Attitudes toward assisted suicide and life-prolonging measures in Swiss ALS patients and their caregivers

Ralf Stutzki1,*, Ursula Schneider2, Stella Reiter-Theil1 and Markus Weber2

1 Clinical Ethics Support and Accompanying Research, University Hospital Basel/Psychiatric University Hospitals Basel, Institut für Bio- und Medizin Ethik, University of Basel, Basel, Switzerland
2 Muskelzentrum/ALS Clinic, Kantonsspital St. Gallen, St. Gallen, Switzerland

Objectives: In Switzerland, assisted suicide (AS) is legal, provided that the person seeking assistance has decisional capacity and the person assisting is not motivated by reasons of self-interest. In this particular setting nothing is known about patients’ and their caregivers’ attitudes toward AS and life-prolonging measures. Methods: Data was retrieved through validated questionnaires and personal interviews in 33 patients and their caregivers covering the following domains: physical function according to the revised Amyotrophic Lateral Sclerosis Functional Rating Scale (ALSFRS-R), demographic data, quality of life, anxiety, depression, social situation, spirituality, burden of disease, life-prolonging, and life-shortening acts. Results: In patients the median time after diagnosis was 9 months (2–90) and the median Amyotrophic Lateral Sclerosis (ALS) FRS-R score was 37 (22–48). The majority of patients (94%; n = 31) had no desire to hasten death. Patients’ and caregivers’ attitudes toward Percutaneous Endoscopic Gastrostomy (PEG) and Non-Invasive Ventilation (NIV) differed. Significantly more patients than caregivers (21.2 versus 3.1%) stated that they were against NIV (p = 0.049) and against PEG (27.3 versus 3.1%; p = 0.031). Answers regarding tracheotomy were not significantly different (p = 0.139). Caregivers scored significantly higher levels of “suffering” (p = 0.007), “loneliness” (p = 0.006), and “emotional distress” answering the questionnaires (p < 0.001). Suffering (p < 0.026) and loneliness (p < 0.016) were related to the score of the Hospital Anxiety and Depression Scale (HADS) in patients. Conclusion: A liberal legal setting does not necessarily promote the wish for AS. However, the desire to discuss AS is prevalent in ALS patients. There is a higher level of suffering and loneliness on the caregivers’ side. A longitudinal study is warranted.

Keywords: ALS, motor neuron disease, quality of life, depression, end of life

INTRODUCTION

During the course of the disease, Amyotrophic Lateral Sclerosis (ALS) patients may suffer from depression, hopelessness, the feeling of loneliness, and loss of control (Rabkin et al., 2000, 2005; Albert et al., 2005; Olney and Lomen-Hoerth, 2005). In the terminal phase respiratory distress, anxiety, and other distressing symptoms may occur (Mandler et al., 2001). Given the suffering associated with the disease, some patients choose to decline life-prolonging measures such as Percutaneous Endoscopic Gastrostomy (PEG) and Non-Invasive Ventilation (NIV) and/or wish to hasten death (Ganzini et al., 1998; Veldink et al., 2002; Fang et al., 2008; Maessen et al., 2009). In an early study from Oregon, about 56% of all ALS patients considered physician-assisted suicide (PAS; legalized after 1997) during the terminal phase and 73% of caregivers and patients had similar attitudes toward PAS (Ganzini et al., 1998). In the Netherlands, during the 2000–2005 period 16.8% of ALS patients decided for euthanasia or PAS (Maessen et al., 2009), while in Sweden (where PAS is not legalized), ALS patients have a sixfold increased risk of committing suicide (Fang et al., 2008). Factors such as depression, hopelessness, loss of meaning, and purpose in life have been discussed to be associated with the wish to hasten death, whereas the contrary applies to religious faith and spiritual beliefs (Rabkin et al., 2000, 2005; Albert et al., 2005; Olney and Lomen-Hoerth, 2005). These findings are not consistent between different countries (Maessen et al., 2009). Moreover, there is a lack of longitudinal studies analyzing changes of these factors over time. It is also unclear whether the legal background in different countries influences patients’ attitudes toward assisted suicide (AS) as comparative studies are lacking.

In Switzerland, however, assistance in committing suicide by a physician or a lay person is not explicitly regulated by law, but article 115 of the Swiss Penal Code allows assistance in suicide provided that the person seeking assistance has decisional capacity and the person assisting – physician or lay person – is not motivated by reasons of self-interest. Based on this article, Swiss “right to die” organizations offer assistance to commit suicide (Fischer et al., 2008). A recent study from the City of Zurich revealed that between 2001 and 2004 “Dignitas or Exit Deutsche Schweiz” had facilitated a total of 421 cases of AS (Fischer et al., 2008). Amongst the patients, 60% had been non-residents in Switzerland emphasizing the problem of “suicide tourism.” Twenty-four percent of ASs were patients with “neurological disorders” including...