Preliminary findings of the consequences of stroke and aphasia on family members’ Activity and Participation

Assunção Matos¹, Luis M. T. Jesus¹ & Madeline Cruice²

¹University of Aveiro, Portugal; ²City University London, UK

Background and Aims: Stroke and aphasia impact not only the individual, but also immediate family members (FM). Understanding this impact on FM enables clinicians to best support them in rehabilitation, as per recent best practices for stroke and aphasia rehabilitation¹. Many positive, neutral and negative outcomes in the different components of the ICF have been reported²,³, however the nature of third-party disability is still incomplete. This study explores how Portuguese FM view the impact of stroke and aphasia by comparing their own daily lives pre and post-stroke using The Activities/ Participation Profile (TAPP)⁴.

Method: Twelve FM (8 male; 4 female; aged 33-70 years; 7 spouses, 4 children, 1 father) completed TAPP in interviewer-administered format, and reported on their own activities undertaken before and after their partner’s/parent’s/child’s stroke (range 3-89 months post stroke), and the reasons for changing its frequency. Quantitative data was analysed descriptively using SPSS 23. Qualitative information was analysed using content analysis, and mapped onto the WHO ICF codes.

Results: Pre-stroke, FM engaged in an average of 68.67 activities (range 43-84; SD=11.19). 106 of the 110 TAPP activities were relevant and carried out by at least one FM. Post-stroke, FM engaged in an average of 64.66 activities (range 42-81; SD=12.72). Pre-post comparison using Wilcoxon’s showed no significant difference. Three FM reported no changes in their activities. Nine FM reported some changes. A total of 38 activities were referred by six FM as not being done anymore. Seven FM altered how often they engaged in activities. Activities undertaken less frequently were classified in the ICF domains of Community, Social and Civic Life, Mobility, Domestic Life, and Interpersonal Interactions and Relationships. Activities undertaken more frequently were related to Self-care, Domestic Life and Major Life Areas. No changes were reported on Communication and General Tasks and Demands. The most common reasons for altered activities were also reported.

Discussion: On the surface, stroke and aphasia appears to have no impact on quantity of FM activities, however the clear heterogeneity in the data, and global counts/analysis masks within-individual change. FM exchanged activities undertaken outside the home, social and leisure activities, for activities that involved caring for the individual with aphasia. Some FM (25%) appeared protected from change, and further analysis investigating age, education, relationship, hours of contact, time post onset, aphasia severity, and physical difficulty is needed to determine what may explain this finding.

Implications for clinical practice: Stroke and aphasia impacts on FM’s activity/participation, placing them at risk for low mood and reduced quality of life. TAPP is useful for its comprehensive scope, but is best administered in combination with clinical discussion of the importance and priority of activities, to identify need and set goals.

Conclusions: TAPP can be useful in determining the previous and current activities/participation of Portuguese FM. A more holistic understanding of these consequences, considering all domains pointed out by the ICF, is important. Further studies should be done in the future and negative, neutral and positive changes for different FM need to be addressed.
References


Correspondence information: maria.matos@ua.pt

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