HOW WELL DO GENERIC PREFERENCE-BASED MEASURES PERFORM IN INFORMAL CARERS? A PSYCHOMETRIC STUDY IN AUSTRALIA

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BACKGROUND AND OBJECTIVE

Using generic preference-based measures (GPBMs) to capture informal care outcomes provides consistency across economic evaluations and facilitates combining patient and carer quality-adjusted life years. This study assesses the psychometric performance of the 5-level EQ-5D (EQ-5D-5L) and Assessment of Quality-of-Life 8-Dimension (AQoL-8D) among Australian informal carers and how well the two GPBMs conceptually overlap with carer-specific measures..

METHODOLOGY

This was a secondary data analysis of an online survey from 500 informal carers containing carer-related measures (Adult Social Care Outcomes Toolkit for Carers [ASCOT-Carer], Care-Related Quality-of-Life [CarerQol], Carer Experience Scale [CES], and Caregiver Reaction Assessment[CRA]) and GPBMs (EQ-5D-5L and AQoL-8D). Descriptive analysis, ceiling effects, test-retest reliability, convergent and known-group validity were conducted. Exploratory factor analysis (EFA) was conducted to understand the conceptual overlap between the GPBMs and carer-related measures.

RESULTS

Descriptive	EQ-5D-5L (n = 476, 95%)	AQoL-8D (n = 469, 94%)
Index - mean (sd)	0.819 (0.213)	0.604 (0.196)
Ceiling effect (full health) – n (%)	45 (9%)	18 (4%)

Test-retest reliability	Weighted Kappa (95% CI)	Agreement
Mobility	0.737 (0.635, 0.838)	93.75%
Self-care	0.704 (0.559, 0.850)	95.57%
Usual activities	0.587 (0.474, 0.700)	88.48%
Pain and discomfort	0.574 (0.470, 0.677)	90.23%
Anxiety and depression	0.603 (0.504, 0.702)	88.67%
Index - ICC (95% CI)	0.825 (0.760, 0.873)	

Kappa interpretation: fair (0.21-0.40), moderate (0.41-0.60), substantial (0.61–0.80) and almost perfect (0.81-1.00) agreement
ICC interpretation: moderate (0.50-0.75), good (0.75–0.90) and excellent (>0.90) reliability

Known-group validity	EQ-5D-5L	AQoL-8D
Weekly care hours (<20 vs 20-39 vs ≥40)	0.08	0.10
Number of tasks (1-4 vs 5-8 vs >8)	0.04	0.10
Number of diagnoses (1 vs 2 vs ≥3)	0.06	0.03
Duration of care in months (<24 vs ≥24)	0.37	0.34
Only carer	0.27	0.15^
More than one care recipient	0.18	0.15^
Sharing household with care recipient	0.14^	0.23

^ - significant at p<0.01, all other significant at p<0.001
Effect sizes:
Kruskal-Wallis (3 groups): <0.06 small, 0.06 to 0.14 moderate and ≥0.14 large
Mann-Whitney (2 groups): <0.30 small, 0.30 to 0.50 moderate and >0.50 large
Both measures were able to discriminate between hypothesized groups

Exploratory Factor Analysis

Convergent validity	EQ-5D-5L	AQoL-8D
CarerQoL Australia value set	0.496	0.613
CarerQoL UK value set	0.496	0.616
ASCOT-Carer	0.558	0.678
CES	0.480~	0.616~
CRA (Schedule)	-0.443	-0.560
CRA (Financial)	-0.352	-0.438~
CRA (Family)	-0.268	-0.394
CRA (Health)	-0.565	-0.675
CRA (Self-esteem)	0.073^	0.232

Coefficient strength: weak (<0.40), moderate (0.40-0.70), strong (>0.70)
~ - overperformed the hypothesis; ^ - non-significant correlation, all other hypotheses were confirmed and significant at p<0.001

Factor loading is ≥0.40, factor loading in italics is ≥0.32
Factors with dark background indicate overlap between GPBMs and carer measures, whereas light background indicate no overlap.

CONCLUSION

- Both EQ-5D-5L and AQoL-8D are acceptable tools for use in informal carers
- The choice of instrument may depend on the constructs intended to be captured
- Economic evaluations may still benefit from using both a generic-preference based measure and a carer-specific measure to capture the broader spillover effects from caring