

Does wellbeing of patients with amyotrophic lateral sclerosis depend on their population of origin?

Katarzyna Ciećwierska¹, Anna Maksymowicz-Śliwińska¹, Krzysztof Nieporęcki¹, Beata Pilczuk¹, Natalia Szejko¹, Jan Sznajder¹, Dorothee Lule², Peter M. Andersen³, Albert C. Ludolph², Magdalena Kuźma-Kozakiewicz^{1,4}

1 Department of Neurology, Medical University of Warsaw, Warsaw, Poland

2 Department of Neurology, University of Ulm, Ulm, Germany

3 Institute of Pharmacology and Clinical Neuroscience, Umeå University Hospital, Sweden

4 Neurodegenerative Diseases Research Group, Medical University of Warsaw, Warsaw, Poland

Introduction: In a recent European study [in press], Polish patients were found to have a significantly lower QoL and a higher depression rate as compared to German and Swedish individuals. They were also characterized by a higher religiousness and lower autonomy.

The aim of the study was to analyze whether the observed changes are related to the ALS patients' conditions (economic/medical/social care) in the country of origin, or if they depend on a reduced perception of the actual well-being characterizing the Polish society.

Material and Methods: 60 Polish patients with ALS (age 29-87, mean 55±12.27, 58.33% males), and 60 healthy controls matched for age, gender and education status (age 29-84, mean 55±12.83, 58.33% males) were included in the study. The subjective and global QoL was assessed by Schedule for the Evaluation of Individual Quality of Life – Direct Weighting (SEIQoL-DW) and the Anamnestic Comparative Self Assessment (ACSA), respectively. We also analyzed the ALS-Depression-Inventory (ADI-12), the Idler's religiosity scale (IIR) and the Shared Decision Scale (SDS).

Results:

The Polish patients had a significantly lower subjective and global QoL compared to healthy controls (SEIQoL-DW 66.21 vs 73.72 and ACSA 4.63 vs 6.57, both $p < 0.05$). Both ALS patients and controls focused on similar domains: family (19.33/17.33%), psychosocial/existential factors (15.67/21.00%), health (14.67/17.33%) and recreation (13.33/19.00%). Compared to healthy controls, ALS had a negative impact on health, recreation and, psychosocial/existential domains. The depression rate was similar in both groups (24.18 vs 23.67). ALS patients considered themselves less religious than healthy controls (88.34% vs 91.67%) but the differences were not significant. The ALS patients also had lower preference to have physician dominate in medical decision-making (30% vs 70%).

Conclusions: We have demonstrated a significantly reduced QoL in Polish ALS patients compared to controls. The results in both groups were however lower than those obtained in German and Swedish patients what suggests a different basic perception of QoL in the Polish society. Also the depression rate was comparable between the Polish patients and controls, which suggests that an overall analysis of well-being should take into account the population-based determinants.