ScienceDirect

Contents lists available at **sciencedirect.com**
Journal homepage: **www.elsevier.com/locate/jval**

Patient-Reported Outcomes

The Psychometric Performance of the EQ Health and Wellbeing in Caregivers of Persons Living With Dementia

Cate Bailey, PhD, Tessa Peasgood, PhD, Bernhard Michalowsky, PhD, Lidia Engel, PhD

ABSTRACT

Objectives: The EQ Health and Wellbeing (EQ-HWB) is a generic instrument recently developed for use in economic evaluations across public health and social care, including impacts on caregivers. Providing informal care to a person living with dementia can significantly affect the health and well-being of carers. However, it is unclear to what extent the EQ-HWB can capture such impacts. We aimed to investigate the psychometric properties of the EQ-HWB compared with other available instruments in caregivers of persons living with dementia.

Methods: An online survey included demographics, informal care-related questions, and quality-of-life measures suitable for caregivers (C-DEMQOL and CarerQol) and the 25-item EQ-HWB. We used the UK pilot value set for the index scores for the EQ-HWB-S (9-item short form). The psychometric properties of the EQ-HWB and EQ-HWB-S were assessed in terms of acceptability (missing data), response distribution, known-groups validity analysis using *t* tests and one-way ANOVAs (Cohen's *d* and Eta squared for effect size), convergent validity (Spearman correlations), and an exploration of dimensionality using exploratory factor analysis.

Results: In known-group validity analysis, the EQ-HWB instruments performed similarly to the C-DEMQOL in terms of effect sizes across a range of variables and slightly better than the CarerQol on some variables. At the item level, 13 of the 25 items could discriminate respondents by caregiving time and 23 of 25 items by caregivers' general self-reported health. Most hypothesized correlations in the convergent validity analysis were found to be above 0.3.

Conclusions: Our results suggest that the EQ-HWB instruments performed well in this population.

Keywords: caregivers, EQ-HWB, persons living with dementia, psychometric performance, validation study.

VALUE HEALTH. 2025; 28(8):1221–1230

Highlights

- The EQ Health and Wellbeing (EQ-HWB) is a new, generic instrument for measuring quality-of-life, suitable for economic analysis across a health, social care, and caregiver sectors. Validating the EQ-HWB in a range of settings is now a priority. Previous studies have investigated the caregivers of children with health conditions and experiencing adversity. The EQ-HWB has yet to be validated in caregivers of people living with dementia.
- To our knowledge, this is the first study to investigate the validity of the EQ-HWB (25-items) and EQ-HWB-S (9-items) in caregivers of people living with dementia. We found that many caregivers had difficulties with exhaustion, anxiety, pain, frustration, and loneliness. Aspects of health and well-being were associated with caregiver general health and time spent caregiving, suggesting avenues for future interventions to support caregivers. Carer impacts appeared to be captured mainly via the psycho-social rather than physical items.
- The EQ-HWB measures performed as well as the caregiver-specific instruments. They included health and well-being dimensions that were not captured by other measures. We recommend the use of the EQ-HWB-S rather than the EQ-HWB for trials in this population to reduce participant burden because its psychometric properties are similar. For the long form, the seeing and hearing items may not be required, except in certain populations (eg, older ages) where these impediments are more common.

Introduction

Caregivers who provide informal care are critical to the quality of life of people living with dementia, but can experience significant health and quality-of-life impacts, such as social isolation, poor physical health, financial distress, and high levels of anxiety and depression.[1] The costs or value of time associated with providing informal care are higher for people with dementia than stroke, mental illness, and multiple sclerosis.[2] Although informal care costs are sometimes considered in economic evaluation, caregivers' health and well-being impacts are rarely included, often because of methodological challenges, such as lack of guidance around appropriate measures.[3-5]

To measure caregiver outcomes, suitable quality-of-life instruments are required. Most of the available caregiver-specific quality-of-life measures are not preference based and cannot be used to calculate quality-adjusted life years (QALYs) (ie, C-DEMQOL[6]). The EQ-5D[7] and SF-6D[8] are often used instead. Although these instruments have been validated extensively in the health sector, they may not capture important aspects of caregiver quality of life, resulting in high ceiling effects in caregivers. Measuring the key factors that predict caregiver quality of life is now required.[9]

The "Extending the QALY Project" was developed through an international collaboration[10] to develop a broad generic measure of quality of life for use in economic evaluation.[11] This measure, the EQ Health and Wellbeing instrument (EQ-HWB), was intended to be applicable across health, social care, and public health sectors and capture the impact of interventions upon both care recipients and caregivers.[11] The EQ-HWB instruments contain additional domains not included in the EQ-5D, such as fatigue, social relationships, and cognition. The EQ-HWB is considered experimental and currently only released for validation purposes.[12] The measure is 25-items long, with a shorter version (EQ-HWB-S) of 9-items.[13] A pilot UK value-set for the EQ-HWB-S is now available,[14] valued from 0 to 1, for use in QALY calculations.[15]

Recent work validating the questionnaire in caregivers focusing on parents of children with health conditions[16] and caregivers of children whose families have experienced adverse life events[17] found that the EQ-HWB-S appeared valid and reliable. In comparison with the EQ-5D in the general Australian population, the EQ-HWB instruments had greater sensitivity for participants with mental health symptoms.[18] In informal caregivers (United States), authors found support for the construct validity of the EQ-HWB instuments.[19] A comparison of the EQ-HWB with the EQ-5D-5L for patient, caregiver, and general public samples in China found good acceptability and construct validity for the EQ-HWB and better known-groups validity when the caregiver sample was included.[20] Across the above studies, the EQ-HWB performed well in regard to item response distribution,[16-18,20] floor/ceiling effects,[19,20] convergent analysis (Spearman correlations),[17-20] exploratory factor analysis,[18,20] known-group validity analysis (*t* tests; one-way ANOVAs),[16,17,19,20] and responsiveness to change.[17]

There are no studies, to date, on validating the EQ-HWB instruments in caregivers of people living with dementia; therefore, it is important to validate the scale in this population. The aim of this study was to examine the psychometric performance of the EQ-HWB and EQ-HWB-S in informal caregivers of persons living with dementia. Specifically, we aimed to investigate response distribution, known groups based on caregiver health, caring time and severity of care recipient's dementia, convergent validity with C-DEMQOL[6] dimensions and CarerQol[21] items, and exploratory factor analysis to investigate the structure of the EQ-HWB in comparison with other caregiver instruments.

Methods

Study Design

Data were sourced from the COCOON project: "incorporating Carer Outcomes in Cost-Effectiveness Analyses of Dementia Interventions," which aimed to develop a preference-based quality-of-life measure for carers of people with dementia. The online survey included the full EQ-HWB (25 items) alongside demographic questions and other carer-related quality-of-life instruments. The survey was not explicitly designed to test the EQ-HWB but is suitable for this purpose. There are no specific sample size recommendations for psychometric validation studies, but 200 cases are potentially suitable for testing the reliability and validity of Patient-Reported Outcome Measures.[22] Samples of over 100 participants are described as "very good" in COnsensus-based Standards for the selection of health Measurment INstruments guidelines for reliability analyses, comparisons with other measurement instruments, and construct validity.[23]

People were eligible to participate in the study if they provided regular, unpaid support to a person living with dementia in Australia and were over the age of 18. Participants were recruited with help from Step Up for Dementia, Dementia Australia, and carer organizations (eg, Carers Victoria) who circulated an advertisement guiding interested participants to an online survey. On completion, participants could enter into a draw to win 1 of 10 $200 gift-cards. Additionally, participants were recruited through PureProfile, a research company with an existing online panel comprising individuals interested in research participation. Participants were reimbursed according to their specific panel agreements. Data were collected May to November 2023.

Materials

Survey data included a range of demographic characteristics of the informal caregivers (caregiver: age, gender, education level, employment status, marital status, household income, and state/country; person living with dementia: gender, living situation, relationship to caregiver, and type of dementia), informal care-related questions (length of caregiving/support in months, time spent caregiving per week, activities supported, income support for caring, as derived from the Resource Utilization in Dementia Questionnaire[24]). Questions were asked about caregivers' chronic health condition (yes/no), general health (poor/fair/good/very good/excellent), and shared care (are there other relatives/friends who significant share in this person's care?).

Sum scores were calculated by summing items for the EQ-HWB (25-items) and the EQ-HWB-S (9-items, included within EQ-HWB). Response options were scored from 1 to 5 for the 5 response levels. EQ-HWB sum scores ranged from 25 to 125. Three positive EQ-HWB items (items 19-21) were reverse scored. We applied preference weights from a pilot UK value set to produce EQ-HWB-S index scores.[14]

Other caregiver quality-of-life instruments included the C-DEMQOL[6] and the CarerQol-7D[21] (scored using the Australian tariff[25]). The 30-item C-DEMQOL was developed to measure quality of life of family caregivers of people living with dementia, with 6 items for each of 5 domains (meeting personal needs, carer well-being, carer-patient relationship, confidence in future, and support). We used simple sum scores for the instrument, with potential range of 30 to 150, such that higher scores indicate better quality of life[26]). The Carer-Qol-7D was developed as a care-related quality-of-life measure for informal caregivers, specifically for economic evaluation, with 7 items plus a happiness visual analog scale. Recall periods were 7 days for the EQ-HWB, 4 weeks for C-DEMQOL, and "at the moment" for the CarerQol-7D. The order of the EQ-HWB, the C-DEMQOL, and the CarerQol were randomized in the survey pack, to eliminate participant fatigue relative to each measure (after the respondents had already completed 35 candidate items for a separate project).

Statistical Analysis

Analyses were performed in STATA 15. Inconsistent and fraudulent respondents were removed, including respondents who completed the survey outside of Australia, as well as bots that were detected. Respondents excluded for low quality included those with inconsistent responses, such as discrepancies between their postal code and nominated state, an inconsistent answer to the repeat question about their relationship with the care recipient, and inconsistent information regarding the care recipient's age and other variables (eg, a grandfather listed as 20 years old). Response distributions were calculated using frequency and percentages across responses. Responses were not forced; therefore, acceptability could be measured by missing data.

We assessed known-group validity of the EQ-HWB sum score and EQ-HWB-S index score across variables hypothesized to be different for carers. We hypothesized that caregivers would have lower quality of life (higher EQ-HWB sum score/lower EQ-HWB-S index score) if (1) the caregiver had a chronic health condition (yes/no); (2) caregivers reported lower general health (5-item general health scale recoded to 2 groups (poor health [poor/

Table 1. Baseline characteristics of caregivers and persons living with dementia.

	Full sample # (%)	Present (missing)
Caregivers		
Gender, *n* (%)		201 (1)
Female	127 (63.18)	
Male	74 (36.82)	
Age, mean (SD, range)	60.35 (13.70, 18-90)	199 (3)
Education, *n* (%)		201 (1)
Year 10 or less	15 (7.46)	
Year 11/12	26 (12.94)	
Cert III/IV or diploma	60 (29.85)	
University degree	100 (49.75)	
Employment, *n* (%)		202 (0)
Employed	98 (48.51)	
Unemployed	7 (3.47)	
Student	3 (1.49)	
Retired	79 (39.11)	
Housewife/husband	7 (3.47)	
Other	8 (3.96)	
Marital status, *n* (%)		200 (2)
Single	32 (16.00)	
Married/de Facto	142 (71.00)	
Separated/divorced	19 (9.50)	
Widowed	7 (3.50)	
Household size, *n* (%)		202 (0)
1 person	32 (15.84)	
2 people	98 (48.51)	
3 people	28 (13.86)	
4 people	28 (13.86)	
5+ people	15 (7.44)	
English is first language, *n* (%)		200 (2)
Yes	185 (92.50)	
No	15 (7.50)	
Hours per day spent in caregiving, mean (SD, range)	8.14 (6.69, 0-18)	202 (0)
Other chronic health condition, *n* (%)		202 (0)
Yes	169 (83.66)	
No	33 (16.34)	
Household with children, *n* (%)		199 (3)
Yes	35 (17.59)	
No	164 (82.41)	
General health, *n* (%)		
Excellent	13 (6.47)	
Very good	57 (28.36)	
Good	72 (35.82)	
Fair	49 (24.38)	
Poor	10 (4.98)	
Relationship to person living with dementia, *n* (%)		199 (3)
My partner	64 (32.16)	
My father or mother	82 (41.21)	
My son or daughter	2 (1.01)	
My grandparent	10 (5.03)	
Another family member	20 (10.05)	
My neighbor	1 (0.50)	
My friend	11 (5.53)	
Other (please specify):	9 (4.52)	
Person living with dementia		
Gender, *n* (%)		200 (2)
Female	90 (45.00)	
Male	109 (54.50)	
Other	1 (0.50)	
Age, mean (SD, range)	78.57 (10.61, 43-100)	198 (4)
Lives with carer, *n* (%)		200 (2)
Yes	110 (55.00)	
No	90 (45.00)	
Diagnosis, *n* (%)		200 (2)
Alzheimer's Disease	91 (45.50)	
Vascular dementia	28 (14.00)	
Lewy Body Disease	10 (5.00)	
Frontotemporal dementia	13 (6.50)	
Don't know	39 (19.50)	
Other (please specify)	19 (9.50)	
Severity, *n* (%)		200 (2)
Mild or early-dementia	67 (33.50)	
Moderate or middle-stage dementia	101 (50.50)	
Severe or late-stage dementia	32 (16.00)	
Other chronic health condition, *n* (%)		200 (2)
Yes	163 (80.69)	
No	39 (19.31)	
Living situation, *n* (%)		200 (2)
Living alone	37 (18.50)	
Living with family	107 (53.50)	
Living in a care home	40 (20.00)	
Other (please specify)	16 (8.00)	

Continued in the next column

fair], good health [good, very good, and excellent], 3 groups: poor health [poor/fair], moderate health [good], or high general health [very good, excellent])[27]; (3) carers undertook caring for longer hours (caregiver time was coded to 2 equal groups [5 hours or less/5 or more hours per day] or 3 equal groups [less than 2.8, 2.8-11, and 11-18 hours per day, with hours capped at 18 hours per day, as commonly agreed for the Resource Utilization in Dementia Questionnaire, which assumes a minimum of 6 hours sleep]); and/or or (4) the care recipient had more severe dementia (categorized as mild or early, moderate or middle-stage, and severe or late-stage dementia).[28,29] We further hypothesized that sole caregivers would have lower quality of life than cases in which there was more than 1 caregiver, on the basis of reduced work due to shared care. We used Student *t* tests when comparing 2 groups with Cohen's *d* for effect size, and one-way ANOVAs when comparing 3 groups with Eta squared for effect size.

We compared known groups for each of the 25 EQ-HWB items by 2 variables: caregiver time (5 hours or less compared with more than 5 hours per day, with the time split chosen pragmatically as a midpoint) and caregiver self-reported health (good, very good, or excellent compared with fair or poor) using *t* tests, to understand performance at the item level. We conducted item-level analysis to understand how much each item might contribute to the instrument in terms of measurement and valuation (for example, an item might be given very low weight in some value sets and therefore the instrument overall at utility-score level might not discriminate between known groups).

Generalized linear regression models were conducted to investigate whether the differences observed by caregiver time (up to 5 hours/more than 5 hours; model 1) and general health (good to excellent health/fair to poor health; model 2) held when we controlled for caregiver gender and age. This analysis was included to determine whether the known-groups results were being affected by differences in the age/gender profile of the subgroups. To address the skewed distribution of utility values we used generalized linear regression models with gamma distribution and log link selected.[18]

To investigate convergent validity, we compared raw scores from the EQ-HWB (25 items) with the 5 C-DEMQOL dimensions and the 8 CarerQol items (including the visual analog scale [VAS]), using Spearman correlations for ordinal data. We made a priori hypotheses regarding which items we expected to be at least moderately correlated (above.3), reaching consensus on expected correlations between 3 researchers (C.B., T.P., and L.E.). Correlation strength was defined as per Cohen 1992,[30] in which a correlation of 0.1 to 0.29 is considered weak, 0.3 to 0.49 moderate, and ≥0.5 strong.

Exploratory factor analysis was conducted to investigate the structure of the EQ-HWB and the extent to which the instrument's items overlapped with other caregiver instruments (C-DEMQOL and CarerQol). We assessed the suitability of the data for factor analysis using the Kaiser-Meyer-Olkin measure of sampling adequacy and Bartlett's test of sphericity. We initially performed the analysis without rotation using the principal axis factor method of extracting factors to investigate the data. To determine the number of factors, we investigated the Kaiser criterion (with Eigen values > 1) and a visual scree plot. We used the Promax method for oblique rotation, allowing for correlated factors to aid in interpreting the extracted factors.

To investigate possible differences between the samples collected through our first community recruitment strategy and the PureProfile online sample, we added a group variable to the 2 regression analyses.

Results

Sample Description

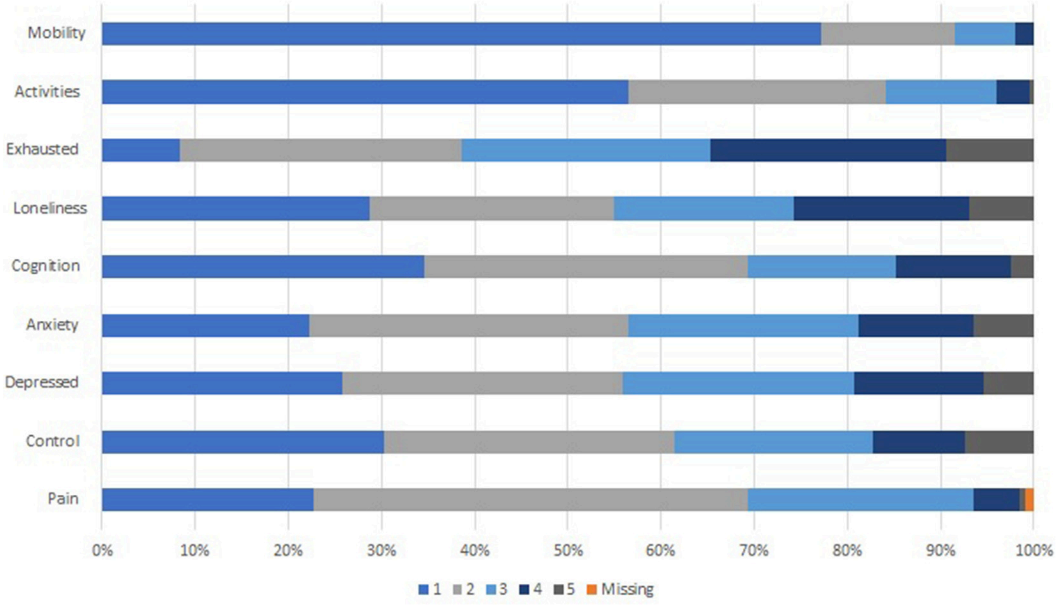
Analyses included 202 caregivers of people living with dementia, of which 127 (63.2%) were women. Caregivers' mean age was 60.4 (SD = 13.7). After exclusions, 100 participants were recruited from dementia and carers organizations and 102 participants from PureProfile. Of the 393 excluded cases, 29 were flagged as low quality based on inconsistencies in responses, 304 were detected as bots, 17 duplicates, 41 completed the survey outside of Australia based on their IP address, and 2 people did not complete the survey.

Baseline characteristics are presented in Table 1. Almost half of the participants had a university degree, nearly half were employed, 71% were married, 49% lived in a 2-person household, and 93% spoke English as a first language. Of people living with dementia, 54% lived with their caregiver, 20% lived in a care home and 18% lived alone, and 80% had another chronic health condition.

Response Distribution and Feasibility

Figure 1 shows the response distribution of the 9 EQ-HWB-S items for caregivers (the EQ-HWB-S is presented here to be comparable to figures in previous studies) and Appendix Figure 1 in Supplemental Materials found at https://doi.org/10.1016/j.jval.2025.04.2168 for all items. Results for the 25 EQ-HWB items with means and standard deviations are presented in Table 2. There were fewer problems in the "physical" items: seeing, hearing, getting around, daily activities, and self-care, as well as item 13,

Figure 1. Distribution of EQ-HWB-S item responses (legend numbers match to the responses displayed in Table 2). Higher scores indicate lower quality-of-life.



EQ-HWB-S indicates EQ Health and Wellbeing Short version.

Table 2. Number and percentage of EQ-HWB item responses, with means and standard deviations (SD).

#	EQ-HWB item name	# (%)	# (%)	# (%)	# (%)	# (%)	# (%)	Mean	SD
		No difficulty	Slight difficulty	Some difficulty	A lot of difficulty	Unable	Missing		
1	Seeing	102 (50.5)	53 (26.2)	40 (19.8)	6 (3.0)	1 (0.5)	0 (0)	1.77	0.90
2	Hearing	136 (67.3)	43 (21.3)	18 (8.9)	5 (2.5)	0 (0)	0 (0)	1.47	0.76
3	Mobility*	156 (77.2)	29 (14.1)	13 (6.4)	4 (2.0)	0 (0)	0 (0)	1.33	0.69
4	Activities*	114 (56.4)	56 (27.7)	24 (11.9)	7 (3.5)	1 (0.5)	0 (0)	1.62	0.83
5	Personal care	164 (81.2)	25 (12.4)	8 (4.0)	5 (2.5)	0 (0)	0 (0)	1.28	0.66
		None of the time	Only occasionally	Sometimes	Often	Most/all of the time	Missing		
6	Sleep problems	31 (15.4)	63 (31.2)	53 (26.2)	28 (13.9)	27 (13.4)	0 (0)	2.79	1.25
7	Exhaustion*	17 (8.4)	61 (30.2)	54 (26.7)	51 (25.3)	19 (9.4)	0 (0)	2.97	1.13
8	Loneliness*	58 (28.7)	53 (30.2)	39 (19.3)	38 (18.8)	14 (6.9)	0 (0)	2.49	1.27
9	Felt unsupported	59 (29.2)	61 (30.2)	47 (23.3)	26 (12.9)	9 (4.5)	0 (0)	2.33	1.16
10	Memory	80 (39.6)	64 (31.7)	34 (16.8)	20 (9.9)	3 (1.5)	0 (0)	2.02	1.05
11	Cognition*	70 (34.7)	70 (34.7)	32 (15.8)	25 (12.4)	5 (2.5)	0 (0)	2.13	1.10
12	Anxiety*	45 (22.3)	69 (34.2)	50 (24.8)	25 (12.4)	13 (6.4)	0 (0)	2.47	1.16
13	Felt unsafe	146 (72.3)	35 (17.3)	14 (6.9)	6 (3.0)	1 (0.5)	0 (0)	1.40	0.75
14	Felt frustrated	35 (17.3)	68 (33.7)	54 (26.7)	33 (16.3)	10 (5.0)	0 (0)	2.58	1.11
15	Sadness/depression*	52 (25.7)	61 (30.2)	50 (24.8)	28 (13.9)	11 (5.5)	0 (0)	2.43	1.17
16	Nothing to look forward to	82 (40.6)	49 (24.3)	44 (21.8)	18 (8.9)	9 (4.5)	0 (0)	2.12	1.17
17	Control*	61 (30.2)	63 (31.2)	43 (21.3)	20 (9.9)	15 (7.4)	0 (0)	2.33	1.22
18	Difficulty coping	95 (47.0)	49 (24.3)	39 (19.3)	11 (5.5)	8 (4.0)	0 (0)	1.95	1.11
		Most/all of the time	Often	Sometimes	Only occasionally	None of the time			
19	Felt accepted	64 (31.7)	53 (26.2)	48 (23.8)	31 (15.4)	6 (3.0)	0 (0)	2.32	1.16
20	Felt good about self	44 (21.8)	45 (22.3)	64 (31.7)	42 (20.8)	7 (3.5)	0 (0)	2.61	1.14
21	Could do things as wanted	36 (17.8)	49 (24.3)	49 (24.3)	58 (28.7)	9 (4.5)	1 (.05)	2.78	1.18
		None of the time	Only occasionally	Sometimes	Often	Most/all of the time	Missing		
22	Pain frequency	40 (19.8)	57 (28.2)	41 (20.3)	28 (13.9)	13 (6.4)	23 (11.4)	2.54	1.21
		No physical pain	Mild	Moderate	Severe	Very severe	Missing		
23	Pain severity*	46 (22.8)	94 (46.5)	49 (24.3)	10 (5.0)	1 (0.5)	2 (1.0)	2.13	0.84
		None of the time	Only occasionally	Sometimes	Often	Most/all of the time	Missing		
24	Discomfort frequency	89 (44.1)	62 (30.7)	30 (14.9)	16 (7.9)	3 (1.5)	2 (1.0)	1.91	1.02
		No physical discomfort	Mild	Moderate	Severe	Very severe	Missing		
25	Discomfort severity	57 (28.2)	94 (46.5)	44 (21.8)	5 (2.5)	1 (0.5)	1 (0.5)	2.00	0.81

EQ-HWB indicates EQ Health and Wellbeing instrument; EQ-HWB-S, EQ Health and Wellbeing Short version.
*EQ-HWB-S items.

"feel unsafe." There were more problems for exhaustion (often/most/all of the time = 35%) and sleep problems (often/most/all of the time = 27%). Pain and discomfort items had a good spread over the response options; pain frequency had the highest amount in the most severe category (6.4%).

There were no missing data in items 1 to 20, suggesting good acceptability. There were 23 missing responses in item 22, possibly due to how the item was laid out in this particular survey, in which the item may have been overlooked by participants (see Appendix Figure 2 in Supplemental Materials found at https://doi.org/10.1016/j.jval.2025.04.2168). There were 2 missing data points in item 23 and 24, and 1 in item 25.

Known-Group Validity

Known-group validity for EQ-HWB-S index score, EQ-HWB sum score, C-DEMQOL sum score, and CarerQol Australian index score

The EQ-HWB level sum scores and EQ-HWB-S index scores significantly differed in the hypothesized directions across

Table 3. Known-group validity analysis effect sizes.

Cohen's *d*	EQ-HWB-S index-score	EQ-HWB sum-score	C-DEMQOL sum-score	CarerQol-7D Index-AU
Caregiver, chronic condition	0.77	0.82	0.54	0.59
Caregiver Health (poor vs good)	1.10	1.01	0.81	1.05
Carer-time hours per day (>5 vs 5+)	0.40	0.45	0.59	0.38
Eta-squared				
Carer-time hours per day (>2.8, 2.8-11, 11-18)	0.04	0.06	0.09	0.04
Caregiver Health (poor vs fair vs good)	0.04	0.03	0.11	0.01
Shared caregiving	0.04	0.05	0.11	0.04
Dementia Severity	0.27	0.27	0.17	0.24
Mean (standard deviation)	.722 (.202)	96.9 (15.9)	94.6 (21.4)	67.0 (16.7)

Lightest blue indicates small effect-size, medium blue indicated moderate effect-size and darker blue large effect-size
Cohen's *d:* 0.2-0.49= small, 0.5-0.79 = moderate, above 0.8 = large
Eta squared: 0.01 = small, 0.06 = moderate, 0.14 = large

caregiver chronic health condition, carer time, and caregiver general health. In analyses in which we compared across 3 groups, time spent in caregiving, dementia severity, number of caregivers, and caregivers' general health were all statistically significantly different in hypothesized directions. Full test results are presented in Appendix Table 1 in Supplemental Materials found at https://doi.org/10.1016/j.jval.2025.04.2168; a summary of color-coded effect sizes is shown in Table 3. When comparing effect sizes between the 4 instruments, the EQ-HWB instruments performed better than the C-DEMQOL on whether the caregiver had a chronic health condition, whereas the C-DEMQOL performed better for many of the carer-related questions. The CarerQol-7D had generally lower effect sizes. Means and standard deviations for the EQ-HWB, EQ-HWB-S index, C-DEMQOL sum score, and CarerQol-7D index are displayed in Table 3.

Known-group validity by EQ-HWB items

We compared 2 known groups (caregiver time and caregiver general health) across all 25-items, shown in full in Appendix Table 2 in Supplemental Materials found at https://doi.org/10.1016/j.jval.2025.04.2168 and in summary in Table 4 in which items not significantly different between groups are highlighted. For time spent in caregiving, there were no significant differences on the 5 physical items (seeing, hearing, activities, mobility, and self-care) and on memory, cognition, felt unsafe, and the 4 pain/discomfort items (items 22-25). Seeing and hearing also failed to show significant differences between groups on caregiver general health.

Known-group validity controlling for demographic covariates

For each model, we ran without (univariate) and with (multivariate) covariates for caregivers' age and gender in which the dependent variable was the EQ-HWB-S index score (Table 5). In the multivariate model 1 (time spent in caregiving, 2 groups), neither gender nor age were significant in the model, and caregiver time remained significant (coefficient = −0.398 [SE = 0.147, *P* = .007]), with only a small change in the coefficient from −.398 to −.379. For caregiver general health, gender was significant in the model (coefficient = −0.0377 [SE.148, *P* = .011]), and caregiver general health remained significant (coefficient = −1.007 [SE = 0.133, *P* < .001]) at the multivariate level. When we added a variable to the models to check for differences between the 2 recruitment samples, this was not significant in either model.

Convergent Validity

Of the 45 items identified a priori as likely to be at least moderately correlated between EQ-HWB and CarerQol (bolded in Appendix Table 3 in Supplemental Materials found at https://doi.org/10.1016/j.jval.2025.04.2168), 6 hypothesized items did not meet this criterion. The seeing, hearing, and mobility items failed to correlate over.3 with the CarerQol "own physical health" item. The EQ-HWB loneliness and felt unsupported items failed to correlate over.3 with the CarerQol support item. EQ-HWB item "felt unsafe" did not correlate over.3 with CarerQol items of relational problems and VAS happiness. Of the 15 items expected to correlate over.3 between the EQ-HWB and C-DEMQOL domains (see Appendix Table 4 in Supplemental Materials found at https://doi.org/10.1016/j.jval.2025.04.2168), all correlated at least moderately.

Exploratory Factor Analysis (EFA)

Exploratory factor analysis was conducted for all instruments (EQ-HWB, C-DEMQOL, and CarerQol). Results from the Kaiser-Mayer-Olkin statistic (.905) and Bartlett's test of sphericity (c^2 = 8234.5, degrees of freedom =1953, *P* < .001) confirm suitability for EFA. Unrotated factor loadings found 13 items with eigenvalues over 1; however, the final 4 factors had items loading higher on other factors, reducing the number extracted for the final solution to 9 (see Appendix Tables 5-7, Appendix Fig. 3 in Supplemental Materials found at https://doi.org/10.1016/j.jval.2025.04.2168). Factors (with variance in brackets) include caregiver's: 1. Caregiving responsibilities and needs (18.2%), 2. Mental health (17.2%), 3. Cognition (11.4%), 4. Relationship (10.8), 5. Personal support (10.2), 6. Confidence in the future (10.0), 7. Professional support (9.5%), 8. Pain (6.5%), and 9. Functioning (physical ability and safety) (5.7%). Total cumulative variance for the 9 factors was 99.4%. Most EQ-HWB items loaded onto a factor (factor 1 = 2-items, 2 = 6-items, 3 = 3 items, 5 = 2 items, 8 = 4-items), and 9 = 4-items). Factors 3, 8, and 9 only included EQ-HWB items. Factors 1, 4, 5, 6, and 7 related to C-DEMQOL dimensions. Of the 4 EQ-HWB items that did not load on any factor, exhaustion is included in the EQ-HWB-S, but seeing, hearing, and sleep are not.

Table 4. Known-group validity by EQ-HWB item for caregiving and general health with nonsignificant differences shaded and positive items in italics.

#	Item name	Caregiving				General health			
		5 hours or less mean	<5 hours mean	Mean difference	*P*	Good mean	Poor mean	Mean difference	*P*
1	Seeing	1.779	1.757	−0.022	.568	1.725	1.864	−0.139	.161
2	Hearing	1.453	1.477	0.024	.412	1.430	1.525	−0.096	.207
3	Mobility*	1.389	1.280	−0.109	.870	1.239	1.559	−0.320	.001
4	Activities*	1.600	1.642	0.042	.362	1.430	2.086	−0.657	<.001
5	Personal care	1.305	1.252	−0.053	.716	1.148	1.576	−0.428	<.001
6	Sleep problems	2.589	2.963	0.373	.017	2.549	3.373	−0.824	<.001
7	Exhaustion*	2.779	3.140	0.361	.011	2.697	3.627	−0.930	<.001
8	Loneliness*	2.074	2.860	0.786	<.001	2.197	1.106	−0.955	<.001
9	Felt unsupported	1.989	2.636	0.646	<.001	2.099	2.864	−0.766	<.001
10	Memory	1.957	2.065	0.108	.234	1.922	2.237	−0.315	.027
11	Cognition*	2.053	2.206	0.153	.163	1.972	2.525	−0.554	.001
12	Anxiety*	2.253	2.654	0.402	.007	2.261	2.949	−0.689	<.001
13	Felt unsafe	1.316	1.481	0.165	.059	1.333	1.576	−0.243	.018
14	Felt frustrated	2.290	2.822	0.532	<.001	2.447	2.897	−0.450	.005
15	Sadness/depression*	2.147	2.682	0.535	.001	2.218	2.915	−0.697	<.001
16	Nothing to look forward to	1.832	2.383	0.552	<.001	1.859	2.746	−0.887	<.001
17	Control*	1.989	2.636	0.646	<.001	2.049	2.983	−0.934	<.001
18	Difficulty coping	1.747	2.131	0.383	.007	1.739	2.458	−0.718	<.001
19	Felt accepted	*3.842*	*3.542*	*−0.300*	*.033*	*3.887*	*3.220*	*0.667*	*<.001*
20	Felt good about self	*3.621*	*3.168*	*−0.453*	*.002*	*3.620*	*2.847*	*0.772*	*<.001*
21	Could do things as wanted	*3.596*	*2.897*	*−0.699*	*<.001*	*3.430*	*2.741*	*0.688*	*<.001*
22	Pain frequency	2.448	2.620	0.171	.172	2.168	3.389	-1.221	<.001
23	Pain severity*	2.085	2.170	0.085	.239	1.893	2.695	−0.802	<.001
24	Discomfort frequency	1.800	2.010	0.210	.074	1.695	2.431	−0.736	<.001
25	Discomfort severity	1.947	2.047	0.100	.191	1.823	2.424	−0.601	<.001

Note. poor = poor and fair, good = good, very good, and excellent.
EQ-HWB indicates EQ Health and Wellbeing instrument; EQ-HWB-S, EQ Health and Wellbeing Short version.
* EQ-HWB-S items.

Discussion

We assessed the psychometric performance of the EQ-HWB and EQ-HWB-S, compared with other caregiving-specific instruments, in caregivers of people living with dementia. Overall, the EQ-HWB instruments performed well, suggesting appropriateness in this setting. We found significant differences between groups on all known-group validity tests. Items differentiated between groups for the variables “time spent caregiving” and “caregiver general health,” with differences retained in multivariate analysis. The EQ-HWB instruments, C-DEMQOL and CarerQol, had similar effect sizes in known-group validity analyses. Most hypothesized correlations were moderately correlated.

EQ-HWB items were generally well distributed, with physical items more likely to be negatively skewed compared with wellbeing items. There were high levels of sleep problems, feeling frustrated, pain frequency, and loneliness in this sample. For the distribution of the EQ-HWB-S scores, our results were similar to our previous studies in parent caregivers[16,17] but with overall higher scores than previously on mobility (worse mobility), pain, and lower sense of control, possibly due to this being an older cohort.

In the item-level known-group analysis comparing caregiver’s health, we found significant differences between groups on all items except seeing and hearing. For time spent caregiving, most of the emotional and mental health EQ-HWB items were significantly different between groups, but the physical items (seeing, hearing, mobility, activities, personal care, memory, cognition, feeling unsafe, and all pain/discomfort items) were not. The EQ-HWB may capture caregiver impacts mainly via the psychosocial items rather than the physical items.

EQ-HWB sum scores and EQ-HWB-S index scores differentiated between groups in known-group validity analyses as

Table 5. Multivariable generalized linear regression modeling results on EQ-HWB-S utility values.

Caregiving (2 groups)		Univariate		Multivariate	
		Coefficient (SE)	*P* value	Coefficient (SE)	*P* value
Caregiving (ref)	less than 5 hours			(ref)	
	more than 5 hours	−0.398 (0.147)	.007	−0.379 (0.148)	.010
Caregiver gender (ref)	male	n/a	n/a	(ref)	
	female	n/a	n/a	−0.264 (0.156)	.089
Caregiver age		n/a	n/a	−0.001 (0.005)	.856
Constant		1.175 (0.12)	<.001	1.388 (0.361)	<.001
Caregiver health (2 groups)					
Caregiver health	fair/poor	-		(ref)	
	good to excellent	−1.007 (0.133)	<.001	−1.049 (0.135)	<.001
Caregiver gender	male	n/a	n/a	(ref)	
	female	n/a	n/a	−0.377 (0.148)	.011
Caregiver age		n/a	n/a	0.004 (0.006)	.523
Constant		1.298 (0.105)	<.001	1.349 (0.373)	<.001

EQ-HWB-S indicates EQ Health and Wellbeing Short version; n/a indicates not available; SE, standard error.

hypothesized for the general health and caregiver time variables. Our results held when controlling for relevant covariates. Being able to determine differences between groups on time spent in caregiving is particularly important for this instrument for it to work well in caregiver populations, lending support for its wider use.

Although the EQ-HWB and EQ-HWB-S are generic instruments that aim to measure quality of life in a range of health and social care situations and populations, including for caregivers, both measures compared favorably with the C-DEMQOL and had higher effect sizes than the CarerQol, which was designed specifically to measure quality of life in caregivers. We also note that the C-DEMQOL has a total of 30 items, making it a cumbersome instrument to include in studies, especially compared with the 9-item EQ-HWB-S. Furthermore, the C-DEMQOL does not have associated preference weights, which are necessary to generate QALYs, making it less useful for economic analysis. When these results were compared with the known-group effect sizes for the EQ-HWB-S in previous studies, we found 1 comparable group, caregiver health: in this study, there was a Cohens' *d* score of 0.45, and in a previous publication with a sample of parents of children with health conditions, we found a similar Cohen's *d* of 0.50.[16]

Of the 45 hypothesized correlations between the EQ-HWB and CarerQol items, 6 items did not meet this criterion. EQ-HWB items "loneliness" and "felt unsupported" did not correlate to at least.3 with the CarerQol support item. We hypothesized that "felt unsafe" would correlate with CareQol item "relationship problems" plus the happiness VAS—it is possible that this was because those answering the felt unsafe question were referring to being physically unsafe rather than experiencing abuse (stated examples are "fear of falling, physical harm, abuse").

Seeing and hearing (items 1 and 2) appeared to be the weakest items in the EQ-HWB (these items are not included in EQ-HWB-S). They had negatively skewed distributions (most participants had no or slight difficulty), they did not discriminate between caregiver time or general health variables, did not load onto a factor in the EFA, and did not perform as expected in the convergent validity analyses. Results suggest that these items may not work well in the context of caregiver-related quality of life and be less relevant for younger caregivers (such as caregivers of children). However, our sample had a mean age of 63 years, suggesting that these items may also not be as useful in an older cohort. Further quantitative and qualitative work on these items is needed to determine their relevance.

When determining the relative merits of quality-of-life instruments, it is important to consider whether the relevant domains are captured, while balancing length and ease of use.[18,31] Effect sizes for the EQ-HWB-S index-scores were almost as high as the EQ-HWB sum scores in the known-group validity analyses, despite the reduced number of items in the shorter measure. The EFA demonstrated that EQ-HWB-S items covered across 5 factors and only exhaustion failed to load onto a factor. Given these results, the EQ-HWB-S may be more suitable than the full instrument for determining quality of life for economic analysis, especially when considering that the lower number of items would result in lower participant burden and be more suitable for the creation of future value sets. Because the results were comparable between the EQ-HWB sum scores and EQ-HWB-S index scores, and the EQ-HWB-S is significantly shorter, we recommend the use of the EQ-HWB-S as the more suitable instrument for inclusion in trials.

Limitations

Limitations to this study include that there may be differences between the samples collected through our first community recruitment strategy and the PureProfile online sample; however, when we added this variable to the regression analysis models, there were no significant differences between the groups, suggesting that this was not an issue. We note that this is a difficult population to recruit and that a larger sample size might have been preferable; however, we achieved a higher number of participants than the minimum required for this type of analysis. We received around 300 bots over 1 night, which were removed. After the removal, we added extra data quality controls. The value set used here is United Kingdom specific and may not capture the nuances of the preferences of the Australian population. The missing data points for item 22 suggest that it is important to determine a clear layout for items so that respondents do not skip a question by accident. Future research could concentrate on other caregiver populations and on the ability of the EQ-HWB to measure change over time, for which there is currently only minimal information.

Conclusions

The results of this study support the discriminative ability of the EQ-HWB sum score and EQ-HWB-S index scores in caregivers of people living with dementia. Both instruments performed well against carer-specific instruments, such as the C-DEMQOL and CarerQol across a range of psychometric tests. As the first study, to our knowledge, to investigate the validity of the EQ-HWB in caregivers of people living with dementia, these results help build the evidence for the use of the EQ-HWB sum score and the EQ-HWB-S index scores in caregiver populations. The analyses included here demonstrate the potential value of the EQ-HWB instruments for capturing health and well-being dimensions that are not well represented in other multiattribute utility instruments, such as loneliness, exhaustion, cognition, and control. Including caregiver quality of life in economic evaluations of interventions for people living with dementia is essential to accurately account for spillover effects. We recommend the use of the shorter measure in trials because psychometric results were similar between the EQ-HWB sum scores and EQ-HWB-S index score, and this would result in lower participant burden.

Author Disclosures

Author disclosure forms can be accessed below in the Supplemental Material section. Views expressed by the authors in the publication do not necessarily reflect the views of the EuroQol Foundation. Dr Engel is an editor for *Value in Health* and had no role in the peer-review process of this article.

Supplemental Material

Supplementary data associated with this article can be found in the online version at https://doi.org/10.1016/j.jval.2025.04.2168.

Article and Author Information

Accepted for Publication: April 21, 2025

Published Online: June 25, 2025

doi: https://doi.org/10.1016/j.jval.2025.04.2168

Author Affiliations: Melbourne Health Economics, School of Population and Global Health, The University of Melbourne, Carlton, Victoria, Australia (Bailey); Sheffield Centre for Health and Related Research, School of Medicine and Population Health, University of Sheffield, UK (Peasgood); Patient-Reported Outcomes & Health Economics Research, German Center for Neurodegenerative Diseases (DZNE) Rostock/Greifswald, Greifswald, Germany (Michalowsky); Monash University Health Economics Group (MUHEG), School of Population Health and Preventive Medicine, Monash University (Engel).

Correspondence: Cate Bailey, PhD, 207 Bouverie St, Carlton, 3035, Victoria, Australia. Email: cate.bailey@unimelb.edu.au

Authorship Confirmation: All authors certify that they meet the ICMJE criteria for authorship.

Funding/Support: This study was funded by the EuroQol Foundation (1566-RA). Dementia Australia funded the data collection as part of L.E.'s Post-Doc Fellowship.

Role of the Funder/Sponsor: The funder had no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; preparation, review, or approval of the manuscript; or decision to submit the manuscript for publication.

Acknowledgment: The authors thank Discussants Jason Madan at HESG Summer 2024, Warwick University, UK, and Stirling Bryan, EuroQol Plenary, Noordwyk, The Netherlands, for their thoughtful input when this work was presented at these conferences.

Ethical Approval: Ethics was obtained from the relevant University Human Research Ethics Committee #35073.

Twitter Post: The new EuroQol health and wellbeing EQ-HWB instruments showed good validity for caregivers of people living with dementia and discriminated well between a range of known groups.

REFERENCES

1. Brodaty H, Donkin M. Family caregivers of people with dementia. *Dial Clin Neurosci*. 2009;11(2):217–228.
2. Oliva-Moreno J. The valuation of informal care in cost-of-illness studies: a systematic review. *Pharmacoeconomics*. 2017;35(3):331–345.
3. Wu Y, Al-Janabi H, Mallett A, et al. Parental health spillover effects of paediatric rare genetic conditions. *Qual Life Res*. 2020;29(9):2445–2454.
4. Dawoud D, Lamb A, Moore A, et al. Capturing what matters: updating NICE methods guidance on measuring and valuing health. *Qual Life Res*. 2022;31(7):2167–2173.
5. Pennington B, Al-Janabi H. Modelling informal carers' health-related quality of life: challenges for economic evaluation. *Appl Health Econ Health Policy*. 2024;22(22):9–16.
6. Brown A, Page TE, Daley S, et al. Measuring the quality of life of family carers of people with dementia: development and validation of C-DEMQOL. *Qual Life Res*. 2019;28(8):2299–2310.
7. EuroQol Research Foundation. EQ-5D. https://euroqol.org/eq-5d-instruments/; 2020. Accessed October 14, 2020.
8. Brazier J, Roberts J, Deverill M. The estimation of a preference-based measure of health from the SF-36. *J Health Econ*. 2002;21(2):271–292.
9. Farina N, Page TE, Daley S, et al. Factors associated with the quality of life of family carers of people with dementia: a systematic review. *Alzheimers Dement*. 2017;13(5):572–581.
10. Brazier J, Peasgood T, Mukuria C, et al. The EQ-HWB: overview of the development of a measure of health and wellbeing and key results. *Value Health*. 2022;25(4):482–491.
11. EuroQol Research Group. EQ-HWB. https://euroqol.org/research-at-euroqol/eq-hwb/; 2025. Accessed May 25, 2025.
12. Peasgood T, Mukuria C, Brazier J, et al. Developing a new generic health and wellbeing measure: psychometric survey results for the EQ-HWB. *Value Health*. 2022;25(4):525–533.
13. Peasgood T, Mukuria C, Carlton J, et al. What is the best approach to adopt for identifying the domains for a new measure of health, social care and carer-related quality of life to measure quality-adjusted life years? Application to the development of the EQ-HWB? *Eur J Health Econ*. 2021;22(7):1067–1081.
14. Mukuria C, Peasgood T, McDool E, Norman R, Rowen D, Brazier J. Valuing the EQ Health and wellbeing Short (EQ-HWB-S) using time trade-off and a discrete choice experiment: a feasibility study. *Value Health*. 2023;26(7):1073–1084.
15. Rowen D. Preference-based measures of health-related quality of life. In: Maggino F, ed. Encyclopedia of Quality of Life and Well-Being Research. Cham: Springer; 2021.
16. Bailey C, Dalziel K, Jones R, et al. The validity of the EuroQol health and well-being short version (EQ-HWB-S) instrument in parents of children with and without health conditions. *Pharmacoeconomics*. 2024;42(Suppl 1):163–179.
17. Bailey C, Dalziel K, Constable L, et al. The performance of the EQ-HWB-S as a measure of quality-of-life of caregivers in families that have experienced adverse events. *Eur J Health Econ*. 2025;26(1):7–21.
18. Lee P, Engel L, Lubetkin E, Gao L. Exploring the comparability between EQ-5D and the EQ health and wellbeing in the general Australian population. *Value Health*. 2024;27(4):508–517.
19. Kuharic M, Mulhern B, Sharp LK, Turpin RS, Pickard AS. Comparison of EQ health and well-being long and short with other preference-based measures among United States informal caregivers. *Value Health*. 2024;27(7):967–977.
20. Long C, Mao Z, Yang Z. A head-to-head comparison of EQ-HWB and EQ-5D-5L in patients, carers, and general public in China. *Value Health*. 2024;27(7):848–856.
21. Brouwer WBF, Van Exel NJA, Van Gorp B, Redekop WK. The CarerQol instrument: a new instrument to measure care-related quality of life of informal caregivers for use in economic evaluations. *Qual Life Res*. 2006;15(6):1005–1021.
22. Frost MH, Reeve BB, Liepa AM, Stauffer JW, Hays RD. Mayo/FDA Patient-Reported Outcomes Consensus Meeting Group. What is sufficient evidence for the reliability and validity of patient-reported outcome measures? *Value Health*. 2007;10(suppl 2):S94–S105.
23. Mokkink LB, Prinsen CA, Patrick DL, et al. COSMIN study design checklist for patient-reported outcome measurement instruments. COSMIN. https://

www.cosmin.nl/wp-content/uploads/COSMIN-study-designing-checklist_final.pdf; Published 2019. Accessed January 23, 2024.

24. Wimo A, Wetterholm AL, Mastey V, Winblad B. Evaluation of the resource utilization and caregiver time in Anti-dementia drug trials—a quantitative battery. In: Wimo A, Jonsson B, Karlsson G, Winblad B, eds. *The Health Economics of Dementia*. London: John Wiley and Sons; 1998:465–499.
25. Hoefman RJ, van Exel J, Brouwer WBF. Measuring care-related quality of life of caregivers for use in economic evaluations: CarerQol tariffs for Australia, Germany, Sweden, UK, and US. *Pharmacoeconomics*. 2017;35(4):469–478.
26. Centre for Dementia Studies. C-DEMQOL-measurement of quality of life in family carers of people with dementia. https://www.bsms.ac.uk/_pdf/cds/c-demqol-instruction-manual-final-v1.2.pdf; Published 2019. Accessed March 18, 2025.
27. Sambasivam R, Liu J, Vaingankar JA, et al. The hidden patient: chronic physical morbidity, psychological distress, and quality of life in caregivers of older adults. *Psychogeriatrics*. 2019;19(1):65–72.
28. Oba H, Matsuoka T, Kato Y, Narumoto J. Factors associated with quality of life of dementia caregivers: direct and indirect effects. *J Adv Nurs*. 2018;74(9):2126–2134.
29. Thomas P, Lalloué F, Preux P, et al. Dementia patients caregivers quality of life: the PIXEL study. *Int J Geriatr Psychiatry*. 2006;21(1):50–56.
30. Cohen J. Quantitative methods in psychology: a power primer. *Psychol Bull*. 1992;112:1155–1159.
31. Devlin N, Pickard S, Busschbach J. The development of the EQ-5D-5L and its value sets. In: Devlin N, Roudijk B, Ludwig K, eds. *Value Sets for EQ-5D-5L: A Compendium, Comparative Review & User Guide*. CH. Cham: Springer; 2022.