

Journal Watch

Euthanasia and Physician-Assisted Suicide among Patients with Amyotrophic Lateral Sclerosis in the Netherlands

Jan H. Veldink,, John H.J. Wokke et al. *N Engl J Med* 2002;346:1638-44

Reviewed by: Dr Y. Tarumi

Presented during: Case Rounds, RPCP

Abstract

Background: Amyotrophic lateral sclerosis (ALS) is a disease that causes progressive paralysis leading to respiratory failure. Patients with ALS may consider physician-assisted suicide. However, it is not known how many patients, if given the option, would actually decide to end their lives by physician-assisted suicide or euthanasia nor at what stage of the disease they would choose to do so.

Methods: We identified physicians of 279 patients in the Netherlands with a diagnosis of ALS who died between 1994 and 1999. Physicians were asked to fill out a validated questionnaire about the end-of-life decisions that were made. Of 241 eligible physicians, 203 returned the questionnaire (84 percent).

Results: Of the 203 patients, 35 (17 percent) chose euthanasia and died that way. An additional six patients (3 percent) died as a result of physician-assisted suicide. Patients to whom religion was important were less likely to have died as a result of euthanasia or physician-assisted suicide. The choice of euthanasia or physician-assisted suicide was not associated with any particular characteristics of the disease or of the patient's care, nor was it associated with income or educational level. Disability before death was significantly more severe in patients who died as a result of euthanasia than among those who died in other ways. Physician-assisted suicide appeared to occur somewhat earlier in the course of the disease than did euthanasia. An additional 48 patients (24 percent) received palliative treatment, which probably shortened their lives.

Conclusions: In the Netherlands, we found that one in five patients with ALS died as a result of euthanasia or physician-assisted suicide.

Comments:

Strengths/Uniqueness:

A previously reported survey showed frequency of physician assisted suicide or euthanasia for general medical diagnosis as 2.7 %, for malignancy as 10 %, and for HIV as 20 % in the Netherlands. A report from Oregon, US, showed 56 % of ALS patients supported physician assisted death with high correlation to lower religiosity, higher education, male patients, strong sense of hopelessness. This latest report aids integration of previous results about the decision-making process regarding physician-assisted death for ALS patients.

This is the first report of the number of patients who actually decided to end their life by physician-assisted suicide or euthanasia. The definition of physician assisted suicide and euthanasia in this survey is clear and easy to understand.

Weaknesses:

Due to the retrospective cohort nature of the study, there are possible information bias and recall bias (some events occurred several years ago). Generalization is limited due to the unique context

of Dutch culture, law, and health care system.
There were no power calculations reported.

Relevance to Palliative Care: We encounter limited number of ALS cases compared to the number of cancer patients. Due to the nature of the disease there is always intensive decision making involved as well as symptom management issues. This article helps to reflect on the limited established palliative care available for neurological degenerative diseases, and highlights the need for validation of the impact of palliative care on patients with progressive neurological disease.