NEEDSinALS
Physical exercise in ALS and its positive impact on wellbeing

The aim of the project NEEDSinALS was to analyse medical decision making in cultural and personal context in the neurological disease amyotrophic lateral sclerosis (ALS). Group members from Poland, Sweden and Germany joined forces to allow cross-cultural and longitudinal comparison of findings.
In total, at least N=78 ALS patients were interviewed twice in the course of a year in each country, in total more than 500 patients were interviewed. Patients were interviewed on their personal preferences regarding medical decision making to prolong or shorten life and possible interacting factors such as personal values, cultural context, wellbeing, and cognitive capacities. Patients in different disease stages were interviewed including N=19 who were in locked-in state (LIS), the state of most severe physical function loss in ALS.

Despite the severity of the disease, patients experienced satisfactory quality of life and an only mildly increased depression rate compared to the healthy population. This was true if social and medical support was sufficiently provided. Patients had a high preference to prolong life and a low wish for hastened death in Germany, Poland and Sweden, also in the locked in state. Many patients were initially undecided but changed their preference towards therapeutic devices in the course. Preferences in favour of therapeutic devices were rarely reversed which was also true in the LIS state. This preference was not only determined by physical function loss, as clinical guidelines suggest to be the main criterion to introduce therapeutic devices which prolong life but instead decisions were also driven by personal values and cultural settings. Some crucial differences were recognized in the course of the ethical analysis of the normative frameworks in each participating country despite almost similar legal prerequisites. These differences also had an impact on preferences as was shown within our ethical analysis. Therapeutic decision making was not associated with mild to moderate cognitive impairments which may evolve in up to 50% of the patients.

Healthy subjects were unable to correctly anticipate this “paradoxical” wellbeing in physical function decline. Also, unexperienced physicians had difficulties to correctly anticipate the patient’s wellbeing; the more acquainted with the disease, the more the physician was aware of the possibility of psychosocial adaptation and thus, the closer was the physician’s peer rating to the actual state of the patients.

Those cultural and personal determinants of vital decision making explain part of the variance in medical decision making between countries: in some countries up to 20% of patients aim for life-shortening interventions (euthanasia), whereas in other countries up to 35% prefer life prolonging devices such as invasive ventilation. Medical guidelines should yield the cultural context since it has a reciprocal impact on therapeutic decision making of ALS patients Overall, the project aim to provide first insight on cultural aspects of therapeutic decision making was successfully reached. ALS patient's handbook on information resources for vital decisions and for emotional support has been designed according to study findings and is available for patients, careigivers and medical staff. Finally, results were published in national and international journals for the public and discussed on national and international conferences.