

Netherlands study establishes number of people in minimally conscious state after severe brain injury for the first time

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Every year, approximately 130,000 Dutch people suffer some form of acquired brain injury. The causes can be traumatic such as a fall or road-

traffic accident, but also a brain hemorrhages or lack of oxygen in the brain (for example after a resuscitation). Sometimes severe brain injuries can lead to a prolonged disorder of consciousness (pDoC). This situation arises after coma when patients open their eyes and breathe on their own, but their consciousness does not return within four weeks after brain injury.

It was unknown how many patients were admitted to Dutch health care institutions with a specific form of pDoC: the minimally conscious state. In this situation, [consciousness](#) is severely diminished, but people do show one or more signs of consciousness. For example, they can follow a simple command, follow an object with their eyes or show emotions.

Researcher and elderly care physician Berno Overbeek approached all Dutch hospitals, the five specialized pDoC rehabilitation facilities and all [nursing homes](#) with the question whether they were treating one or more patients with pDoC. If so, after permission from the legal representative, the level of consciousness was determined with the Coma Recovery Scale-Revised, the most widely used scale in these patients worldwide.

Through [questionnaires](#) completed by the attending physician, the researchers collected medical characteristics. The number of institutionalized patients in minimally conscious state in the Netherlands is 32.

These 32 patients were on average 45 years old, two-thirds were male, and more than half (53%) stayed in a facility where specialized, intensive neurorehabilitation for pDoC patients was offered. In two-thirds (65%) of patients, the brain injury was caused by a trauma, such as an accident or a fall. In the remaining patients, there was a non-traumatic brain injury, such as lack of oxygen in the brain after resuscitation, or a large brain hemorrhage.

This is the first study nationwide on the number of people in a minimally conscious state in an entire country. Researchers Jan Lavrijsen and Willemijn van Erp have already done similar research. They investigated another entity of pDoC, the unresponsive wakefulness syndrome (previously called vegetative state).

In this type of pDoC, no signs of consciousness are observed; observed behavior is based on reflexes. Elderly care physician and Ph.D. candidate Berno Overbeek: "The group of patients in unresponsive wakefulness syndrome is also small, especially compared to other countries."

The research is [published](#) in the journal *Neurology*.

Expertise network for severe acquired brain injury

This study was possible because of the existence of EENnacoma, an expertise network for severe acquired brain injury, founded in 2016. The EENnacoma network provides more information about coma and different levels of consciousness, such as unresponsive wakefulness syndrome and minimally conscious state. In the EENnacoma network, institutions that provide specialized treatment and care to people with severe acquired [brain injury](#) and a research group are connected to each other.

In recent years, with the support of, among others, the Dutch Brain Foundation, work has been done on the realization of appropriate treatment in a chain of care embedded in a nationwide network of academic expertise for patients with pDoC after the comatose phase in the hospital. The group of patients with pDoC is one of the so-called low prevalence and high complexity target groups. The Ministry of Health initiated the development of knowledge and expertise centers for patient groups with a low prevalence and high complexity.

More information: Berno U Overbeek et al, Prevalence of the minimally conscious state among institutionalized patients in the Netherlands: a nationwide study, *Neurology* (2023). [DOI: 10.1212/WNL.000000000000207820](https://doi.org/10.1212/WNL.000000000000207820)

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