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## Agreement between People with Aphasia and Their Proxies on Health-Related Quality of Life after Stroke, Using the Greek SAQOL-39g

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### ABSTRACT

Health related quality of life (HRQL) measures are increasingly used to evaluate stroke interventions. People with severe aphasia after stroke may be unable to self-report on such measures, necessitating the use of proxy respondents. This study explored the level of agreement between people with aphasia and their proxies on the Greek Stroke and Aphasia Quality of Life Scale-39 generic version (SAQOL-39g) and whether this agreement was influenced by proxy levels of depression and carer strain. Methods: Participants were people with aphasia (PWA) who were over six months post-stroke and medically stable. Proxies were nominated by the PWA and had to see them at least twice a week. PWA completed the Frenchay Aphasia Screening Test and the Greek SAQOL-39g. Proxies completed the Greek SAQOL-39g proxy version, the General Health Questionnaire-12 and the Caregiver Strain Index. Results: 23 pairs of people with aphasia and their proxies took part. Proxies rated people with aphasia as more severely affected than they rated themselves. The difference was significant for the overall scale and the physical and communication domains ( $p < 0.05$ ); yet the bias introduced by these differences was small to moderate, with effect sizes ranging from 0.15 to 0.47. The strength of the agreement between people with aphasia and proxies was excellent for the overall scale and all three domains ( $ICC = 0.79 - 0.97$ ). The level of agreement was not associated with carer strain or emotional distress. We conclude that clinicians and researchers can use proxy ratings to evaluate the quality of life of people with severe aphasia but need to be aware of trends in proxy reporting and take these into account when interpreting data.

### KEYWORDS

Proxy; Stroke Outcome; Health-Related Quality Of Life; Aphasia; SAQOL-39g

### Cite this paper

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