of the authors and do not necessarily reflect the views of the EuroQol Research Foundation.

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