

Prevalence Differences of Patients in Vegetative State in the Netherlands and Vienna, Austria: A Comparison of Values and Ethics

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Objective: Little is known about prevalence of persistent vegetative state/unresponsive wakefulness syndrome and comparisons between countries. The aim of this column was to explore reasons for the comparable count of patients in vegetative state found in prevalence studies in nursing homes in 1 European country (Netherlands) compared with a single European city (Vienna, Austria). **Design:** The column is based on a literature review of vegetative state in the Netherlands and Vienna in the period 2007-2008, in the context of professional interactions with families and physicians of patients in vegetative state. In addition, in both countries, families and physicians were interviewed to illustrate views. **Results:** Comparable between the 2 settings are the population characteristics and the definition of, and criteria, for vegetative state. A difference can be found in the development of authoritative policy guidelines in the Netherlands, after public debates and jurisdiction, which did not exist in Vienna at the time. There also seem to be different societal values concerning rehabilitation and end-of-life decisions for patients in vegetative state. **Discussion:** The most important explanation for the vegetative state prevalence differences between the Netherlands and Vienna can be found in the different societal values about patients in vegetative state and their treatment and rehabilitation. In the Netherlands, life prolonging medical treatment, including artificial nutrition and hydration, is considered futile and can be withdrawn if there is no prospect of recovery. In Vienna, however, patients in vegetative state are regarded as severely disabled and in need of long-term rehabilitation and social reintegration. There is no end-of-life discussion in this context. **Key words:** *medical ethics, persistent vegetative state, prevalence, rehabilitation, unresponsive wakefulness syndrome, withdrawing treatment*

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IN SEVERAL COUNTRIES, the fate of patients in a permanent vegetative state (VS), recently renamed "unresponsive wakefulness syndrome" (UWS),¹ leads to public debates, mostly concerning rehabilitation options in the postacute phase and jurisdiction about withdrawing medical treatment, including artificial nutrition and hydration (ANH), when rehabilitation was not successful. Examples are the cases of Eluana Englaro (Italy) and Terri Schiavo (United States).^{2,3} These cases led to discussions about contexts and cultural influences on the medical-ethical dilemmas, rehabilitation, and end-of-life decisions concerning these patients.^{4,5}

Confusion about terminology and a lack of accepted diagnostic and inclusion criteria have interfered with the understanding of prevalence of VS and comparisons between countries. Until 2002, estimations of VS in the literature varied between 5 and 140 per 1 000 000 inhabitants^{4,6}

In 2005, discussions continued following 2 prevalence-measurement studies in 2 different locations:

one was a country (the Netherlands) and the other a city (Vienna, Austria). These studies showed 32 patients in VS in all Dutch nursing homes in 2003,⁷ and 32 patients in different institutions in Vienna in 2001.⁸ This meant a prevalence of 2/1 000 000 and 19/1 000 000, respectively. The repetition of the Viennese study in 2003 showed nearly the same prevalence.⁹

The aim of this ethics column was to explore possible reasons why the same count of patients in VS in 1 European country corresponded with the count in a single European city. We reviewed in the prior studies the proposed explanations for the differences between the prevalence of VS discovered in these settings.⁷⁻¹¹ In the context of our experiences with VS patients, through interviews with their families and healthcare providers in both countries, we arrived at conclusions that differ from the speculations about differences in methods of investigation or treatment offered in the prior studies.⁷⁻¹¹ Reviewing differences and similarities in cultural values and approaches to care for patients in VS could (a) increase our understanding of other cultures and our own, (b) potentially better inform and improve our care of people in VS, and (c) guide policy development.

DIFFERING VALUES

The Netherlands

The most important finding of the exploration for the comparable prevalence of patients in VS/UWS between the Netherlands and Vienna, Austria seems to be the difference in societal values about the situation of these patients and their medical treatment and rehabilitation. In the Netherlands, the Royal Dutch Medical Association (KNMG) has stated that there might come a moment during treatment that the physician is called to discontinue life-prolonging treatment; that is, when the patient has a poor prognosis of regaining consciousness and the perpetuation of the status of the patient is in contrary to human dignity. From the perspective of the KNMG, there is a limited biological life that is insufficient in shaping human existence. It even expects physicians to withdraw medical treatment at a certain time and to convince families of the futility of continuing treatment.¹² The National Health Council considers it morally justified to withdraw life-prolonging medical treatment in patients for whom the VS has been determined irreversible.¹³

The dying process, which had stopped, is put back in motion by stopping futile medical treatment.¹² The practice in the Netherlands of letting patients in VS die is illustrated by statistics showing that of the 43 Dutch VS patients that died in nursing homes between 2000 and September 2003, 24 died from comorbidity after a nontreatment decision and 9 after withdrawal of ANH.⁷

Debate in society facilitates the expression of views on VS. The 2 policy guidelines of the KNMG and Health Council in the Netherlands were developed after public debates and juridical investigation of cases. Public opinion, and the attitude of patients' families, regarding VS and (dis)continuing ANH has been influenced by a lot of media attention about the Dutch "Stinissen case."⁴ This can be illustrated by the fact that 1 patient in the Netherlands had expressed her opinion about VS in the past after seeing a documentary about the Stinissen case, which eventually was a factor in the decision of withdrawing ANH after being in a VS for 12 years. Thus, policy guidelines for physicians and jurisdictions, reflecting the shared values of the citizenry, combine with previously established or reconstructed individual wishes, to facilitate (1) the withholding of life-prolonging medical treatment for medical complications and (2) the withdrawal of ANH from patients in permanent VS.

Vienna, Austria

In contrast to the Netherlands, there is currently no written guideline in Austria about end-of-life decisions, and, given the values of Viennese society and possibly the Austrian society, there does not seem to be a need for such guidelines at this time. In Vienna, patients in VS are regarded as being severely disabled but stable, and withdrawal of ANH in stable VS patients is legally not allowed in Austria. An Austrian physician is less likely to intentionally make decisions concerning the withdrawing of futile medical treatment in patients in VS. Preserving human life, in all of its forms, however limited, is considered essential. As stated by the Österreichische Wachkoma Gesellschaft (ÖWG), "VS is considered to be one of the severest neurological conditions and the patients have the right to live a valuable life with all needed treatments."^{14,15} This statement is supported by most of the physicians and family members in Vienna who were interviewed. They stated that patients in VS are not sick or dying but are in more of a neutral physical state and that discontinuing life-prolonging medical treatment and ANH or failing to provide needed procedures would be unthinkable.

PATIENT'S WILL

In both countries, a physician should act according to the medical-professional standards: a treatment must never be disproportionate to the aim and the patient's permission is needed.¹⁶⁻¹⁹ If a patient is legally incapable to express his or her opinion, the legal representative should be approached. In both countries, the physician as well as the patient's representative should pursue a relevant patient's will in refusal of medical treatment. Both countries agree that in case of doubt concerning the validity, in general life should be supported. However, in

the context of VS, the Dutch policy emphasizes more the futility of life-prolonging treatment when patients will never regain consciousness.

TRAFFIC ACCIDENTS

Another factor that could have influenced the differing prevalence rates of VS between the Netherlands and Vienna is that although Austria managed to decrease the count of traffic deaths dramatically in the last few years, there are still more traffic accidents in Austria compared with the Netherlands.²⁰⁻²³ This could mean a higher chance for VS to occur.

TERMINOLOGY

A factor that did not influence the prevalence of VS in the 2 settings is the use of the terms VS and apallic syndrome full stage. In the Netherlands, the term “vegetative state” was used, which was introduced by Jennett and Plum (1972) and confirmed by the Multi Society Task Force (MSTF, 1994) and a Dutch expert meeting in 2002.^{4,24,25} It is defined as a clinical condition of complete unawareness of the self and the environment, accompanied by sleep-wake cycles with complete or partial preservation of hypothalamic and brainstem autonomic functions.

In Vienna, this condition was called “apallic syndrome” and was defined as a condition in which patients are awake but not aware and not able to be in contact with their environment.²⁶ Apallic syndrome is the general term used in Vienna and Austria and pursued by the ÖWG.²⁷⁻²⁹ This term is a dichotomy for full stage (comparable to persistent VS) and remission stage (comparable to minimally conscious state) and was first described by Kretschmer³⁰ and Gerstenbrand.³¹ The recent introduction of the new name UWS contributes to harmonization of terminology.¹

SPECIALIZED REHABILITATION

There are differences in the availability of specialized rehabilitation between the Netherlands and Vienna. During our review period, there was only 1 specialized rehabilitation center in the Netherlands for patients in VS. To be admitted, the patients had to be medically stable after a brain injury, admitted within 6 months after trauma or 3 months after nontraumatic causes, and between 0 to 25 years of age. Patients who did not meet these criteria were admitted in general to nursing homes for long-term care, although a few nursing homes offer a kind of rehabilitation program despite financial restrictions. Recently, there was broad media attention about the lack of specialized rehabilitation facilities in the Netherlands, referring to a patient who had followed a specialized rehabilitation program abroad for this reason.^{32,33}

In Vienna, in general, every patient with brain injury is offered rehabilitation.³⁴⁻³⁶ During the review period, the ÖWG was making an inventory of the number of registered rehabilitation and long-term care facilities. With the known data at the time, Vienna had the highest number of rehabilitation and long-term care beds, compared with the other 8 federal states. Two centers could offer this specialized rehabilitation in Vienna.^{37,38}

However, we could not conclude in our review from the literature that Vienna was a specialized center for VS patients concerning rehabilitation and long-term care, because not all beds in Austria available for the rehabilitation and long-term care for patients with disorders of consciousness were registered during the time covered by our review. Moreover, these statistics concern all stages of apallic syndrome (defined differently in different places) and not only full stage/VS.

RESTRICTIONS

One restriction of this exploration is the comparison between a European country and a European city. However, even if the prevalence of VS in Dutch nursing homes is corrected for the population of the capital Amsterdam (4/1 000 000), the Viennese VS prevalence for only the nursing facilities still remains higher (11/1 000 000).¹⁰ Recently, the difference is confirmed by an Austrian study in 2010, providing the prevalence of VS in all nursing facilities across Austria (3.36 patients per 100.000)³⁹ and a new Dutch prevalence study in all care institutions in 2012 (Van Erp, Lavrijsen et al, publication in progress).

CONCLUSION

Policy guidelines are typically developed after public debates on relevant cases, mostly with involvement of courts and politicians. If a population believes that living in a VS is a fate worse than death, life prolonging medical treatments will be seen as futile and can be withheld or withdrawn, allowing more patients in a VS to pass away. In contrast, if a population believes that patients in VS are severely disabled persons who need maximal support, then more treatment will be continued and more patients will survive. We recommend further investigations into different societal values and the impact of such values on medical-ethical dilemmas. Discussion of these issues jointly across country borders will likely facilitate healthcare practice and patient well-being. In this way, not every society will be forced to experience its own tragic public VS case before generating policy guidelines that reflect the shared values of its citizens. The worldwide unrest about these cases confirms the need to provide for policies before emotions lead the debate.

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