Living with ALS
Perspectives of patients and next of kin

Akademisk avhandling

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av
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The thesis is based on the following papers

I Olsson A G, Markhede I, Strang S, Persson L I. **Well-being in patients with amyotrophic lateral sclerosis and their next of kin over time.** *Acta Neurol Scand. 2010;121:244–250. DOI. 10.1111/j.1600–0404.2009.01191.x (2009).*

II Olsson A G, Strang S, Persson L I. **Quality of life, anxiety and depression in ALS patients and their next of kin.** *Manuscript – Submitted.*

III Olsson A G, Markhede I, Strang S, Persson L I. **Differences in quality of life modalities give rise to needs of individual support in patients with ALS and their next of kin.** *Palliat Support Care. 2010;8:75–86.*

IV Olsson A G, Graneheim Hällgren U, Persson L I, Strang S. **Fluctuation in the everyday life of living with ALS in both patients and next of kin.** *Manuscript – Submitted.*

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Abstract

ALS is a neurodegenerative disease without curative treatment. The knowledge of the relationship between patients and their next of kin with respect to quality of life (QoL) is deficient. The overall aim of this thesis is to describe different perspectives of QoL of patients with ALS and their next of kin, and to describe strengths and hindrances in the manageability of their daily lives.

The participants were recruited from Sahlgrenska University Hospital in Gothenburg, Sweden. In the quantitative studies I–III, 35 couples participated. Fourteen patients and thirteen next of kin participated in the qualitative study (IV).

Few changes were found over time in studies I and III, but in patients, there was a decreased rating in some of the physical subscales and in general health in the health-related QoL (HRQoL). The ratings in those subscales were worse in patients than in next of kin, even though next of kin also gave a decreased rating in some of the physical and mental subscales. Next of kin estimated individual QoL to be worse than patients did. No changes were found over time in anxiety, depression, or individual QoL. The ratings in discrete pairs were often similar, indicating that if one person felt bad, the other one did also. Even though the pairs gave relatively good ratings of QoL, study II showed that QoL was worse than in a subset of the general population. Study IV found a constant fluctuation between factors that facilitated and hindered the manageability for each individual person, as well as similarities and differences between patients and their next of kin.

QoL was worse in our participants compared with the general population and did not change much over time. The similarities and differences between the patients and next of kin show the need to offer them physical, psychosocial, and existential support, both together and individually, to ensure the best possible QoL. The knowledge that the manageability can change from one moment to another makes it necessary to meet the individuals with a wide perspective and to support them in the situation in which they are currently living.

Keywords: ALS, anxiety, coping, depression, manageability, next of kin, patient, sense of coherence, QoL, well-being

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