

Quality of Life in Older Adults with Neurocognitive Disorders: A Comparison of Self- and Caregiver-Reports in a Chinese Population

Poster
#0927

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Take away messages: 1) We addressed an evidence gap by examining agreement between self- and proxy-reported health-related quality of life across mild and major neurocognitive disorders using domain-level analyses; 2) Self–proxy agreement is generally low to moderate and declines with cognitive impairment, with the largest discrepancies in function-related domains such as mobility and usual activities. 3) Self-proxy disagreement was further shaped by patient characteristics, caregiver burden, caregiving intensity, and caregiver psychosocial factors. 4) Our findings highlight dual-source HRQoL assessment and careful interpretation of proxy reports within different caregiver contexts in HEOR and healthcare decision making,

INTRODUCTION	METHODS	RESULTS	CONCLUSIONS	Appendix Table																																																																																																																																										
Accurate assessment of health-related quality of life (HRQoL) is crucial for understanding and developing care interventions for older adults with neurocognitive disorders (NCD). However, reliance on self-reports may be compromised by cognitive decline, while proxy-reports by caregivers can diverge from participant perceptions.	- Data were collected from Hong Kong Mental Morbidity Survey for Older People, a population-based and cross-sectional study to investigate NCD prevalence and disease burden in Hong Kong. - Eligible participants were Chinese adults aged ≥60 and their unpaid caregivers aged ≥18 who handled communication, care, decision-making, and could speak Chinese. - In total, 302 pairs of participants and their caregivers (normal cognition [NC]: 96; mild cognitive impairment [MCI]: 173; dementia: 33) were included in analysis. - HRQoL was measured using the EQ-5D-5L, reported by both participants and caregivers. Agreement was evaluated using Intraclass Correlation Coefficient (ICC). - Multinomial logistic regression and linear regression were employed to identify factors associated with the directional and absolute discrepancies of self-proxy data.	- Agreement between self- and proxy-reports of HRQoL was generally moderate-to-poor among three groups. ICC for the overall utility index declined with cognitive impairment severity (NC 0.544, MCI 0.290, dementia 0.301). The same trends were observed on subdomains of mobility (NC 0.254, MCI 0.135, dementia 0.048) and mood (NC 0.305, MCI 0.103, dementia -0.066). Higher caregiving burden in caregivers was associated with an increased likelihood of carers’ overstating in patients’ mobility problems (<i>p</i><.05) and usual activity difficulties (<i>p</i>=.001). Conversely, higher depression scores in caregivers increased odds of understating patients' emotional distress (<i>p</i><.01). - Factors such as caregiving hours, participants’ educational level, and their physical and mental health conditions were also associated with discrepancies between patient-proxy reported HRQoL (<i>p</i><.05).	Significant discrepancies exist between participant and caregiver assessments of HRQoL, exaggerated by the participant's cognitive status and caregivers’ worsened well-being, and higher caregiving intensity. - Larger discrepancies where caregivers providing lower ratings were observed among individuals with older age and chronic conditions. Neuropsychiatric manifestations were generally associated with smaller self–caregiver discrepancies in mood domain. - Clinical professionals should exercise caution when utilizing caregiver-reported quality of life as a substitute for patient-reported, also considering physical and psychological burden of caregivers.	<table><tr><th colspan="6">Table. EQ5D rating by cognitive groups and raters</th></tr><tr><th></th><th></th><th>Normal</th><th>MCI</th><th>Dementia</th><th>P-value (ANOVA)</th></tr><tr><td rowspan="4">Mobility</td><td>Self-report</td><td>1.09±0.44</td><td>1.21±0.48</td><td>1.09±0.35</td><td>0.081</td></tr><tr><td>Proxy-report</td><td>1.24±0.51</td><td>1.59±0.77</td><td>2.13±0.82</td><td><0.001</td></tr><tr><td>P-value (Wilcoxon)</td><td>0.004</td><td><0.001</td><td>0.002</td><td></td></tr><tr><td>Absolute Discrepancy ICC</td><td>0.27±0.58 0.254</td><td>0.59±0.74 0.135</td><td>1.07±0.84 0.048</td><td><0.001</td></tr><tr><td rowspan="4">Self care</td><td>Self-report</td><td>1.00±0.00</td><td>1.02±0.13</td><td>1.00±0.00</td><td>0.396</td></tr><tr><td>Proxy-report</td><td>1.00±0.00</td><td>1.04±0.29</td><td>1.57±1.10</td><td><0.001</td></tr><tr><td>P-value (Wilcoxon)</td><td>1.000</td><td>0.248</td><td>0.039</td><td></td></tr><tr><td>Absolute Discrepancy ICC</td><td>0.00±0.00 a</td><td>0.05±0.32 -0.025</td><td>0.57±1.10 a</td><td><0.001</td></tr><tr><td rowspan="4">Usual activity</td><td>Self-report</td><td>1.01±0.91</td><td>1.06±0.25</td><td>1.04±0.27</td><td>0.241</td></tr><tr><td>Proxy-report</td><td>1.08±0.34</td><td>1.39±0.85</td><td>2.60±1.49</td><td><0.001</td></tr><tr><td>P-value (Wilcoxon)</td><td>0.084</td><td><0.001</td><td>0.002</td><td></td></tr><tr><td>Absolute Discrepancy ICC</td><td>0.09±0.35 -0.021</td><td>0.37±0.81 0.227</td><td>1.56±1.45 0.147</td><td><0.001</td></tr><tr><td rowspan="4">Pain</td><td>Self-report</td><td>1.53±0.91</td><td>1.40±0.72</td><td>1.44±0.97</td><td>0.464</td></tr><tr><td>Proxy-report</td><td>1.62±0.74</td><td>1.81±0.81</td><td>1.89±0.99</td><td>0.141</td></tr><tr><td>P-value (Wilcoxon)</td><td>0.143</td><td><0.001</td><td>0.021</td><td></td></tr><tr><td>Absolute Discrepancy ICC</td><td>0.61±0.72 0.520</td><td>0.77±0.73 0.310</td><td>0.70±0.69 0.748</td><td>0.254</td></tr><tr><td rowspan="4">Mood</td><td>Self-report</td><td>1.22±0.56</td><td>1.09±0.31</td><td>1.02±0.13</td><td>0.013</td></tr><tr><td>Proxy-report</td><td>1.36±0.65</td><td>1.42±0.67</td><td>1.45±0.66</td><td>0.771</td></tr><tr><td>P-value (Wilcoxon)</td><td>0.091</td><td><0.001</td><td>0.020</td><td></td></tr><tr><td>Absolute Discrepancy ICC</td><td>0.44±0.65 0.305</td><td>0.45±0.65 0.103</td><td>0.46±0.66 -0.066</td><td>0.987</td></tr><tr><td rowspan="4">Overall score</td><td>Self-report</td><td>0.90±0.17</td><td>0.92±0.11</td><td>0.93±0.15</td><td>0.437</td></tr><tr><td>Proxy-report</td><td>0.86±0.12</td><td>0.80±0.16</td><td>0.66±0.20</td><td><0.001</td></tr><tr><td>P-value (Wilcoxon)</td><td>0.001</td><td><0.001</td><td>0.001</td><td></td></tr><tr><td>Absolute Discrepancy ICC</td><td>0.11±0.13 0.544</td><td>0.16±0.14 0.290</td><td>0.29±0.20 0.301</td><td><0.001</td></tr></table> Note. a. Each of the following component variables has zero variance and is removed from the scale.	Table. EQ5D rating by cognitive groups and raters								Normal	MCI	Dementia	P-value (ANOVA)	Mobility	Self-report	1.09±0.44	1.21±0.48	1.09±0.35	0.081	Proxy-report	1.24±0.51	1.59±0.77	2.13±0.82	<0.001	P-value (Wilcoxon)	0.004	<0.001	0.002		Absolute Discrepancy ICC	0.27±0.58 0.254	0.59±0.74 0.135	1.07±0.84 0.048	<0.001	Self care	Self-report	1.00±0.00	1.02±0.13	1.00±0.00	0.396	Proxy-report	1.00±0.00	1.04±0.29	1.57±1.10	<0.001	P-value (Wilcoxon)	1.000	0.248	0.039		Absolute Discrepancy ICC	0.00±0.00 a	0.05±0.32 -0.025	0.57±1.10 a	<0.001	Usual activity	Self-report	1.01±0.91	1.06±0.25	1.04±0.27	0.241	Proxy-report	1.08±0.34	1.39±0.85	2.60±1.49	<0.001	P-value (Wilcoxon)	0.084	<0.001	0.002		Absolute Discrepancy ICC	0.09±0.35 -0.021	0.37±0.81 0.227	1.56±1.45 0.147	<0.001	Pain	Self-report	1.53±0.91	1.40±0.72	1.44±0.97	0.464	Proxy-report	1.62±0.74	1.81±0.81	1.89±0.99	0.141	P-value (Wilcoxon)	0.143	<0.001	0.021		Absolute Discrepancy ICC	0.61±0.72 0.520	0.77±0.73 0.310	0.70±0.69 0.748	0.254	Mood	Self-report	1.22±0.56	1.09±0.31	1.02±0.13	0.013	Proxy-report	1.36±0.65	1.42±0.67	1.45±0.66	0.771	P-value (Wilcoxon)	0.091	<0.001	0.020		Absolute Discrepancy ICC	0.44±0.65 0.305	0.45±0.65 0.103	0.46±0.66 -0.066	0.987	Overall score	Self-report	0.90±0.17	0.92±0.11	0.93±0.15	0.437	Proxy-report	0.86±0.12	0.80±0.16	0.66±0.20	<0.001	P-value (Wilcoxon)	0.001	<0.001	0.001		Absolute Discrepancy ICC	0.11±0.13 0.544	0.16±0.14 0.290	0.29±0.20 0.301	<0.001
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We aims to compare self- and caregiver-reports on HRQoL among older adults with NCD in a Chinese population and to examine factors associated with these discrepancies. Specifically, we assess: - whether caregivers report lower EQ-5D utility than older adults, - whether self–proxy discrepancies in EQ-5D increase with cognitive impairment and vary by domain observability; - whether self–proxy discrepancies are related to caregiver burden, depressive symptoms, and caregiving hours.			Presenter: Daisy SHUTING LI daisy.li@cuhk.edu.hk Correspondence: Prof. Linda Lam cwlam@cuhk.edu.hk	 ALZHEIMER'S ASSOCIATION AAIC>26																																																																																																																																										