

Publication

Attitudes towards hastened death in ALS : a prospective study of patients and family caregivers

JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)**ID** 2310119**Author(s)** Stutzki, Ralf; Weber, Markus; Reiter-Theil, Stella; Simmen, Urs; Borasio, Gian Domenico; Jox, Ralf J.**Author(s) at UniBasel** [Reiter-Theil, Stella](#) ; [Stutzki, Ralf](#) ;**Year** 2014**Title** Attitudes towards hastened death in ALS : a prospective study of patients and family caregivers**Journal** Amyotrophic lateral sclerosis & frontotemporal degeneration**Volume** 15**Number** 1-2**Pages / Article-Number** 68-76**Keywords** Ethics, palliative care, wish to hasten death, assisted suicide, depression**Mesh terms** Adult; Aged; Amyotrophic Lateral Sclerosis, psychology; Attitude to Death; Caregivers, psychology; Cohort Studies; Female; Germany; Humans; Male; Middle Aged; Odds Ratio; Predictive Value of Tests; Quality of Life; Stress, Psychological, psychology; Suicide, Assisted, psychology; Surveys and Questionnaires; Switzerland

Amyotrophic lateral sclerosis (ALS) may be associated with the wish to hasten death (WTHD). We aimed to determine the prevalence and stability of WTHD and end-of-life attitudes in ALS patients, identify predictive factors, and explore communication about WTHD. We conducted a prospective questionnaire study among patients and their primary caregivers attending ALS clinics in Germany and Switzerland. We enrolled 66 patients and 62 caregivers. Half of the patients could imagine asking for assisted suicide or euthanasia; 14% expressed a current WTHD at the baseline survey. While 75% were in favour of non-invasive ventilation, only 55% and 27% were in favour of percutaneous endoscopic gastrostomy and invasive ventilation, respectively. These attitudes were stable over 13 months. The WTHD was predicted by depression, anxiety, loneliness, perceiving to be a burden to others, and a low quality of life (all $p > 0.05$). Lower religiosity predicted whether patients could imagine assisted suicide or euthanasia. Two-thirds of patients had communicated their WTHD to relatives; no-one talked to the physician about it, yet half of them would like to do so. In conclusion, physicians should consider proactively asking for WTHD, and be sensitive towards neglected psychosocial problems and psychiatric comorbidity.

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