Conference abstract

Expectations and experiences of informal caregivers of stroke patients in Portugal

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Abstract

Introduction: We discuss knowledge and expectations of services and other help available in the community to informal caregivers of stroke patients in Portugal, and their perceptions on actual experience within the next six months after patient discharge from the acute care hospital.

Theory and methods: Most stroke patients are supported by close kin members, the informal caregivers, who play an important role in their daily care and rehabilitation. Therefore, it is important to understand how these carers cope with the stroke and identify needs and expectations that might help design and implement support measures. The discharge from the hospital is a moment of truth between informal caregiver’s expectations and the system’s performance that deserves to be investigated. Identified informal caregivers of patients diagnosed with stroke, admitted to the stroke unit of a hospital in Centre Region, Portugal and included in an RCT were followed within the next six months after patients’ discharge. Their initial expectations towards the health and social system and their ability to cope with change brought by the disease and associated costs and further experiences with entities involved in health and social care delivery are evaluated.

Results: We discuss explanations for preliminary findings. We conclude stressing the contribution of the society awareness and participation in the development and integration of health and social care services.

Conclusions and discussion: Awareness on services and help available for stroke patients together with entities which provide them is limited among informal caregivers of stroke patients.

Keywords

informal caregiver, informal caregiver expectations, informal caregiver experiences, health and social services, stroke, RCT, Portugal