INDIVIDUAL QUALITY OF LIFE IS NOT CORRELATED WITH GENERAL HEALTH STATUS IN PATIENTS WITH AMYOTROPHIC LATERAL SCLEROSIS

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Objectives: To compare the change over time of individual quality of life (QoL) vs. functional and generic health status in palliative care patients with amyotrophic lateral sclerosis (ALS).
Methods: 42 ALS patients performed three health status measures: the ALS functional rating scale (ALSFRS), the Sickness Impact Profile (SIP), and the Short Form 36 (SF-36), as well as the Schedule for the Evaluation of Individual QoL - Direct Weighting (SEIQoL-DW), which assesses individual quality of life. Patients were examined at least three times at two-month intervals. The SIP and ALSFRS were filled out by all patients, the SF-36 and the SEIQoL-DW were assigned at random.
Results: There was a significant decrease from visit 1 to 3 in the SIP (76.3 to 71.9, $p<0.001$), the SF-36 (94.4 to 87.4, $p=0.018$), and the ALSFRS (68.8 to 55, $p<0.001$). Despite this progressive decline of physical function and general health status, there was no significant difference for the same period in the SEIQoL-DW, which actually increased slightly from 75.4 to 75.6. Correspondingly, there was no correlation between the SEIQoL-DW and the functional scales.
Conclusions: Individual QoL in neurological palliative care patients with ALS does not correlate with measures of function and general health, and is likely to be largely based on other factors such as psychosocial and spiritual well-being.