

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

Mental health	Outlook	Relations	Activities outside role	Physical health	Pain	Impact of role	Role fulfilment	Support
Mental health problems	Space and time for yourself	Social participation and involvement	Occupation	Getting a round	Frequency of pain	Personal safety	Fulfillment	Feeling encouraged and supported
Physical health problems	Assistance from organisations and government	Support	Control over daily life	Community role	Mobility	Fulfillment	Relational problems	Support
Sadness	Energy level	Support from family and friends	Self-care	Frequency of pain	Degree of pain	Relational problems	Fulfillment from caring	Support from family and friends
Confidence	Self-harm	Social exclusion	Social participation and involvement	Family role	Pain interference	Mental health problems	Control over caring	
Calm	Enthusiasm	Close relationships	Space and time for yourself	Mobility	Mobility	Problems combining daily activities	Getting on with the person you care for	
Communication	Happiness	Happiness	Feeling encouraged and supported	Self-harm	Pain and discomfort	Financial problems		
Sleep	Coping	Enjoy close relationships	Problems combining daily activities	Self-care		Physical health problems		
Worthlessness	Pleasure	Pleasure	Activities outside of caring	Degree of pain				
Anger	Contentment	Contentment	Social exclusion	Pain interference				
Self-harm	Vision	Social isolation	Social isolation	Vision				
Worry	Control	Intimacy		Household tasks				
Coping	Personal care			Hearing				
Feeling a burden				Mobility				
Control				Personal care				
Depression				Usual activities				
Despair				Pain and discomfort				
Anxiety/depression								

Legend

ASCOT-Carer

CarerQoL

CES

AQoL-8D

EQ-5D-5L

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.

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		

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