

Expert Opinion Article

Gap in stroke patients' and carers' education

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Abstract

Stroke is a multidimensional illness as it affects various aspects in a person's quality of life. The rehabilitation team focuses mainly on complications but there seems to be a gap in the education of the patients and their carers in skills relevant to the competencies required for community, aged care, health, housing and disability support services. Stroke patients' and carers' education-training, as well as their satisfaction has not been studied adequately. The current article presents important studies in the field about the association of patients' and carers' satisfaction and based on authors' opinion suggests appropriate interventions in order to improve the health of the patients.

Keywords: Stroke, Carers, Patient satisfaction, Education, Carers' burden

Introduction

Current studies support the demand for more and improved education as well as training for both patients and carers on various issues, as a part of the continuity of care^{1,2}. Stroke patients tend to be satisfied by the in-patient care as well as the treatment and recovery during hospitalization. However, they tend to be dissatisfied by the amount of their treatment with that dissatisfaction being associated with other aspects of care such as rehabilitation and community services. According to carers, stroke educational programs and information provided after discharge are considered as measures of support³. Additionally, the findings of the research demonstrate that stroke patients and their carers have numerous and diverse educational needs, many of which are unmet⁴. The current article provides an overview of based on experts studies as far as to patients' and carers' satisfaction as well as the educational needs after a stroke.

Epidemiological data

In most studies, the lowest rate of satisfaction was about the services after discharge, with less than 25% of patients satisfied³. Over 80% of interviewed patients were completely satisfied by in-patient care, and 52.7% were satisfied by the treatment and recovery during hospitalization, but more patients were dissatisfied by the amount of their treatment. Patients' satisfaction by the health professionals' attitude during the hospitalization and after discharge was high for all responses³. Six to ten patients were satisfied from the kind of the treatment they received, while the correspondence

proportions for the satisfaction by the duration of treatment and the level of rehabilitation that they achieved were in the middle. However, none of the patients had the support he/she wished for by the out-hospital health services, while 74.2% were satisfied by the communication with the hospital after discharge. The satisfaction by the information given about their health problem was low. Only, 8.6% of the patients agreed that they received all the information they wished to for their, after hospitalization, development. 42.9% of the patients received adequate information about the causes of the stroke, 54.3% about quitting smoking and 40% about healthy diet. Only 2.9% received adequate information about emotional disorders and incontinence problems, while the correspondence proportions for reducing weight, health services, legal and financial issues were 8.8%, 8.6% and 5.7%, respectively. Only 22.9% received adequate information about the prevention of stroke and only 17.1% received adequate information for the treatment. 88.6%

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of the carers stated that the patient did not receive all the information needed for their, after discharge, life, while most of them (91.4%) were satisfied with patient's communication with the rehabilitation centre after the hospitalization⁴.

Almost half of the patients stated that they had been adequately informed about the causal factors and the evolution of their disease, while only 9,9% of them were aware of the pathophysiological mechanisms of the disease⁵.

Almost none to the patients and their carers received adequate information. 65% of the patients received few or no information about the way stroke would affect their sexual activity, 60.5% didn't receive information about incontinence problems, and almost more than the half of them stated that they were not informed about potential visual and tactile sensory disorders, as well as about stress management, while most of them admitted that they had the adequate information about the diagnosis⁶.

Concerning caregivers' satisfaction in the period of hospitalization and after discharge, most of the caregivers were satisfied by the care provided during hospitalization and by their private conversations with the physician (82.8%)⁴.

Almost half of the caregivers were satisfied by the information or descriptions provided about the stroke (54.3%), the rehabilitation at the hospital (54.3%) and the training at the hospital (51.5%)⁴. Additionally, 74.1% of carers were satisfied by the information provided. Stroke educational programs were available to 63.5% of caregivers, and 42.4% were supported after discharge. Hoffmann et al⁷, in their study stated that during the acute phase, 40% of the patients and 67% of the caregivers reported a gap of knowledge about the disease due to the lack of answers in their questions, in a 6 months period the percentages of individuals with unanswered questions were decreased to 26% of patients and 11% of caregivers⁸.

Discussion

According to former studies, symptoms of depression of the patients during admission are associated in the period after stroke with their dissatisfaction³. Dissatisfaction was also associated with other aspects of care, including rehabilitation and support by community services⁹.

Findings showed high satisfaction regarding the quantity and quality of care received by different health professionals as the patients' satisfaction during the hospitalization and after discharge was high for all responses. None of the patients was satisfied from the support by the out-hospital services and only a small percentage considered adequate the information given after their discharge. Most of the patients were unevenly informed about various aspects of the stroke they suffered. Additionally, half of their carers were satisfied by the information and the training they received at the hospital. The carers were satisfied by the communication with the rehabilitation centre after the hospitalization but also believed that the patients did not receive adequate information or training about their condition⁴.

Haralambous et al¹⁰ described the impressions by the information provided by the health professionals to the patients and their carers, and determined the level of their satisfaction by information given. According to this study, the time medical staff dedicates for the patients' and their carers' information seems to be insufficient. It was noteworthy that patients asked for more information in multiple forms and this was associated to the unmet need for information, which is respectively associated to the confidence about health professionals' adequacy and the treatment's efficiency. Veenendaal et al⁵ in their study about stroke patients' and their carers' needs reached the same conclusions. Finally, in Hafsteinsdottir et al. systematic review⁶, most of the studies about stroke patients' information and training reveal that patients considered as hotspots the potential medication treatment of their disease, stress management and the dietary patterns proposed after the stroke. Additionally, younger patients stressed their need for information about physical and sexual activity. Concerning caregivers' satisfaction in the period of hospitalization and after discharge, most of the caregivers were satisfied by the care provided during hospitalization and by their private conversations with the physician. In the study of Smith et al¹¹, caregivers seemed to have neither the knowledge nor the skills and experience to meet the patient's needs, so they have to acquire them while they are forced to adapt to the changes introduced by the stroke and to find ways and alternatives in order to avoid the negative consequences in their personal life. In the Mackenzie et al study¹², carers report that they feel alone and that the available health services for such neurological patients are often uncoordinated and give the priority to the information about potential psychological, emotional and behavioural changes of the patient. Finally, a study focused on the causal factors of the disease, the potential recovery from the stroke, the risk of recurrence, the prevention measures in order to avoid further strokes, physical activity and understanding medical jargon and abbreviations found decrease in focusing on the recovery process, the effects, the risk of stroke recurrence and the medications available⁴.

It is therefore suggested that the educational programs provided by different professionals, in the context of a multidisciplinary team, have to be better coordinated, with an efficient documentation of the information provided, taking full advantage of the communication skills and capabilities of the team. Intervention programs should integrate the knowledge that stroke patients and carers have to possess, while the information given has to be active and generalizable. Modern technology, such as computers and tablets, could be used in order to tailor the information to patients' and carers' specific needs during all the phases after stroke.

Conclusion

Stroke patients' and carers' dissatisfaction by some aspects of stroke rehabilitation constitutes a point, which deserves a special attention. Although the total of the

satisfaction by the information provided was high, a certain dissatisfaction regarding the treatment and the social support after the hospital discharge is detected. Systematic information and training programs for after hospitalization period should be included in the whole program of stroke rehabilitation and social support should be encouraged as well. Community interventions should be integrated to the rehabilitation program and stroke patients and carers should be encouraged to use the available social services properly. Major investments in this area could provide promising developments in the future.

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