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Titolo tesi: The moderating role of caregiver preparedness on the relationship between depression and stroke-specific quality of life in stroke dyads: a longitudinal study

ABSTRACT

Background: Stroke is the leading cause of disability in low- and middle-income countries, second only to dementia, and a leading cause of death worldwide with over 13 million new cases each year. After the event, stroke survivors usually experience stroke-related problems, such as mood disturbances, aphasia, dysphagia, hemiplegia, and poor social interaction, which could have a significant impact on the psychological health of stroke survivors. Stroke negatively impacts not only survivors, but also their caregivers, who provide the bulk of care during the recovery process. In the stroke survivor-caregiver couple, depression and quality of life have an interdependent and transactional nature, and several studies have investigated these 2 variables simultaneously. While the relationship between depression and physical and emotional quality of life in the stroke survivor-caregiver couple is well known, there is no evidence that this relationship could be moderated by other variables that could mitigate the influence of depression on quality of life. Previous studies have investigated the role of caregiver preparation in the affected population and observed that caregiver preparation was usually associated with lower caregiver anxiety and better depression outcomes in stroke survivors. Knowing the moderating role of caregiver preparedness on the association between depression in stroke survivor-caregiver dyads and QOL could be important because it would be possible, through this knowledge, to develop tailored interventions that could improve caregiver preparedness and consequently moderate the effect of depression on their QOL.

Objective: The objective of this doctoral program was (1a) to first investigate the longitudinal growth trajectories of disease-specific QOL dimensions in stroke survivors discharged from rehabilitation hospitals, then (1b) to examine significantly associated sociodemographic and clinical variables to disease-specific dimensions of quality of life in stroke survivors and their longitudinal trajectories, (2) then to analyze the moderating role of caregiver preparation on the association between depression and quality of life in stroke survivor-caregiver dyads, (3) to examine the moderating role of caregiver preparation on the association between stroke survivor depression and specific QOL dimensions [Stroke Impact Scale (SIS)].

Methods: We adopted a longitudinal design to study a sample composed of dyads of stroke survivors-caregivers at the time of discharge from different rehabilitation hospitals located in Central and Southern Italy and followed-up every 3 months for a period of 1 year. To address each research objective, three separate

studies were conducted on a sample of 405 stroke survivors and 244 carers enrolled during discharge from rehabilitation hospitals. (1) Data collected in the first study were initially analyzed using descriptive statistics, including means, standard deviations, frequencies, and percentages. (2) Four longitudinal dyadic moderation models (one for each QOL domain: physical, psychological, social, and environmental) were used for the second study using version 7 of the linear hierarchical model. (3) Finally, for the third study, we used a multilevel modeling approach to analyze the trajectories of change in the eight Stroke Impact Scale 3.0 subscales using hierarchical linear modeling.

Results: Disease-specific QoL significantly increased from baseline to 12-month follow-up, especially in physical dimensions. Lower age, hypercholesterolemia, better physical function, and diagnosis of peripheral vascular disease appear to be associated with better QoL. Through the analysis of associated variables, we have identified stroke survivors who are most at risk and who need more targeted interventions to improve their physical, psychological, emotional and social dimensions. Concerning the moderating role of caregiver preparation on baseline quality of life, caregiver preparation significantly moderated the association between survivor depression and survivor psychological and environmental quality of life at baseline. Regarding the moderating role of caregiver preparation on the association between stroke survivor depression and stroke-specific dimensions of QOL [Stroke Impact Scale (SIS)] it was found that preparation significantly moderated the association between survivor's depressive symptoms and survivor's communication, mobility and ADL/IADL) at baseline; linear variation for force and communication and quadratic variation for force. Stroke survivors with higher depressive symptoms had lower strength, communication, mobility, ADL/IADL ability, memory, emotion, hand function, and participation.

Conclusions: The research studies conducted in this PhD program have highlighted the importance of Caregiver preparation in the care process of stroke survivors. Stroke has a large impact on the QOL of stroke survivors, but through the analysis of associated variables, it is possible to identify stroke survivors who are more at risk and who need more targeted interventions to improve their physical size , psychological, emotional and social, and by intervening on some of these, significant improvements in QOL can be obtained. Among the variables that nurses and physicians should consider when rehabilitating stroke survivors, caregiver preparation was found to be an important variable. Early inclusion of caregivers in the care process, through psycho-educational training, would mean having more prepared caregivers and consequently healthier stroke survivors.

Keywords: nurse, nursing, patient, caregiver, dyads, preparedness, burden, quality of life, stroke, stroke impact scale, survivors, trajectories, anxiety, depression.