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Titolo tesi: Quality of life in stroke survivor and caregiver dyads: a longitudinal study

ABSTRACT

Background. Stroke is the second leading cause of death in the world and the third leading cause of death in industrialised countries, after heart disease and cancer. Stroke has a significant impact on stroke survivor–caregiver dyads' quality of life (QOL). Depending on the site and type of stroke, survivors present physical, psychological, or emotional disabilities. Stroke survivors experience mood disorder, aphasia, dysphagia, depression, and decreased social interaction. Stroke also has a significant impact on caregivers' QOL. Several studies have shown that it can be burdensome for caregivers. Stroke caregivers often feel overloaded, unprepared, and a lack of confidence in their ability to care for the stroke survivor. Lower caregiver preparedness contributes to caregivers' burden, and caregivers who are burdened have a lower QOL. Although stroke survivors' and caregivers' QOL has been studied by several researchers, (1) no studies have analysed the existence of several trajectories in stroke survivors' QOL, (2) no prior studies have analysed the psychometric characteristics of the Caregiver Preparedness Scale (CPS) in the stroke population, and (3) no prior studies have analysed the interdependence within stroke dyads' QOL.

Objective. The objective of this doctoral program was (1) to identify distinct trajectories of physical, psychological, and social QOL in stroke survivors discharged home from rehabilitation hospitals and to evaluate their association with burden, anxiety, and depression in their caregivers, (2) to evaluate the factorial structure and reliability of the CPS for caregivers of stroke survivors, and (3) to examine, using a statistical approach that controls for the interdependence of stroke dyads, changes in stroke survivors' and caregivers' QOL and to determine if changes in survivors' physical functioning and caregivers' burden influence changes in stroke survivors' and caregivers' QOL.

Methods. A longitudinal design was used in this dissertation program, with data collection at baseline (T0) and after three (T1), six (T2), nine (T3), and 12 (T4) months. We enrolled a sample of 405 stroke survivors and 244 caregivers from 10 Italian provinces, and then, we conducted three separate studies to correspond with each doctoral objective. Stroke survivors and their caregivers were enrolled during the stroke survivors' discharges from the rehabilitation hospitals. Data were analysed with descriptive statistics and with latent growth curve modelling and latent growth mixture modelling (LGMM; Study 1), with confirmatory factor analysis (CFA; Study 2) and with multilevel modelling and Hierarchical Linear Modelling (HLM; Study 3).

Results. In the first study, three distinct trajectories of change in stroke survivors' QOL were identified in a good model solution (entropy = 0.90, posterior probabilities exceed 0.95%, smallest trajectory > 5%, Lo-Mendell-Rubin test = 1525.01 p = 0.001, parametric bootstrap test p < 0.001). The first trajectory of QOL (54.4%) included stroke survivors with relatively a high QOL that was stable across time in all domains (e.g., "stable high trajectory"). The second trajectory (37.0%) included stroke survivors with a relatively moderate QOL that was stable across time in all domains (e.g., "stable moderate trajectory"). The third trajectory (8.6%) included stroke survivors who had a marked improvement in QOL over the course of one year of follow-up (e.g., "recovery trajectory"). Quite interestingly, we saw patterns in caregiver strain that reflected stroke survivor trajectories of QOL: caregivers of survivors with a "stable high trajectory" had relatively low burden, anxiety, and depression; caregivers of survivors with a "stable moderate trajectory" had high caregiver burden, anxiety, and depression; and lastly, caregivers of survivors belonging to the "recovering trajectory" had a marked reduction in caregiver burden, anxiety, and depression over time. In the second

study, CFA supported the unidimensionality of the scale (comparative fit index = 0.98; RMSEA = 0.074 (90% CI 0.03–0.11), p = 0.14; TLI = 0.98; and SRMR = 0.024). Reliability also was supported: item-reliability index and item-total correlations above 0.30; composite reliability index = 0.93; Cronbach's alpha = 0.94; factor score determinacy = 0.97; and test– retest reliability = 0.92. In the third study, over 12 months, stroke survivors' physical (= 1.59, p < 0.001) and psychological (= 0.86, p < 0.05) QOL significantly improved; social and environmental QOL did not (p > 0.05). Caregivers' QOL, on average, did not change significantly over time p > 0.05. Improvements in survivors' physical functioning were associated with increases in survivors' and caregivers' physical and psychological QOL and survivors' environmental QOL. Decreases in caregivers' burden were associated significantly with improvements in caregivers' physical, psychological, and environmental QOL, but not with survivors' QOL.

Conclusion. This doctoral program has shown the existence of three distinct trajectories for stroke survivors' QOL that are associated with distinct trajectories of caregivers' burden, anxiety, and depression. Knowing these specific trajectories and their associations with caregivers' burden, anxiety, and depression may help providers tailor intervention to improve QOL in stroke survivor–caregiver dyads. The CPS can be used in clinical practice and research to identify caregivers with less preparedness who may need specific interventions. We also observed that stroke survivors' and caregivers' QOL is interdependent within the dyad and is affected greatly by changes in survivors' physical functioning. Dyadic approaches in stroke rehabilitation that acknowledge the interdependence of the stroke patient–caregiver dyads are needed.

Key Words. stroke, patient, caregiver, dyad, longitudinal, trajectory, preparedness, quality of life, instrument development, burden, anxiety, depression.