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Dottorando: Dott. Silvio Simeone

Tutor: Dott. Ercole Vellone Prof.ssa Rosaria Alvaro

Titolo tesi: The Lived Experience of Patients and Caregivers After a Stroke

ABSTRACT

Background. Stroke is the leading cause of disability in adults, and has a significant impact on the patient–caregiver dyad. Returning home after a stroke represents a challenging experience for patients and caregivers who struggle to adapt to their new life conditions. This might influence their life experience that might change overtime. The international literature reports that during the first month after a stroke, stroke survivors direct their attention only to the recovery of physical function; so a comprehensive first experience after a stroke can be described after three months that the stroke occurs. So far, few studies have been guided by a specific conceptual framework which considers the interactions among pre-existing situations prior to stroke, the new situation caused by the stroke and the moderating effects of environmental and caregiver related variables. Although many studies have been conducted on stroke survivors, few studies have focused on the lived experience of patients at three months after they came home after rehabilitation. Also, few studies have described the experience of stroke caregivers three months after discharge of patients from rehabilitation hospitals.

Objective. The objective of this doctoral program was: (1) to design a quantitative and qualitative study to describe stroke survivor-caregiver dyads quality of life after discharge from rehabilitation hospital; (2) to describe the experience of stroke survivors three months after being discharged home from rehabilitation hospitals; (3) to describe the lived experience of stroke caregivers three months after patients are discharged home from a rehabilitation hospital.

Methods. In a multi-site longitudinal study aimed at studying quality of life in patients after stroke, a sample of stroke survivor–caregiver dyads has been enrolled at patient discharge from rehabilitation hospitals; then we conducted three separate studies corresponding to each doctoral objective. A Longitudinal study was designed to study stroke trajectory in stroke patient-caregiver dyads and two phenomenological studies were conducted for the aim two and three.

Results. The first study has shown a new conceptual framework to guide the entire project where a model including how pre-existing situation prior to the stroke, the new situation mediation post stroke and situation moderators will predict patient-caregiver dyad outcomes. In the second phenomenological study five themes emerged from the phenomenological analysis of the interviews and the field notes: deeply changed life, vivid memory of the acute phase of the stroke, slowed lives, relief after recovering from stroke, being a burden for family members. Seven themes emerged from the phenomenological analysis of the third study: deeply-changed life; re-appreciation of the relationship with patient and family members; increased workload; difficulties in getting support from the national health-care system; lack of preparation for caregiving; difficulties in coordinating caregiving, family and personal life; relief after patient's recovery.

Conclusion. This doctoral program has provided a new conceptual framework to study the stroke trajectory in stroke patient-caregiver dyads. The two phenomenological studies have shown the early and comprehensive experience of stroke survivor-caregiver dyads. Findings of this doctoral program could inform educational interventions that could be implemented by healthcare professionals to help stroke survivor-caregiver dyads, to better cope with life changes and encourage them to adapt to daily life limitations caused by stroke. For stroke caregivers, future interventions



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UNIVERSITÀ DEGLI STUDI DI ROMA

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should improve caregiver preparation for caring for patients and should educate caregivers about how to use the resources of the national health system.