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INTRODUCTION

Despite affecting millions globally, **dementia research** faces a **critical methodological challenge**: the widespread use of 'proxy' reporting in health economics studies.

Evidence reveals substantial disparities between proxy assessments and individuals' self-reported experiences, raising concerns about the validity of current quality-of-life assessment in dementia research.

OBJECTIVE

This study addresses this critical gap by directly engaging with people living with dementia, offering insights into their authentic perspectives on quality-of-life. Specific objectives are:

1 - Capture authentic experiences of quality-of-life from people with mild to moderate dementia.

2 - Compare these lived experiences with existing preference-based outcome measures.

3- Inform development of more accurate, person-centered evaluation methods.

METHOD

STUDY DESIGN & PARTICIPANTS

We conducted a qualitative phenomenological study with 24 people living with mild and moderate dementia in the community. Participants were purposively sampled through Dublin memory clinics and dementia support groups to ensure diverse representation across dementia severity, age, and location.

DATA COLLECTION

Semi-structured interviews (2022-2023) explored participants' journey with dementia and their personal understanding of 'a good life'. Interviews were conducted in-person or via video call, with care partner presence for support.

ANALYSIS

Dementia severity classified using DCDS and GPCOG scales. Identified themes compared with established preference-based measures (DEM-QOL, QOL-AD, AQOL-4D, 15D, QWB, HUI2 and HUI3, EQ-5D, ICECAP-O, ICECAP-SCM)

RESULTS

KEY DEMOGRAPHICS

Diagnosis: 50% Lewy Body dementia, 46% Alzheimer's , 4% Other

Severity: 50% Mild, 46% Moderate, 4% Advanced

Age range: 55-85 years

Gender: 54% Male, 46% Female

THEMES OF A 'GOOD LIFE'

- Social interactions
- Supportive companionship
- Enjoyable activities
- Independence and autonomy
- Physical health
- Cognitive function
- Fear of disease progression
- Adaptation to changing abilities
- Privacy concerns and stigma
- Emotional wellbeing
- Comfortable environment
- Financial stability

KEY INSIGHTS

- While QOL-AD demonstrates the strongest coverage (10/12 themes), even this comprehensive measure fails to capture crucial aspects of the dementia journey, particularly adaptation to changing abilities and privacy/stigma concerns.
- The dynamic nature of dementia experience is evident in how perceptions of a 'good life' transform between mild and moderate stages, yet current measures largely employ static assessment approaches.
- Core elements of human experience - social connections, autonomy, and emotional wellbeing - persist in importance across disease stages, emphasizing the need to preserve these fundamental aspects of life.

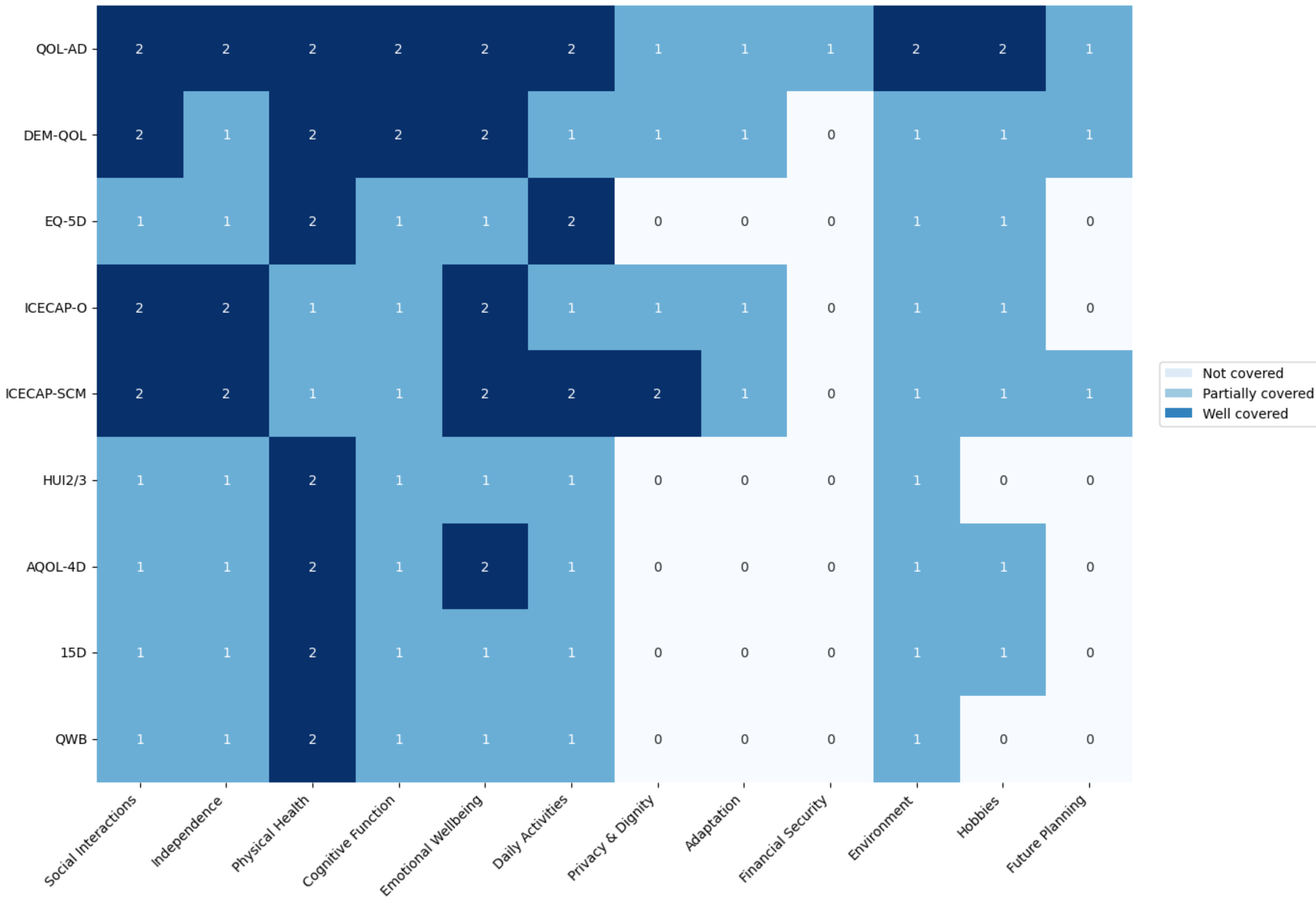


Table 1: Cross-tabulation of themes of the ‘good life’ against commonly used preference-based outcome measures used in dementia research

IMPLICATIONS

MEASUREMENT REFORM

- Development of adaptive assessment tools that can flex with disease progression
- Integration of both universal and stage-specific quality of life indicators
- Development of measures that capture nuanced interplay between physical, cognitive, and social wellbeing

METHODOLOGICAL INNOVATION

- Prioritization of direct input from people living with dementia in measure development
- Implementation of mixed-method approaches that combine quantitative assessment with qualitative insights
- Development of innovative data collection methods suitable for varying cognitive abilities

PRACTICE EVOLUTION

- Shift from proxy-dominated to person-centered assessment approaches
- Recognition of the need for routine quality of life assessment
- Integration of both clinical and personal experiences

CONCLUSION

This study provides evidence that current preference-based measures in dementia research require significant evolution to fully capture the lived experience of a 'good life' from the perspective of people living with dementia. Our findings reveal both the complexity of measuring quality of life in dementia and the urgent need for inclusive practice reform.

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