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## Original Study

# The Vegetative State: Prevalence, Misdiagnosis, and Treatment Limitations



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## A B S T R A C T

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**Introduction:** Patients in a vegetative state/unresponsive wakefulness syndrome (VS/UWS) open their eyes spontaneously, but show only reflexive behavior. Although VS/UWS is one of the worst possible outcomes of acquired brain injury, its prevalence is largely unknown. This study's objective was to map the total population of hospitalized and institutionalized patients in VS/UWS in the Netherlands: prevalence, clinical characteristics, and treatment limitations.

**Methods:** Nationwide point prevalence study on patients in VS/UWS at least 1 month after acute brain injury in hospitals, rehabilitation centers, nursing homes, institutions for people with intellectual disability, and hospices; diagnosis verification by a researcher using the Coma Recovery Scale-revised (CRS-r); gathering of demographics, clinical characteristics, and treatment limitations.

**Results:** We identified 33 patients in VS/UWS, 24 of whose diagnoses could be verified. Patients were on average 51 years old with a mean duration of VS/UWS of 5 years. The main etiology was hypoxia sustained during cardiac arrest and resuscitation. More than 50% of patients had not received rehabilitation services. Most were given life-sustaining treatment beyond internationally accepted prognostic boundaries regarding recovery of consciousness. Seventeen (39%) of 41 patients presumed to be in VS/UWS were found to be at least minimally conscious.

**Conclusions:** Results translate to a prevalence of 0.1 to 0.2 hospitalized and institutionalized VS/UWS patients per 100,000 members of the general population. This small figure may be related to the legal option to withhold or withdraw life-sustaining treatment, including artificial nutrition and hydration. On the other hand, this study shows that in certain cases, physicians continue life-prolonging treatment for up to 25 years. Patients have poor access to rehabilitation and are at substantial risk for misdiagnosis.

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All authors have completed the Unified Competing Interest form at [www.icmje.org/coi\\_disclosure.pdf](http://www.icmje.org/coi_disclosure.pdf) (available on request from the corresponding author). The study sponsors and funders had no role in the study design; in the collection, analysis, and interpretation of data; in the writing of the report; and in the decision to submit the article for publication.

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The vegetative state, recently renamed “unresponsive wakefulness syndrome” (VS/UWS),<sup>1</sup> is one of the worst possible outcomes of acquired brain injury. A patient in VS/UWS opens his or her eyes spontaneously, but shows no signs of consciousness; only reflexive responses to the outside world are seen.<sup>2,3</sup> Although often a transitional state in the process of recovery,<sup>4</sup> certain patients remain in VS/UWS for the rest of their lives, sometimes decades after the causative event.

The differential diagnosis of VS/UWS includes the locked-in syndrome in which the patient is fully conscious while incapable of speech and most motor reactions due to near-complete paralysis,<sup>5,6</sup> and the minimally conscious state (MCS), characterized by at least one sign of consciousness but absence of functional communication

and functional use of objects.<sup>7</sup> Bruno et al<sup>8,9</sup> recently argued to distinguish patients who reproducibly follow commands (MCS+) from those who do not (MCS-).

Although the neurophysiological substrates of disorders of consciousness are steadily being unravelled,<sup>10</sup> their epidemiology remains unclear. In many countries, including the United States and Great Britain, the prevalence of VS/UWS is unknown.<sup>11</sup> A recent systematic review of prevalence studies on VS/UWS yielded 14 publications with a wide variation in both outcome (0.2–6.1 patients per 100,000 members of the general population) and methodological quality.<sup>12</sup>

Uncertainty about the exact number of people in a condition referred to as “a fate worse than death”<sup>13</sup> not only compromises our scientific picture, it also can be a barrier to the provision of the specialized health care these patients and their families need. In 2003, a Dutch prevalence study resulted in what appears to be the lowest reported prevalence of VS/UWS in the world: 0.2 patients per 100,000 members of the population.<sup>14</sup> However, it targeted the nursing home population exclusively and verified only a small subset of cases, whereas it has been shown that up to 43% of patients presumed to be in VS/UWS turn out to be at least in MCS when examined with a validated assessment tool.<sup>15,16</sup>

This article describes a point prevalence study of VS/UWS carried out nationwide in hospitals, nursing homes, hospices, facilities for people with intellectual disability (ID), and rehabilitation centers in the Netherlands.

## Methods

The Netherlands is inhabited by 16.7 million people and has a population density of 401 people per square kilometer<sup>17</sup> (in comparison, the United States has a population density of 33.7 per square kilometer<sup>18</sup>). Medical aid, including long-term care, is available for all citizens and reimbursed through a dually financed insurance system. Nursing homes are staffed by specialized medical doctors, called elderly care physicians.<sup>19</sup>

In the last week of April 2012, we contacted medical directors from all of the 635 nursing homes (merged in 187 organizations); 20 rehabilitation centers; 90 hospitals with an intensive care unit, neurology, and/or neurosurgery ward; and 70 hospices, plus the 270 members of the Dutch Association of ID Physicians via e-mail. The e-mail provided the internationally established diagnostic criteria for VS/UWS.<sup>3</sup> The addressee was asked whether any patients with this diagnosis at least 1 month after acute brain injury (eg, hypoxia, stroke, trauma) were present within the population under the responsibility of the medical staff on May 1, 2012. Replies were given by e-mail. If a missing response could not be retrieved by telephone, the institution or physician was considered a nonresponder.

Representatives, mostly family members, of all patients reported received an information letter about the study and were asked for written informed consent. On permission, one researcher (WvE) assessed the level of consciousness by means of the Coma Recovery Scale-revised (CRS-r), a validated instrument for bedside determination of the level of consciousness in the post-acute setting.<sup>20,21</sup> Staff and family were invited to the assessment. Any additional behavior possibly indicative of consciousness they mentioned, for example command-following exclusively on request of a relative, was evaluated for contingency in a structured manner.<sup>22</sup> We documented medication, factors of possible influence on the level of consciousness (eg, infections) that had occurred up to 2 weeks before the study visit, and asked whether staff or family thought that the patient's state was any different from his or her normal condition. The time between the last administration of artificial nutrition and hydration (ANH) and the start of the assessment was registered, as patients have been shown

to be less responsive shortly after administration of ANH.<sup>23</sup> The treating physician was requested to complete a secured online questionnaire about demographic and clinical characteristics, treatment goals, and limitations to treatment (eg, a do-not-resuscitate order). To prevent research participation from interfering with the relationship between the patient's proxies and the treating physician, study findings were communicated only to the latter. The families were notified of this before they gave consent.

## Statistics

From the sum of the absolute number of verified and unverified cases of VS/UWS, a prevalence figure of hospitalized and institutionalized VS/UWS patients per 100,000 members of the Dutch population was calculated. Clinical characteristics were analyzed using SPSS 20.0 (IBM SPSS Statistics, IBM Corporation, Chicago, IL). We calculated means, medians, confidence intervals, SDs, and percentages where applicable.

## Ethical Approval

According to the Dutch Medical Research Involving Human Subjects Act (1998), the study did not meet criteria for medical scientific research. The protocol was judged by an accredited medical research ethics committee, which on these grounds decided that no additional ethical evaluation was indicated. Nevertheless, the families of all patients were asked for written informed consent.

## Results

Response rates were 96% for nursing homes, 100% for rehabilitation centers, 97% for hospitals, 53% for hospices, and 20% for ID physicians.

A total of 53 patients were reported to be in VS/UWS for at least 1 month after sustaining acute brain injury. Representatives of 46 of them consented to inclusion. The patients were visited with a median time lapse from the point prevalence date of 20 days: 30 patients were seen within 30 days, 14 patients between 30 and 60 days and 2 after over 60 days. We obtained CRS-r scores in all 46 patients. In 38 cases, additional behavior was reported by medical staff or families and evaluated for contingency. Among the observed personally salient stimuli were proxies' voices, music, family pictures, the smell of chocolate, the presence of a patient's dog, and watching a stand-up comedian on TV. Results of the initial inquiry and of the verification are shown in [Figure 1](#).

On the day of verification, 2 patients were reported by their physician to have emerged from VS/UWS since the point prevalence date. Both had sustained neurological damage due to subarachnoid hemorrhage. According to their respective physicians, one had been in VS/UWS up until 2 months after the incident (4 days after the point prevalence date), and the other up to 10 months (30 days after the point prevalence date). Testing by means of the CRS-r confirmed MCS+ in both patients. Combined with the 7 cases in which we obtained no consent, this resulted in 9 unverified cases. Thus, the diagnosis could be verified in 44 patients. Six patients had recently had infections, seizures, or other events possibly influencing level of consciousness, 15 were on medication with sedative side-effects, and 13 patients were assessed within 1 hour after the administration of artificial nutrition.

In 24 of 44 individuals, CRS-r assessment confirmed the diagnosis of VS/UWS. In 3 other cases, the treating physician expressed doubts about the diagnosis. One of these patients was found to be in MCS-, the other 2 were conscious, as demonstrated by the ability of functional use of objects and/or functional communication

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