

Thesis summary

Specialised ALS care and Quality of Life

Jan-Paul van den Berg
[S.l.: s.n.], 2006, pp. 205,
Thesis University of Utrecht,
ISBN-10 90 9020314 1, ISBN-13 978 90 9020314 0

The results presented in this review are based on my thesis presented at the University of Utrecht on 23 January 2006. The main aim of this thesis was to examine the effects of multidisciplinary ALS care on the Quality of Life (QoL) in patients with ALS and their caregivers and to examine the effects of coping styles on the QoL of patients and their caregivers.

Amyotrophic lateral sclerosis (ALS) is a devastating neuromuscular disorder characterized by degeneration of lower and upper motor neurons. The incidence ranges from 1.5 to 2.0 per 100,000 population per year with an overall male predominance. The course of the disease is relentlessly progressive, but the rate of deterioration varies from patient to patient. Approximately 50% of the patients die within 3 years after onset of the disease. About 20% of the patients survive diagnosis more than five years. Patients usually die from respiratory failure. Because there is no cure for ALS, the best treatment we can offer patients is optimal supportive care. In recent years, multidisciplinary ALS clinics emerged that exclusively provide symptomatic and palliative care to patients with ALS. The concentration of larger numbers of patients in these ALS clinics leads to an accumulation of resources and clinical expertise that facilitates the management of this relatively rare, progressive disease. Although multidisciplinary ALS care prolongs survival of patients with ALS, the effect on quality of life (QoL) is not known. QoL in patients with ALS is determined by several factors which include psychological and existential factors, relationships and other support factors, religion and spirituality, in addition to strength and physical function. Identifying the determinants of QoL may be helpful when assessing the needs for care of patients with ALS, although the effect of standard of care on QoL is largely unknown.

Two hundred and eight patients with ALS and their caregivers were interviewed between June 2001 and March 2004. Patients and their caregivers were recruited from all regions of The Netherlands through the Dutch Neuromuscular Patient Association (Vereniging Spierziekten Nederland) and two national referral centres for patients with Motor Neuron

Disease (University Medical Centre Utrecht and Academic Medical Centre Amsterdam). All patients met the El Escorial diagnostic criteria for probable or definite ALS. The subjects included in the study were not different from those who did not participate in the study ($n=8$, mean age 59.1, 61.9% men). Patients were excluded if they had insufficient knowledge of the Dutch language, or if they were suffering from cognitive disorders or other diseases that could affect the musculoskeletal system. Standard of care of patients was qualified as multidisciplinary ALS care or general ALS care. Criteria for multidisciplinary ALS care were: (1) care provided by a multidisciplinary ALS team headed by a consultant in rehabilitation medicine and consisting of at least a physical therapist, occupational therapist, speech pathologist, dietician and social worker; (2) care given according to the Dutch consensus protocol for rehabilitative management in ALS and (3) all members of the multidisciplinary ALS team see at least 6 incident ALS patients per year.

In our study of 208 patients with ALS, we found that patients with multidisciplinary ALS care had a better mental QoL than patients who were provided with general care. In addition to the previous finding that multidisciplinary ALS care prolongs survival of patients with ALS, our study provides further support for a beneficial effect of a multidisciplinary approach to ALS care given by experienced professionals.

Both patients and caregivers demonstrated a pattern of normal healthy coping mechanisms as compared to standard norms. Yet, a passive coping style in both patients and their caregivers appeared to be the strongest predictor for a lower Mental QoL. Reassuring thoughts and an active approach were positively related to Mental QoL in patients with ALS. Results suggest that a passive coping style should be avoided in favour of an active approach and reassuring thoughts. Further research should focus on the effect of psychological interventions, aimed at optimising coping styles, which may positively influence the QoL of ALS patients and their caregivers.

For the readers of the IJIC it is of special interest to learn that QoL is multidimensional and QoL should be measured with a health-related QoL scale and individual, subjective QoL scale.

Considering that to date the causes of ALS remain a mystery, and no effective therapy is able to at least

stabilize the disease has been discovered, particular attention must be paid to the patients' QoL, and support for relatives and caregivers.

Treatment should be given by a multidisciplinary dedicated team with expertise in symptomatic treatment of

ALS and palliative therapy, who should fulfil the requirements of the patients and their caregivers.

Jan-Paul van den Berg
Utrecht, The Netherlands
E-mail: JP.vanden.Berg@meandermc.nl