Patient-Reported Outcomes

Comparison of the EQ-HWB and EQ-HWB-S With Other Preference-Based Measures Among United States Informal Caregivers

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A B S T R A C T

Objectives: Several measures have been used or developed to capture the health and well-being of caregivers, including the EQ Health and Well-being (EQ-HWB) and its short form, EQ-HWB-S. This study aimed to evaluate the psychometric properties and construct validity of the EQ-HWB/EQ-HWB-S in a US caregiver population.

Methods: A cross-sectional survey was conducted involving 504 caregivers. Eligible participants were 18+ years old, provided unpaid care to a relative/friend aged 18+ in the past 6 months, and spent on average of at least 1 hour per week caregiving. Survey included the following measures: EQ-HWB, Adult Social Care Outcomes Toolkit for Carers-Carer, CarerQol, and EQ-5D-5L. Psychometric properties were assessed using response distributions, floor/ceiling effects, Spearman's correlation for convergent validity, and effect sizes (ES) for known-group validity based on caregiving situations and intensity.

Results: The average age of caregivers was 49.2 (SD = 15.4), with 57.5% being female. More than half (54.4%) reported high caregiving intensity, and 68.3% lived with the care recipient. The EQ-HWB-S index showed a strong positive correlation with the EQ-5D-5L (r_s = 0.72), Adult Social Care Outcomes Toolkit for Carers (r_s = 0.54), and CarerQol (r_s = 0.54) indices. Notably, the EQ-HWB-S index showed the largest ES among measures in differentiating caregiving scenarios with a large ES for caregiver's general health (d = 1.00) and small ES for caregiving intensity (d = 0.39).

Conclusions: Results support construct validity of EQ-HWB and EQ-HWB-S as measures for assessing health and well-being of adult informal caregivers in comparison with other validated instruments. Differing levels of known-group validity across anchors emphasize the importance of selecting appropriate measures for caregivers, depending on research question and/or intervention aims.

Keywords: ASCOT-Carer, caregivers, CarerQol, EQ-HWB, EQ-HWB-S.

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Highlights

- Various preference-based measures, including Adult Social Care Outcomes Toolkit for Carers-Carer, CarerQol-7D, and EQ-5D-5L, can be used to assess the health and quality of life of informal caregivers. The EQ Health and Well-being (EQ-HWB) was developed as a broader measure of health and well-being, including for caregivers. However, its psychometric properties have yet to be examined in relation to other validated measures, specifically in caregivers.

- This study evaluated the psychometric properties of EQ-HWB and its short form, EQ-HWB-S, in a heterogeneous US caregiver population, demonstrating construct validity with other preference-based measures. Notably, care recipients' self-perceived burden to caregivers proved to be a valid anchor-based criterion for distinguishing groups based on the influence of caregiving on their health and well-being.

- The findings highlight the importance of selecting appropriate measures for assessing health and well-being of informal caregivers. This choice should depend on the specific aims of the intervention being evaluated and perspective of economic evaluation. Using the appropriate measures can lead to more accurate assessments of the effectiveness and cost-effectiveness of interventions with impacts on broader quality of life and well-being, which is essential for informed decision making in healthcare policy.

Introduction

Informal caregivers play a vital role in providing support to individuals facing illness, disability, or age-related challenges, making significant contributions to the healthcare systems worldwide and in the United States.[1-3] The care and assistance these caregivers provide to their loved ones often come at considerable personal costs in terms of physical, emotional, and financial well-being.[4,5] As the demand for informal care continues to grow because of aging populations and the growing prevalence of chronic illnesses,[6,7] understanding the health consequences of caregiving, caregiver well-being, and the economic costs of care-related interventions becomes increasingly important.[2,8,9] To better understand these consequences, valid and reliable measures of caregiver quality of life (QoL) and well-being are essential. These measures enable policymakers and healthcare professionals to develop effective strategies that support informal caregivers and their care recipients.[10,11] Recognizing the challenges faced by informal caregivers is crucial; however, it is equally important to acknowledge the positive benefits of caregiving, such as personal growth, strengthened family bonds, and a sense of fulfillment from supporting loved ones.[12-14]

Several preference-based measures have been developed specifically for use with informal caregivers. Measures such as the Adult Social Care Outcomes Toolkit for Carers (ASCOT-Carer)[15] and the Care-Related Quality of Life (CarerQol-7D),[16] with evidence of validity in the literature, assess the impact of interventions on caregiver-related

QoL.[17,18] However, these measures have limitations in estimating quality-adjusted life years (QALYs).[19,20] Their valuation is based on care-related (CarerQol-7D) or social-care related QoL (ASCOT-Carer), which encompasses other important dimensions of caregiving.[21] Nonetheless, they are unsuitable for cost-effectiveness analysis, in which health-related quality of life (HrQoL) is the outcome of interest.[21] As a result, care- or social-care-related QoL utilities in caregivers cannot be directly aggregated or compared with HrQoL utilities measured in patients.[21] Choosing between sector-specific instruments poses challenges because measuring instruments that overlap could result in double counting, whereas including an instrument focused on a single sector could omit significant benefits.[22,23] Generic measures of health, such as the EQ-5D,[24] are widely used in studies involving informal caregivers, despite not being specifically developed for this population.[25] Furthermore, generic HRQoL measures have been shown to have limited ability to capture the impacts of healthcare interventions on others who are indirect beneficiaries, such as informal caregivers.[22,26] Current guidelines and frameworks, such as the National Institute of Health and Care Excellence and the Second US Panel on Cost-effectiveness, emphasize the importance of measuring and valuing caregiver HRQoL effects but provide limited guidance on which measures to use.[27,28] Furthermore, the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) Special Task Force on US Value Assessment Frameworks, known as the "ISPOR value flower," identifies "caregiver spillovers" as a core element of value, including caregiver QoL.[29] However, economic evaluations often overlook the costs and effects of informal caregivers, potentially affecting cost-effectiveness inferences and recommendations.[30-32] Uncertainty over the appropriateness of different QoL measures for caregivers is a common reason for the exclusion of caregiver effects.[17,33]

The EQ Health and Well-being (EQ-HWB) measures were developed to assess the impact of interventions on health and well-being of people with long-term conditions, disabilities, and informal caregivers.[34-36] It has 2 versions: a 25-item version and a short 9-item version (EQ-HWB-S) designed for economic evaluations, facilitating comparisons across health and social care sectors.[37] However, no study has yet compared the psychometric properties of the EQ-HWB with other measures in a diverse caregiver population to guide instrument selection. Choosing the right measure is context dependent, and interventions may affect caregivers differently in various situations. Existing literature is predominantly based on non-US samples, limiting generalizability to the US caregiver population.[18] A comparative psychometric study can reveal each instrument's strengths and weaknesses, helping researchers and policymakers make informed decisions. This study aimed to compare psychometric properties of EQ-HWB/EQ-HWB-S with the ASCOT-Carer, CarerQol-7D, and EQ-5D-5L in informal caregivers by examining response distributions, floor/ceiling effects, convergent validity, and the ability of measures to reflect known-group differences by care situations and caregiving intensity. By addressing the existing gaps in the literature, the findings will provide valuable insights for future instrument selection in economic evaluations including informal caregivers and enhance the understanding and application of EQ-HWB/EQ-HWB-S.

Methods

Survey Development and Data Collection

A web survey was conducted as part of a larger cross-sectional, quantitative investigation of care recipient-caregiver dyads. The survey was developed, piloted, and administered between August 2022 and February 2023 on the Qualtrics survey platform. Our survey underwent a pretesting with 12 individuals who were informal caregivers or receiving care to ensure survey clarity, logical flow, and correct operational procedures, including randomization. After correcting any errors and adjusting survey length and wording, a pilot study with 50 participants (10% of our target demographic) was conducted. This assessed the feasibility of data collection, response quality, completion time, and participant engagement. Feedback from the pilot indicated no further changes to the survey were necessary. Participant recruitment was conducted using Qualtrics' panel management system, in which the survey was made available to self-identified caregivers on the Qualtrics platform. Caregivers provided informed consent and answered eligibility questions. Subsequently, they answered questions about their relationship with the care recipient and the care provided. To minimize order effects, a randomized set of QoL and caregiver burden measures was administered.[38] Caregivers then provided demographic, clinical, and socioeconomic information. After caregivers completed their part, the survey was passed to the care recipients, who completed a similar sequence of questions. Incentives as per Qualtrics' multiple vendor panel agreements, ranged from $19 to $28 per participant for completed survey. Approval for the study was obtained from the Institutional Review Board at the University of Illinois Chicago (#2022-0490).

Participants

Eligibility criteria

Eligible caregivers were individuals aged 18 or older who provided unpaid care or assistance to a relative or friend aged 18 or older within the last 6 months. Caregivers had to spend on average, at least 1 hour per week providing care and have a care recipient who was willing and able to complete their part of the survey. Care recipients were required to confirm they received care from their caregiver within the previous 6 months and be 18 years or older.

Sample size

Based on Fayers' recommendation to have sample sizes exceeding 100 participants for discriminative validity estimates, a target sample size of 500 informal caregivers was set.[39] This larger sample size was chosen to accommodate potential subanalyses and ensure an adequate representation of participants across various caregiver subgroups.

Quality checks

To verify the authenticity of caregiver-care recipient dyads, validity checks were implemented using demographic and relationship variables.[40] Consistency in reported relationship, years of knowing each other, and demographic information (eg, gender) were assessed.[40] Age was used as a duplicate demographic question.[41] Data quality was ensured through pre- and post-data-collection checks. Pre-data collection measures included Completely Automated Public Turing test to tell Computers and Humans Apart, cookies, IP address, and geolocation data,[42] to target the rise in survey bots.[43] Honeypot questions, misspelled words, images, and attention-check questions tailored to the study were also used to filter out bots and inattentive respondents.[44] After data collection, open-ended responses were assessed, and "speeders" who completed the survey in less than 50% of the median sample time were excluded.

Measures

The CarerQol, ASCOT-Carer, and EQ-5D-5L were selected as comparators to EQ-HWB/EQ-HWB-S because of their established use and relevance in caregiver research and their application in economic evaluations.

The EQ-HWB/EQ-HWB-S is a measure of QoL and well-being, comprising a 25-item profile measure (EQ-HWB) and a 9-item classifier (EQ-HWB-S).[34-36] The EQ-HWB encompasses 7 domains: activity, relationships, cognition, self-identity, autonomy, feelings, and physical sensations. Each item has 5 levels of frequency, severity, or difficulty. Although there is no established method for scoring the profile or classifier, a study has investigated these aspects.[45] In this study, the EQ-HWB-S was calculated as a single-level summary score and EQ-HWB with 3 subscales: (1) activities level summary score (LSS) (3 items), (2) physical sensation LSS (4 items), and (3) psychosocial well-being LSS (16 items).[45] The EQ-HWB-S index values were derived from a UK pilot study using the EuroQol Valuation Technology adapted for the new measure.[46]

The EQ-5D-5L is a preference-based measure designed to assess an individual's overall HRQoL. It comprises 5 dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression.[47] Each dimension has 5 levels, resulting in 3125 possible health states. The EQ-5D-5L is complemented by the Visual Analog Scale (EQ VAS), which measures an individual's self-rated health on a scale from 0 (worst possible health) to 100 (best possible health).[48] The EQ-5D-5L Index score reflects how good or bad a particular health state is based on the general population's preferences in a specific country.[48] In this study, EQ-5D-5L Index values were obtained using the recommended scoring function based on US population-based preference weights.[49]

The Care-Related Quality of Life (CarerQoL) is a measure of caregivers' subjective burden and overall well-being, consisting of 2 components: CarerQol-7D and CarerQol-VAS.[16] CarerQol-7D includes 7 dimensions: fulfillment in caregiving, relational problems, mental health issues, difficulties in combining daily activities, financial concerns, social support, and physical health problems. Respondents can indicate the extent of problems they experience in these dimensions, with possible answers ranging from "no" to "a lot." An overall score, ranging from 0 to 100, can be calculated using a tariff to calculate care-related QoL scores. CarerQol-7D value sets have been developed for 6 countries using discrete choice experiments. The weights for this study were calculated using the US tariff.[21]

The Adult Social Care Outcomes Toolkit for Carers (ASCOT-Carer) is a preference measure of social care-related quality of life (SCRQoL) for caregivers.[15] It assesses SCRQoL across 7 domains: occupation, control over daily life, self-care, personal safety, social participation, space and time to be oneself, and feeling supported and encouraged. Each domain is rated on a 4-level scale, ranging from the ideal state (level 1) to high needs (level 4). An index score from 0 (worst possible SCRQoL) to 1 (best possible SCRQoL) is calculated by summing the preference weights for each selected outcome level. These weights were developed through best-worst scaling with a general population sample in England and were used for this study.[50]

To examine discriminative validity, the authors (A.S.P. and M.K.) used a global item to assess care recipient self-perceived burden to caregivers as an independent anchor (available upon request from the corresponding author).[51] Additionally, the Burns Relationship Scale, a 7-item self-report inventory, was used to measure satisfaction in various aspects of the relationship.[52]

Analysis

Psychometric properties, including response distributions, floor/ceiling effects, convergent validity, and known-group validity, were examined following The Consensus-Based Standards for the Selection of Health Measurement Instruments guidelines.[53,54] Continuous variables were reported as means and standard deviations (SD), whereas frequencies and proportions were reported for categorical variables. Analyses were performed using SAS Version 9.4 and RStudio Version 2021.09.

Floor/ceiling effect

Floor and ceiling effects were assessed based on the percentage of participants obtaining the minimum and maximum possible scores for each measure, which potentially indicates limited discriminative and/or evaluative ability.[55] A common threshold for floor or ceiling effects is when over 15% of respondents score at either extreme (eg, reporting no problems on all dimensions).[56]

Convergent validity

Convergent validity was analyzed using Spearman rank-order correlation to assess the association between scores of different measures.[57] The strength of correlations (r_s) was interpreted according to Cohen's guidelines, ie, strong (>0.50), moderate (0.31-0.50), weak (0.11-0.30), and trivial/none (<0.10).[58] We hypothesized strong correlations between EQ-HWB-S and EQ-5D-5L given that they focus on health and well-being and at least moderate between EQ-HWB subscales/EQ-HWB-S and ASCOT-Carer and CarerQol-7D because they include various aspects of well-being that are related concepts but tend not to include functional aspects of health.

Known-group comparison

Known-group comparisons (KGC) were carried out to examine the ability of index and aggregate scores, ie, LSS, to distinguish between groups expected to differ in intensity of caregiving. We used Cohen's d effect sizes (ES) with specific thresholds to examine each known group: small (d = 0.2), medium (d = 0.5), large (d = 0.8), and very large (d = 1.40).[56] In addition, 95% confidence intervals were calculated by bootstrapping ES using R package bootES.[59] A priori hypotheses were based on evidence from studies that support the use of these anchors and other constructs related to caregiver burden.[60-66]

We hypothesized that lower index scores (indicating worse health) on the EQ-5D-5L, EQ-HWB-S, ASCOT-Carer, and CarerQol and higher EQ-HWB-S LSS and EQ-HWB subscales LSS (indicating worse health and well-being) would be associated with the following categories: (1) lower overall general caregiver's health[61] and lower satisfaction with their relationship with care recipient (assessed using the Burns Relationship scale) based on previous evidence of its association with caregiver burden.[62] (2) Higher care recipient self-perceived burden to caregivers. This proxy assessment of caregiver burden by the care recipient, collected as part of a broader study (to be described elsewhere), was chosen because of previous research suggesting that care recipients self-perceived burden is moderately correlated with caregiver burden.[63] (3) For caregiving situation and caregiving intensity, we hypothesized lower scores for groups in which caregiving had an impact on their employment, more time in the caregiver role, being a primary caregiver, sharing a household with care recipient, caring by free choice, and providing a greater number of hours per week to caregiving (stratified by 1-20 hours or 21+ hours of care per week).[18,64,65] In addition, to measure the intensity of the caregiving, we used the Level of Index Care, which categorizes caregiving intensity based on a combination of hours of care per week and types of care provided (activities/instrumental activities of daily living).[66]

Results

Sample Results

Out of 4714 initial survey participants, 2651 were excluded after eligibility screening (56.2%), 957 following validity checks

Table 1. Sociodemographic characteristics and caregiving situation of informal caregivers.

Sociodemographic characteristics (n = 504)	Frequency (%)
Age (years), mean (± SD)	49.2 (15.4)
Age group (years)	
18-44	226 (45.2)
45-64	164 (32.5)
65 +	114 (22.6)
Gender	
Male	213 (42.3)
Female	290 (57.5)
Agender (self-described)	1 (0.2)
Race/Ethnicity*	
White	369 (73.2)
Black or African American	79 (15.7)
American Indian or Alaskan Native	13 (2.6)
Asian	27 (5.4)
Hispanic or Latino or Spanish Origin of any race	62 (12.3)
Native Hawaiian/Other Pacific Islander	1 (0.2)
Other race	3 (0.6)
Employment status	
Employed (full-time, part-time or self-employed)	311 (61.7)
Retired, homemaker	138 (27.4)
Student, unemployed (unable to work due to disability, looking or not looking for work)	55 (10.9)
Marital status	
Married, engaged, living with partner	350 (69.4)
Widowed, divorced, or separated	71 (14.1)
Single, never married	83 (16.5)
Educational attainment	
High school degree/GED or less	103 (20.4)
Technical school, associate, or some college (no degree)	204 (40.5)
Bachelor's degree	106 (21.0)
Master's, professional or doctorate degree	91 (18.1)
Current living arrangements	
Alone (own home), may have a pet	57 (11.3)
Care recipient's household	234 (46.4)
Household with other people	193 (38.3)
Other (assisted living, temporary staying with relative or somewhere else)	20 (4.0)
Difficulty in meeting monthly household expenses	
Not difficult	195 (38.7)
Slightly difficult	146 (29.0)
Somewhat difficult	81 (16.1)
Very difficult	52 (10.3)
Extremely difficult	30 (6.0)

Caregiving Situation	Frequency (%)
Relationship to care recipient	
Spouse/Partner	174 (34.5)
Parent	21 (4.2)
Child	150 (29.8)
Sibling	31 (6.2)
Another relative (not child, sibling, parent, grandchild)	30 (6.0)
Friend/Family Friend	60 (11.9)
Grandchild	38 (7.5)
Reason for providing assistance to care recipient *	
Physical condition (short term)	75 (14.9)

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Table 1. Continued

Caregiving Situation	Frequency (%)
Physical condition (long-term)	297 (58.9)
Emotional or mental health problem	148 (29.4)
Developmental or intellectual disability or delay	35 (6.9)
Behavioral issue	50 (9.9)
Memory problem	127 (25.2)
Old age, aging	237 (47.0)
Other	31 (6.2)
Duration of caregiving (years)	
6 months-1	48 (9.5)
1-2	141 (28.0)
3-5	158 (31.4)
6-10	88 (17.5)
10>	69 (13.7)
Primary caregiver for care recipient	
Yes	439 (87.1)
No	10 (2.0)
Sharing caregiving responsibilities about equally with someone else	55 (10.9)
Level of Care Index (intensity of caregiving) †	
Level 1	27 (5.4)
Level 2	38 (7.5)
Level 3	87 (17.3)
Level 4	274 (54.4)
Level 5	78 (15.5)
Average weekly time spent on caregiving (hours)	
1-5	35 (6.9)
6-10	69 (13.7)
11-20	176 (34.9)
21-30	99 (19.6)
31-40	28 (5.6)
40>	46 (9.1)
Number of instrumental activities of daily living provided	
0-2	5 (1.0)
3-4	30 (2.4)
5-6	168 (6.0)
7	301 (59.7)
Number of activities of daily living provided	
0-1	125 (24.8)
2-3	119 (23.6)
4-5	114 (22.6)
6	146 (29.0)
Providing care to multiple individuals (yes)	49 (9.7)
Choice in taking on this responsibility for caring for care recipient (yes)	296 (58.7)
Employment interference due to caregiving (yes)	284 (56.4)
Living in the same household as care recipient (yes)	344 (68.3)

Health and relationship quality	Frequency (%)
General health (caregiver)	
Excellent	48 (9.5)
Very good	144 (28.6)
Good	180 (35.7)
Fair	113 (22.4)
Poor	19 (3.8)

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Table 1. Continued

Health and relationship quality	Frequency (%)
Burns Relationship Scale	
Dissatisfied	205 (40.7)
Satisfied	299 (59.3)

Caregiver-proxy view	Frequency (%)
Care recipient self-perceived burden to caregivers [‡]	
Not at all	192 (38.1)
Slightly	137 (27.2)
Moderately	91 (18.1)
A lot	53 (10.5)
Extremely	31 (6.2)

Note. Activities of daily living (ADLs) are basic self-care tasks, such as personal hygiene, dressing, eating, continence, and mobility. IADLs (Instrumental Activities of Daily Living) involve more complex activities necessary for independent living, including managing finances, meal preparation, shopping, housekeeping, transportation, medication management, and using communication devices.
*Not mutually exclusive.
[†]The Level of Care Index, comprising 5 levels, categorizes caregivers based on caregiving intensity by combining hours of care per week and types of care provided (IADLs and ADLs). The index groups hours of care and types of care into 4 levels each. Caregivers are assigned a level based on their combined score in hours and types of care, which is then condensed into 5 categories. Level 1 signifies the least intense caregiving, whereas level 5 represents the most intense caregiving.
[‡]Reported by care recipient on question asked: "Overall, I am a burden to my caregiver due to my health situation (how I think my caregiver would answer about me)."

Table 2. Descriptive statistics of the survey instruments in caregivers.

Instruments	Mean (SD)	(Min, Max)
EQ-5D-5L Index	0.73 (0.28)	(−0.45, 1.00)
EQ VAS	71.45 (20.63)	(0, 100)
EQ-HWB-S Index	0.67 (0.26)	(−0.29, 1.00)
ASCOT Index	0.72 (0.23)	(0.03, 0.99)
CarerQol Index	70.28 (21.86)	(0, 100)
CarerQol VAS	6.72 (2.26)	(0, 10)
EQ Health and well-being LSS		
EQ-HWB-S (short)	21.01 (7.68)	(9, 42)
EQ-HWB (psychosocial subscale)	38.44 (13.96)	(16, 76)
EQ-HWB (physical sensation)	9.51 (3.68)	(4, 20)
EQ-HWB (activities)	5.11 (2.61)	(3, 15)

| Proportion of respondents scoring minimum and maximum values	Number of domains	Minimum N (%)	Maximum N (%)
EQ-5D-5L Index	5	0 (0)	88 (17.46)
EQ-HWB-S Index	9	0 (0)	17 (3.37)
CarerQol Index	7	1 (0)	23 (4.56)
ASCOT Index	7	0 (0)	29 (5.75)

Note. EQ-5D-5L, ASCOT-Carer (Adult Social Care Outcomes Toolkit for Carers), and CarerQol (The Carer-related Quality of Life) index scores were calculated using UK-specific utility values, and EQ-HWB-S used pilot data utility values for the UK. More details on scoring are provided in the Methods section. Higher scores on EQ-HWB LSS and subscale LSS indicate worse health and well-being, whereas higher scores on EQ-5D-5L, EQ VAS, EQ-HWB-S, ASCOT-Carer and CarerQol-7D represent better caregiver's quality of life.
EQ-HWB Act indicates EQ Health and Well-being Activities Subscale Level Summary Score (3 items); EQ-HWB LSS, EQ Health and Well-being Level Summary Score (on 23-items, excluding Hear and See items); EQ-HWB MH LSS, EQ Health and Well-being Psychosocial Subscale Level Summary Score (16 items); EQ-HWB PD LSS, EQ Health and Well-being Pain/Discomfort Subscale Level Summary Score (4 items); EQ-HWB-S LSS, EQ Health and Well-being Short Form Level Summary Score (9 items); LSS, Level Summary Score.

(46.4%), 317 because of quality checks (28.7%), and 285 once race and gender quotas were met (36.1%). Ultimately, 504 care recipient-caregiver dyads (11.7%) completed the survey. Among the 504 informal caregivers analyzed, 290 (57.5%) were female with an average age of 49.2 years (SD = 15.4) (Table 1). The types of caregivers included spouses/partners 174 (34.5%), parents 21 (4.2%), children of care recipients 150 (29.8%), siblings 31 (6.2%), other relatives 30 (6.0%), friends/family friends 60 (11.9%), and grandchildren 38 (7.5%). Employment was reported by 311 (61.7%) caregivers, and 284 (56.4%) reported that caregiving responsibilities interfered with their employment. Compared with the general population of informal caregivers in the US, our study had a similar percentage of female informal caregivers (57.5% vs 58.1% in the general population), age distribution, and race/ethnicity.[67]

Caregiving situations differed in terms of caregiving duration and hours spent weekly. Caregivers, on average, dedicated 11 to 20 hours per week to providing care, with the majority 439 (87.1%) serving as primary caregivers. The Level of Care Index revealed that 352 (69.9%) were at level 4 or 5, signifying high caregiving intensity. Approximately 344 (68.3%) of caregivers lived with their care recipient, and 296 (58.7%) had the option of choice in taking on the caregiving role. In the Burns Relationship Scale results, 205 caregivers (40.7%) were dissatisfied, whereas 299 caregivers (59.3%) were satisfied with their relationship with care recipient.

Distributions, Ceiling, and Floor Effect

The mean scores for the EQ-5D-5L Index were 0.73 (SD = 0.28), EQ VAS 71.45 (SD = 20.63), EQ-HWB-S Index 0.67 (SD = 0.26), and the ASCOT Index 0.72 (SD = 0.23) (Table 2). The mean score for the CarerQol Index was 70.28 (SD = 21.86), whereas the mean score for the CarerQol-VAS was 6.7 (SD = 2.3). Fig. 1A and Appendix Figure 1 in Supplemental Materials found at https://doi.org/10.1016/j.jval.2024.03.003 present the distributions of scores for the measures, showing that they are similar in shape with a slightly skewed distribution to the right (better health and QoL). Only the EQ-5D-5L exhibited a slight ceiling effect in 17.5% of respondents, and none of the measures demonstrated floor effects.

Convergent Validity

As hypothesized, EQ-HWB-S Index exhibited a strong positive correlation with the EQ-5D-5L Index (r_s = 0.72), ASCOT Index (r_s = 0.54), and CarerQol-7D Index (r_s = 0.54) (Table 3). Similarly, the EQ-HWB-S LSS had strong negative correlations with EQ-5D-5L Index (r_s = −0.68), ASCOT Index (r_s = −0.60), and CarerQol Index (r_s = −0.61). Among the EQ-HWB subscales, the psychosocial subscale showed strongest negative correlations with the caregiver-related instruments: ASCOT Index (r_s = −0.66), and CarerQol Index (r_s = −0.61). The correlations between EQ-HWB subscales (physical sensation and activities) and the other caregiver instruments were mostly moderate to weak, indicating that they measure different aspects of caregiver health and well-being.

Figure 1. Overlay 4 Kernel Density Lines.
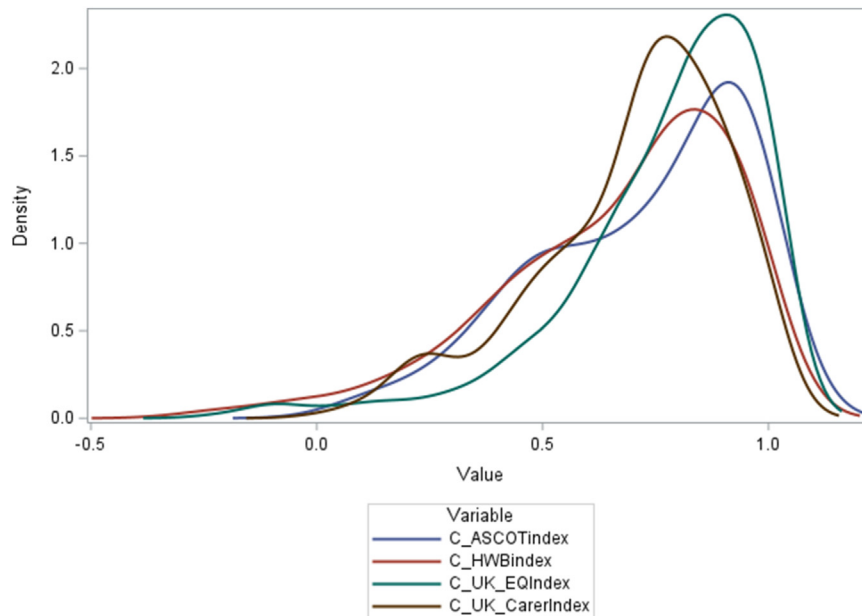
Known-group Comparison

In terms of differentiating groups based on the caregiver's general health (Tables 4 and 5, Appendix Table S1 in Supplemental Materials found at https://doi.org/10.1016/j.jval.2024.03.003), the EQ-HWB-S index demonstrated the highest sensitivity, with an F-statistic of 35.17 ($P < .0001$). This was higher than the F-statistics for ASCOT-Carer (30.80, $P < .0001$), EQ-5D-5L (23.39, $P < .0001$), and CarerQol Index (16.80, $P < .0001$). Furthermore, EQ-HWB-S exhibited the largest ES for differentiating better vs worse caregiver general health with large ES (d = 1.00, 95% CI: 0.77, 1.23), whereas EQ-5D-5L and ASCOT-Carer showed similarly large, albeit slightly smaller, ES magnitudes (d = 0.86, 95% CI: 0.62, 1.10, and d = 0.96, 95% CI: 0.72, 1.20, respectively), and CarerQol-7D demonstrated a medium ES (d = 0.77, 95% CI: 0.54, 0.99).

Caregiving intensity, measured by the Level of Care Index, elicited the largest ES for EQ-HWB-S, albeit with a small magnitude (d = 0.39, 95% CI: 0.20, 0.55). This was followed by small ESs for EQ-5D-5L (d = 0.35, 95% CI: 0.19, 0.51), ASCOT-Carer (d = 0.31, 95% CI: 0.13, 0.48), and a negligible ES for CarerQol (d = 0.19, 95% CI: 0.01, 0.26). Hours of care per week had an impact, with EQ-HWB-S demonstrating the largest ES with a small magnitude

(d = 0.46, 95% CI: 0.28, 0.63). Employment interference due to caregiving yielded the largest ES for CarerQol with medium magnitude (d = 0.55, 95% CI: 0.37, 0.71), followed by small ESs for ASCOT-Carer (d = 0.49, 95% CI: 0.32, 0.67), EQ-HWB-S (d = 0.36, 95% CI: 0.19, 0.53), and EQ-5D-5L (d = 0.32, 95% CI: 0.15, 0.47). The Burns Relationship Scale showed medium to large ESs in differentiating between caregivers who are dissatisfied and satisfied in their relationship with their care recipient, ranging from 0.45 (95% CI: 0.27, 0.63) for EQ-5D-5L to 0.99 (95% CI: 0.77, 1.19) for ASCOT-Carer. Care recipients' self-perceived burden elicited the largest ES for EQ-HWB-S with medium magnitude (d = 0.80, 95% CI: 0.51, 1.06), followed by medium ESs for CarerQol-7D (d = 0.70, 95% CI: 0.43, 0.96), and EQ-5D-5L (d = 0.63, 95% CI: 0.32, 0.93), whereas ASCOT-Carer showed a small ES (d = 0.38, 95% CI: 0.11, 0.64).

Discussion

To our knowledge, this study is among the first to examine the psychometric properties of the EQ-HWB and its shorter version, EQ-HWB-S, in comparison with other caregiver-related measures, such as ASCOT-Carer and CarerQol, as well as the HRQoL measure

Table 3. Correlations between EQ-5D-5L, EQ-HWB, ASCOT-Carer, and CarerQol scores.

Instrument	EQ-5D-5L Index	EQ VAS	ASCOT Index	CarerQol Index	CarerQol VAS
EQ-HWB-S index	0.72	0.56	0.54	0.54	0.48
EQ-HWB-S LSS	−0.68	−0.55	−0.60	−0.58	−0.54
EQ-HWB (psychosocial subscale)	−0.59	−0.49	−0.66	−0.61	−0.62
EQ-HWB (physical sensation)	−0.65	−0.53	−0.33	−0.38	−0.27
EQ-HWB (activities)	−0.55	−0.42	−0.23	−0.33	−0.16

Note. All Pearson's correlation coefficient were statistically significant ($P < .001$). Correlations were interpreted according to Cohen's guidelines, ie, "strong" (0.51), "moderate" (0.31-0.50), "weak" (0.11-0.30), and "none" (0-0.10). Strong correlations are bolded. (+) indicates positive direction; (−) negative direction. More details on scoring are provided in the Methods section.
ASCOT-Carer, Adult Social Care Outcomes Toolkit for Carers; CarerQol, The Carer-related Quality of Life; EQ-HWB LSS, EQ Health and Well-being Level Summary Score; EQ-HWB-S LSS, EQ Health and Well-being Short Form Level Summary Score; LSS, Level Summary Score.

Table 4. Mean caregiver-related index scores by informal caregiving situation.

		EQ-5D-5L Index	EQ-HWB-S Index	ASCOT-Carer Index	CarerQol Index
N Mean (SD)					
Type of relationship					
Spouse/partner	174	0.74 (0.25)	0.69 (0.24)	0.73 (0.22)	69.50 (20.94)
Parent	21	0.71 (0.27)	0.63 (0.32)	0.58 (0.26)	59.73 (29.25)
Child	150	0.73 (0.29)	0.66 (0.25)	0.70 (0.24)	69.85 (22.96)
Sibling	31	0.66 (0.32)	0.64 (0.28)	0.76 (0.22)	71.03 (18.79)
Another relative	30	0.73 (0.30)	0.72 (0.21)	0.76 (0.18)	79.22 (14.29)
Friend/family friend	60	0.72 (0.29)	0.61 (0.30)	0.76 (0.24)	68.80 (23.33)
Grandchild	38	0.71 (0.32)	0.68 (0.28)	0.78 (0.22)	76.11 (19.44)
F-statistic (P value)		0.39 (.888)	1.13 (.342)	2.45 (.024)	2.23 (.039)
Level of Care Index					
Level 1	27	0.89 (0.13)	0.83 (0.19)	0.82 (0.21)	77.56 (16.26)
Level 2	38	0.78 (0.21)	0.74 (0.22)	0.75 (0.23)	72.57 (19.84)
Level 3	87	0.77 (0.22)	0.71 (0.22)	0.77 (0.18)	72.00 (18.76)
Level 4	274	0.70 (0.31)	0.65 (0.27)	0.74 (0.23)	71.09 (22.08)
Level 5	78	0.69 (0.29)	0.59 (0.27)	0.57 (0.26)	61.91 (24.97)
F-statistic (P value)		4.21 (.002)	6.36 (<.0001)	11.73 (<.0001)	4.03 (.003)
Hours of care per week (average)					
1-20	280	0.76 (0.24)	0.72 (0.21)	0.76 (0.20)	72.72 (20.25)
21 +	224	0.65 (0.34)	0.60 (0.30)	0.71 (0.23)	70.01 (21.58)
F-statistic (P value)		14.70 (.0001)	19.65 (<.0001)	4.59 (.032)	1.51 (.220)
Duration of caregiving (years)					
>2 years	189	0.75 (0.26)	0.69 (0.23)	0.75 (0.22)	73.17 (20.97)
2≥ years	315	0.71 (0.29)	0.65 (0.27)	0.71 (0.24)	68.55 (22.23)
F-statistic (P value)		2.84 (.09)	2.50 (.114)	2.62 (.106)	5.30 (.021)
Employment interference due to caregiving					
No	220	0.78 (0.21)	0.72 (0.23)	0.79 (0.20)	76.83 (19.22)
Yes	284	0.69 (0.32)	0.63 (0.27)	0.68 (0.24)	65.21 (22.46)
F-statistic (P value)		12.37 (.001)	16.37 (<.0001)	28.89 (<.0001)	37.54 (<.0001)
Primary caregiver to care recipient					
No	65	0.76 (0.25)	0.69 (0.24)	0.76 (0.18)	75.83 (15.77)
Yes	439	0.72 (0.28)	0.66 (0.26)	0.72 (0.24)	69.46 (22.52)
F-statistic (P value)		1.09 (.297)	0.69 (.405)	2.08 (.028)	4.43 (.003)
Support more than one care recipient with a disability or chronic condition					
No	455	0.73 (0.27)	0.68 (0.25)	0.72 (0.23)	71.02 (21.51)
Yes	49	0.61 (0.32)	0.54 (0.25)	0.67 (0.23)	63.44 (23.99)
F-statistic (P value)		9.29 (.002)	12.95 (.0004)	2.48 (.116)	5.35 (.021)
Choice in taking on this responsibility for caring for care recipient					
No	208	0.71 (0.29)	0.65 (0.27)	0.65 (0.25)	66.93 (21.86)
Yes	296	0.74 (0.27)	0.68 (0.25)	0.77 (0.21)	72.64 (21.58)
F-statistic (P value)		1.36 (.244)	1.92 (.166)	35.25 (<.0001)	8.46 (.004)
Living in the same household as care recipient					
No	160	0.77 (0.25)	0.70 (0.24)	0.78 (0.21)	77.03 (19.17)
Yes	344	0.71 (0.29)	0.65 (0.27)	0.70 (0.24)	67.44 (21.84)
F-statistic (P value)		5.17 (9.023)	3.96 (.047)	16.71 (<.0001)	15.92 (<.0001)
Burns Relationship Scale					
Dissatisfied	205	0.65 (0.30)	0.57 (0.26)	0.60 (0.24)	60.92 (21.01)
Satisfied	299	0.78 (0.25)	0.73 (0.23)	0.80 (0.19)	76.77 (18.39)
F-statistic (P value)		24.65 (<.0001)	55.04 (<.0001)	119.38 (<.0001)	81.21 (<.0001)

Table 4. Continued

		EQ-5D-5L Index	EQ-HWB-S Index	ASCOT-Carer Index	CarerQol Index
Care recipient self-perceived burden to caregivers (caregiver burden-proxy)					
Not at all	192	0.79 (0.23)	0.72 (0.25)	0.78 (0.23)	77.19 (21.50)
Slightly	137	0.74 (0.24)	0.69 (0.24)	0.75 (0.19)	70.99 (21.50)
Moderately	91	0.71 (0.26)	0.68 (0.22)	0.64 (0.23)	66.09 (17.63)
A lot	53	0.62 (0.38)	0.54 (0.28)	0.66 (0.25)	59.14 (24.73)
Extremely	31	0.52 (0.41)	0.44 (0.33)	0.63 (0.28)	55.74 (22.68)
F-statistic (*P* value)		54.75 (<.0001)	60.97 (<.0001)	41.16 (<.0001)	88.63 (<.0001)
General health					
Excellent	48	0.80 (0.27)	0.80 (0.22)	0.90 (0.13)	75.99 (22.27)
Very good	144	0.84 (0.17)	0.78 (0.19)	0.80 (0.19)	76.68 (19.41)
Good	180	0.74 (0.20)	0.67 (0.24)	0.73 (0.21)	71.56 (18.93)
Fair	113	0.58 (0.22)	0.52 (0.25)	0.58 (0.24)	58.86 (22.92)
Poor	19	0.41 (0.30)	0.34 (0.31)	0.54 (0.30)	55.71 (25.42)
F-statistic (*P* value)		23.39 (<.0001)	35.17 (<.0001)	30.80 (<.0001)	16.80 (<.0001)

Note. F-statistic for the Analysis of Variance (ANOVA) analysis is presented, indicating the ratio of the between-group variability to the within-group variability, with a higher F-statistic suggesting a statistically significant difference among the group means. More details on scoring are provided in the Methods section.
ADLs indicates Activities of Daily Living; ASCOT-Carer, Adult Social Care Outcomes Toolkit for Carers; CarerQol, The Carer-related Quality of Life; EQ-HWB LSS, EQ Health and Well-being Level Summary Score; EQ-HWB-S LSS, EQ Health and Well-being Short Form Level Summary Score; IADLs, Instrumental Activities of Daily Living; LSS, Level Summary Score.

Table 5. Known-group comparison effect sizes by informal caregiving situation.

Variable for comparison	EQ-5D-5L Index	EQ-HWB-S Index	ASCOT-Carer Index	CarerQol Index
Effect Sizes (95% CL)				
Level of Care Index				
Levels 1,2,3 vs Levels 4,5	0.35 (0.19, 0.51)	0.39 (0.20, 0.55)	0.31 (0.13, 0.48)	0.19 (0.01, 0.26)
Hours of care per week (average)				
0-20 vs 21 or more	0.33 (0.15, 0.51)	0.46 (0.28, 0.63)	0.43 (0.24, 0.61)	0.25 (0.08, 0.43)
Care recipient self-perceived burden to caregivers (caregiver burden-proxy)				
No/slight/moderately vs a lot/extremely	0.63 (0.32, 0.93)	0.80 (0.51, 1.06)	0.38 (0.11, 0.64)	0.70 (0.43, 0.96)
Duration of caregiving (years)				
Less than 2 vs more than 2 years	0.16 (−0.02, 0.33)	0.15 (−0.03, 0.32)	0.15 (−0.02, 0.32)	0.21 (0.03, 0.38)
Employment interference due to caregiving				
Yes vs no	0.32 (0.15, 0.47)	0.36 (0.19, 0.53)	0.49 (0.32, 0.67)	0.55 (0.37, 0.71)
Primary caregiver to care recipient				
Yes vs no	0.14 (−0.11, 0.36)	0.11 (−0.13, 0.35)	0.19 (−0.02, 0.39)	0.29 (0.09, 0.49)
Support more than 1 care recipient with a disability or chronic condition				
Yes vs no	0.45 (0.13, 0.81)	0.54 (0.24, 0.84)	0.24 (−0.05, 0.55)	0.35 (0.03, 0.68)
Choice in taking on this responsibility for caring for care recipient				
Yes vs no	0.11 (−0.07, 0.28)	0.13 (−0.06, 0.31)	0.54 (0.35, 0.72)	0.26 (0.08, 0.44)
Living in the same household as care recipient				
Yes vs no	0.22 (0.03, 0.38)	0.19 (0.01, 0.37)	0.39 (0.21, 0.57)	0.26 (0.08, 0.44)
Burns Relationship Scale				
Dissatisfied vs satisfied	0.45 (0.27, 0.63)	0.67 (0.48, 0.87)	0.99 (0.77, 1.19)	0.81 (0.62, 1.00)
General health				
Excellent/very good/good vs fair/poor	0.86 (0.62, 1.10)	1.00 (0.77, 1.23)	0.96 (0.72, 0.96)	0.77 (0.54, 0.99)

EQ-5D-5L. The results support the validity of EQ-HWB and EQ-HWB-S in assessing health and well-being in informal caregivers, demonstrating sensitivity to a variety of caregiving situations and by caregiving intensity. Strong correlations between the EQ-HWB-S and the EQ-5D-5L, ASCOT and CarerQol indices, suggest that these measures capture related constructs. EQ-HWB and EQ-HWB-S were sensitive to differences in caregiving situations and intensity, at least comparable to other measures, depending on the KGC anchor. Although ASCOT-Carer and CarerQol measures showed larger ES in some cases, the EQ-HWB-S index and EQ-5D-5L still demonstrated significant differences in mean scores between groups and may offer a more concise and practical measure for assessing caregiver-related health and well-being by focusing key aspects of HRQoL. This finding is consistent with previous studies on informal caregivers, which have indicated that the EQ-5D-5L is valid for use as an outcome measure for this population.[17]

Toward demonstrating discriminative validity of the measures, KGC based on living in the same household or Level of Care Index performed poorly, whereas care recipient self-perceived burden and caregiver general health were better anchor-based criteria. The global item for care recipient self-perceived burden to caregivers is comprehensive in its ability to identify a broad range of burden, from those who reported no burden to those who reported extreme burden. This is important for future assessment of caregiver burden because it offers the possibility of an external source of caregiver burden, ie, the care recipient. In this way, the care recipient could serve as the single source of information for treatment effects for both the care recipient and their caregiver in health economics and outcomes studies that seek to capture spillover effects.[51]

The findings provide valuable insights into the psychometric properties of these instruments, informing their selection. The KGC demonstrated that different caregiving situations have a significant impact on the health and well-being of informal caregivers.[68,69] The wide range of scores across different caregiving situations emphasizes the importance of selecting the appropriate instruments used in economic evaluations of interventions targeting informal caregivers. When considering the implications of various health and well-being measures in economic evaluations, each measure has unique value and inherent constraints. The EQ-HWB-S, for example, is a promising new measure for assessing health and well-being. Its performance in our study, particularly with a wide range of mean values across caregiver general health and hours of care per week highlights its potential for comprehensive assessments. Conversely, for situations involving high caregiving intensity or employment interference, measures such as ASCOT-Carer and CarerQol may be preferable because of their focus on these specific aspects of caregiving. Although ASCOT-Carer and CarerQol cannot be aggregated for QALY estimations, their value lies in that they cover specific domains of caregiving, which can inform cost-effectiveness analysis focused on caregiving interventions. Finally, the EQ-5D-5L's demonstrated validity as an outcome measure for informal caregivers is particularly relevant when prioritizing health maximization in economic evaluations. This context-driven approach to selecting health and well-being measures ensures that the chosen instrument aligns with the specific characteristics of the caregiving situation and the overarching objectives of the intervention or study. The choice of measure can significantly influence cost-effectiveness analyses and policy decisions. Consequently, the EQ-HWB-S, recently endorsed by The Netherlands Health Technology Assessment, has shown considerable promise in its performance across a variety of caregiving contexts. This versatility is a significant advantage, particularly because the EQ-HWB-S is designed to enable the assessment of outcomes within and across different sectors (eg, health and social care).

When interpreting this study's results, several limitations inherent in online survey research must be considered. The use of an online panel for recruitment may not fully capture all care recipient-caregiver situations in the United States. Additionally, it is unclear how many dyads chose not to participate or their reasons for opting out. Our survey, conducted solely in English, may have excluded non-English speaking caregivers, suggesting the need for future research to include multiple languages for broader inclusivity. The potential exclusion of older caregivers less familiar with the internet and the focus solely on adult caregiver-care recipient dyads, omitting caregivers of children, further narrows the study's scope. It is noted that individuals, especially parents, may take up to 2 years to identify as informal caregivers, which could affect future research directions. The study also faced potential social desirability bias, despite efforts to minimize it by instructing participants not to discuss their responses until they completed the survey. Additionally, the convergent validity results might be influenced by shared method variance or random measurement error.[70] Finally, these study findings are based on cross-sectional data, highlighting differences in caregiver health at a single time point; they do not assess responsiveness or changes over time. Future research should prioritize longitudinal studies to address this gap and provide a more comprehensive understanding of caregiver health trajectories over time.

In conclusion, the findings suggest that the EQ-HWB and EQ-HWB-S are valid measures for assessing health and well-being in informal caregivers. The study underscores the importance of choosing suitable measures based on the intervention's aims because each instrument can capture unique aspects of the intricate caregiving experience. This tailored approach is vital for developing more effective support strategies for both care recipients and their informal caregivers, ultimately leading to more comprehensive evaluations of healthcare interventions and their cost-effectiveness.

Author Disclosures

Author disclosure forms can be accessed below in the Supplemental Material section.

Supplemental Material

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