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ORIGINAL ARTICLE

Ten-to-twelve years after specialized neurorehabilitation of young patients with severe disorders of consciousness: A follow-up study

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Abstract

Objective: To explore the long-term outcome of young patients with disorders of consciousness who had received intensive neurorehabilitation.

Methods: A cross-sectional cohort study, in which the survival, level of consciousness, functional independence, mobility, communication and living situation were determined by means of a structured questionnaire. The cohort consisted of 44 children and young adults, originally either in a prolonged Vegetative State/Unresponsive Wakefulness Syndrome (VS/UWS, $n = 33$) or a Minimally Conscious State (MCS, $n = 11$) who had received a specialized neurorehabilitation programme 10–12 years earlier.

Results: Response rate was 72% (34/44). Eleven patients were deceased, 10 of whom were in VS/UWS or MCS at discharge from the programme. Of the remaining 23 patients, 19 were conscious. Twelve lived independently, of whom six required some household support. One conscious patient lived permanently in a long-term care facility. All other patients lived either independently or with their parents. None of the VS/UWS or MCS patients showed any functional recovery.

Conclusion: Two main long-term outcome scenarios can be recognized. Two-thirds of the participating patients who were conscious at programme discharge were able to live independently, whereas almost two-thirds of the participating patients who were in VS/UWS or MCS at discharge subsequently died.

Keywords

Vegetative state, unresponsive wakefulness syndrome, minimally conscious state, neurorehabilitation, long-term follow-up, outcome, living situation

History

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Introduction

The long-term outcome of patients with disorders of consciousness (DOC) caused by acute severe brain injury, particularly 5 years or more post-injury, is a largely neglected area of research. Little is known of the survival, possible changes in level of consciousness, living situation and functioning of DOC patients at longer follow-up periods. The current study focuses on the long-term outcome of young DOC patients, aged between 0–25, who had been admitted to a specialized Early Intensive Neurorehabilitation Programme (EINP) 10–12 years earlier [1]. EINP aims at the recovery of consciousness, as well as all physiological functions, in order to enhance the possibilities for further rehabilitation.

Disorders of consciousness

Acute severe brain injury inevitably results in coma, in which the eyes are closed and no sleep–wake cycle is apparent [2].

Coma typically resolves within 2–4 weeks in those who survive [3]. Coma may shift into Vegetative State (VS) [4], recently renamed into Unresponsive Wakefulness Syndrome (UWS) [5]. VS/UWS is characterized by complete absence of behavioural evidence for awareness of self and environment, with preserved capacity for spontaneous or stimulus-induced arousal. In the next phase, when some voluntary and sustained reactivity to the environment can be seen, patients are in a minimally conscious state (MCS) [6]. In MCS, consciousness is still severely altered, yet there is minimal but definite behavioural evidence of self or environmental awareness. Emergence from MCS requires the demonstration of reliable and consistent interactive communication or functional use of at least two objects. Patients who emerge from MCS may first enter a confused state, characterized by impairments in attention and anterograde amnesia [7,8].

Prognosis and outcome

The prognosis and outcomes of DOC patients are generally considered in terms of mortality, recovery of consciousness, and recovery of function. In 1994, the Multi-Society Task Force on Persistent Vegetative State reported high mortality rates after 1 month of VS/UWS. Age, underlying cause, injury severity, duration of coma and duration of VS/UWS

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influence the prognosis [9]. Chances of regaining consciousness are reported to be extremely low 1 year after traumatic brain injury (TBI) and after 3 months in non-traumatic brain injury (nTBI). Following the introduction of the MCS in 2002 [6], it has been suggested that the Multi-Society Task Force outcome figures should be revised [3,10]. Also, improvement of acute medical care [3], increasing knowledge of recovery possibilities [11] and better opportunities of neurorehabilitation [3,12–14] may contribute to changed expectancies of recovery in DOC patients.

Several studies have reported on the long-term outcome of VS/UWS and MCS (Table I). Most studies presented data between 2–5 years post-injury, only two beyond 5 years post-injury.

Neurorehabilitation

In the past decade, research has increasingly focused on recovery possibilities following the application of some kind of treatment programme. Garcia et al. [22] discussed various interventions for TBI based on experimental animal models. Environmental enrichment—an enlarged living environment with increased social interaction and novel stimuli, together with physical and cognitive stimulation—was found to induce various neuroplastic changes after brain injury. Recently, Seel et al. [12] described several steps and the components of a specialized early treatment programme for DOC patients, involving the admission process, acute medical management, rehabilitative treatments focusing on functional communication, recovery of consciousness, mobilization and activities, family education, discharge planning and post-discharge programmatic support. EINP does meet those components, as described earlier [1]. In the only specialized rehabilitation centre in the Netherlands, EINP was carried out for 3 months or less when patients were recovered to full consciousness. Only children and young adults up to the age of 25 are allowed to participate in EINP. In EINP the recovery progress has been monitored by an expert team of clinicians using structured assessment instruments.

The aim of the current study was to gain insight into the long-term outcomes of a cohort of young DOC patients, up to the age of 25, who were admitted to EINP 10–12 years earlier.

This study presents the survival rate of the participating group, their level of consciousness, their living situation and the global level of functioning of those who survived.

Methods

Participants and procedure

Possible participants were 44 patients (TBI, $n = 32$; nTBI, $n = 12$) who were admitted to EINP between January 2001 and September 2003 [21]. Criteria for admission were: acquired brain injury, age 0–25 years, within 6 months after injury, or 3 months in case of hypoxia, and a diagnosis of VS/UWS or MCS. At admission, 75% of the patients were in VS/UWS, 25% in MCS. The patients' files were examined in order to identify those known to have died following discharge. If not known, patients or their families were contacted and informed about the follow-up study. All patients, or their legal representative,

who gave permission to be contacted were sent a letter with further information about the study and they were asked for informed consent. In total, 34 patients or their representative gave consent to participate. In October 2012, a questionnaire survey was carried out. According to the local Committee on Research Involving Human Subjects, the study did not require ethical review because, in accordance with the criteria of the Dutch Medical Research Involving Human Subjects Act, no medical scientific research was involved.

Instruments

The questionnaire

A questionnaire was developed, consisting of both open-ended questions and closed questions on the following issues: level of consciousness, living situation, level of mobility and level of communication. It was also asked what other treatments had been received.

The questionnaire was designed in consultation with expert clinicians and was completed either by the patients themselves or by a family member.

The participants were first asked to score the patients' current level of consciousness in one of three categories:

- (1) VS/UWS, described as: eyes are sometimes open, a sleep–wake cycle can be seen; no reactions on stimuli other than stretching or startle reflexes; sometimes emotional expression, not related to the surroundings.
- (2) MCS, described as: fluctuating reactions on stimuli or the surroundings, occasionally obeying simple commands; total dependency.
- (3) Conscious, described as: adequate reactions on simple commands; stable alertness and spontaneous reactions to the surroundings; functional understandable mutual communication is possible, sometimes with technical support; cognitive and behavioural disturbances can still be present.

The questionnaire asked whether a professional has confirmed the classification, in order to be able to verify the participants' score.

Participants' living situation was established with a single question: 'What is the current living situation?', with six possible answers: (1) lives independently; (2) lives independently with some household support; (3) lives in a family setting, is dependent of their support; (4) lives with parents because of younger age; (5) lives in a nursing home; and (6) other, to be specified.

The validity and reliability of the questionnaire was not investigated, although some parts of it (i.e. the Barthel index) are known to be valid and reliable in cases of patients with brain injury [23].

All questionnaires were anonymously processed by the second author (VW).

Barthel Index

To describe the level of independence on Activities of Daily Living (ADL), the Barthel Index was incorporated into the questionnaire [24]. This index covers the following domains: bowel function, bladder function, grooming, transfer, mobility, dressing, use of stairs, bathing and feeding.

Table 1. Overview of long-term follow-up studies since 2002 of patients in prolonged (>1 month) DOC.

Study	Follow-up	N	Etiology	Assessment Scale DOC	DOC	Age at injury (SD)	Rehabilitation/ time of Treatment	Assessment scales outcome	Results (% deceased and % consciousness states)	Results (functional) of surviving patients	Results (social)
Lamm et al. (2005) ¹⁵	2 to 5 years	20	TBI	WNSSP	MCS	37.9 (14.7) M (SD)	Specialized inpatient brain injury rehabilitation program	WNSSP, DRS, FIM, SPRS	10% deceased 10% MCS	50% independent on ADL, 50% required supervision or physical assistance; 30% severe or greater disability	22% working on a part-time basis; 72% no relationships (remaining marriages: uninjured spouse became caregiver); 44% no contact with old friends 43% of TBI and 29% of nTBI able to participate in, partly selected, work and school activities
Eilander et al. (2007) ¹⁵	2.4 to 15.7 years	90	TBI and nTBI	Class scores of the PALOC-s, using the patients' medical files	51% VS/ UWS 49% MCS at admission	12.6 (0.6- 25) M (range)	Early intensive neuro-rehabilitation Program	DRS, GOSE	19% of TBI and 48% of nTBI deceased; 0% of TBI and 29% of nTBI VS/UWS	51% of TBI and 14% of nTBI completely independent or mildly dependent; 18% of TBI and 50% of nTBI completely dependent	79% remained at a disability pension; 17% were involved in adjusted education; none employed.
Skandsen et al. (2008) ¹⁶	3 to 8 years	37	TBI	Review of medical notes in three categories: oriented, confused, or VS/UW's or MCS	VS/UWS and MCS (not differentiated)	33 (1-88) M (range)	Unknown	GOSE	32% deceased; 8% VS/UWS	52% severely disabled; 24% moderately disabled;	14% returned to work or school, 11% at a full level, or close to premorbid level.
Katz et al. (2009) ¹⁷	At 1, 2, 3 and 4 years	36	TBI and nTBI	CRS-r	31% VS/ UWS 69% MCS	38 (21) M(SD)	Specialized, slow- to-recover brain injury program in an acute rehabilitation hospital	CRS-r, DRS, FIM	8% VS/UWS	28 % achieved household independence	
Lauté et al. (2010) ¹⁸	At 5 years	47	TBI and nTBI	Retrospectively established using information from the medical files	VS/UWS (11) or MCS (36), 1 year after coma onset	40 (10-85) M(range)	Regional rehabilitation center or long stay-hospital dedicated to patients in chronic VS/UWS or MCS	GOS, to which a specific category for MCS was added	Of the VS/UWS patients 9 (82%) deceased, 2 (18%) remained VS/UWS (both young anoxic patients); of the MCS patients 14 (39%) deceased; 9 (25%) remained MCS	13 patients (36%) emerged from MCS with severe disabilities.	All 13 patients showed functional communication skills, all but one verbal; 7 stayed at home with assistance, 6 lived in an institution
Esraneo et al. (2010) ¹⁹	At 1, 2, 3, and 4 years	50	TBI and nTBI	Using the standard diagnostic criteria ²⁵	VS/UWS > 6 months postonset	51.1 ± 9.6 M(SD)	Comprehensive neurorehabilitati on program to adults in a prolonged state of disordered consciousness	CRS-r, DRS	21 (42% deceased); 17 (34%) VS/UWS; 5 (10%) MCS; 7 (14%) conscious	All showed severe to extremely severe disability	n/a

(Continued)

Table 1. (Continued).

Study	Follow-up	N	Etiology	Assessment Scale		DOC	Age at injury	Rehabilitation/ time of Treatment	Assessment scales outcome	Results (% deceased and % consciousness states)	Results (functional) of surviving patients	Results (social)
				DOC	DOC							
<i>Nakase-Richardson et al. (2012)</i> ²⁰	At 1, 2 and 5 years	128	TBI	The occurrence of 2 consecutive days of command following as documented in the medical record review	Yes/no conscious	19/24/35 (quartiles)	Inpatient Rehabilitation Centers participating in the TBI Model Systems Programs (TBIMS) National Database	DRS	59% regained ability to follow commands at 1 year, 66% at 2 years, and 74% at 5 years follow-up	n/a	n/a	
<i>Eitlander et al. (2013)</i> ²¹	2 to 4.4 years	32	TBI	WNSSP, PALOC-s	VS/UWS (24) or MCS (8) at admission	16 (1.6-25.5) M (range)	Early intensive neuro-rehabilitation program	DRS	4 patients deceased No patients in VS/UWS	None recovered to no disability level; 3 (11%) recovered to mildly to partially disabled; 13 (46%) recovered to moderately disabled; 12 (43%) recovered to moderately severe to extremely disabled	n/a	

Abbreviations:

N=Number of patients; DOC=Disorders of Consciousness; SD=Standard Deviation; TBI=Traumatic Brain Injury; nTBI=non-Traumatic Brain Injury; UWS=Unresponsive Wakefulness Syndrome; MCS=Minimally Conscious State; WNSSP=Western Neuro Sensory Stimulation Profile; PALOC-s=Post-Acute Level Of Consciousness scale; DRS=Disability Rating Scale; GOS(E)=Glasgow Outcome Scale (Extended); FIM=Functional Independence Measure; SPRS=Sydney Psychosocial Reintegration Scale; CRS-1=Coma Recovery Scale revised; n/a=not-applicable

Post-Acute Level of Consciousness-scale (PALOC-s)

In the original study of the cohort, the Post-Acute Level of Consciousness scale (PALOC-s) was used to classify the DOC [25]. This scale was developed in 1998, based on the introduction of different levels of consciousness by the International Working Party on the Management of the VS [26], to evaluate the DOC in children and young adults. It differentiates eight levels of consciousness: coma, three sub-levels of VS/UWS, three sub-levels of MCS and consciousness. To be able to compare the level of consciousness of this long-term study with the scores at admission to and discharge from the treatment programme, the PALOC-s scores of the original study were reduced into four categories: coma, VS/UWS, MCS and consciousness.

In the original study, the PALOC-s was scored after administering the Western Neuro Sensory Stimulation Profile (WNSSP), that has been developed to assess cognitive function in patients with severe head injury [27].

Data analysis

To control for possible differences between participants and non-participants, analyses of variance in SPSS for Windows, version 20.0 (SPSS Inc., Chicago, IL) were performed on the following variables of the original cohort: age at injury, duration between injury and start of the programme, level of consciousness at the start of the programme and level of consciousness at discharge of the programme (p -value < 0.05). To investigate the differences concerning gender and cause of injury, Chi-square analyses were performed.

Results

No follow-up information could be gathered from 10 patients: two patients or their relatives refused to participate and eight patients could not be traced. Statistical analyses showed no significant differences on any of the patients' characteristics between the 34 patients who participated in this long-term outcome study and the 10 who did not participate.

Of the 34 participating patients, 11 had died at follow-up, thus 23 patients or their next of kin completed the questionnaire. The questionnaire was generally completed by a family member, except for three patients completing the questionnaire themselves.

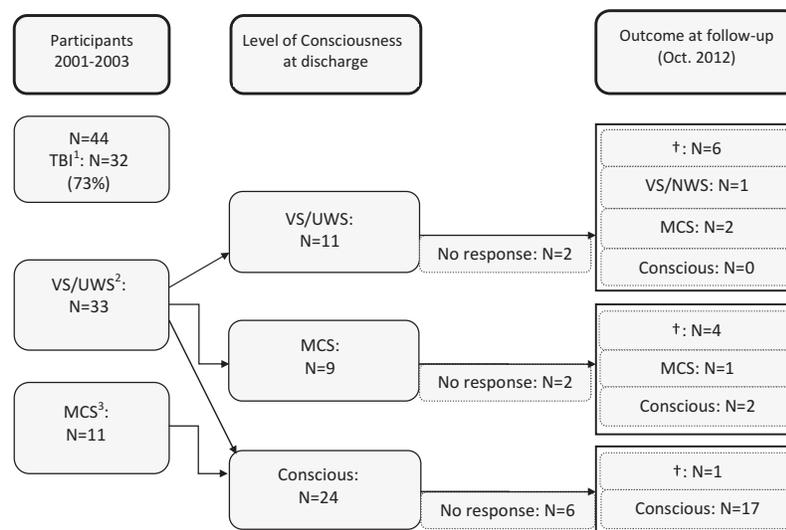
At admission to the programme, 33 out of all 44 participants were in VS/UWS and 11 were in MCS. In Figure 1, the participants' recovery patterns are displayed. At discharge, 24 patients had recovered to full consciousness, nine were in MCS and 11 were in VS/UWS. At follow-up, of the 34 participating patients, 19 were fully conscious (TBI: $n = 18$), three were in MCS (TBI: $n = 2$), one nTBI patient was still in VS/UWS and 11 patients were deceased (TBI: $n = 4$; nTBI: $n = 7$).

In two MCS patients, a professional had confirmed the level of consciousness reported by the relatives. For the other MCS patient and the patient in VS/UWS, there was no mention of a professional confirmation. Of the two patients who had emerged from MCS into full consciousness, one was confirmed by a professional.

Level of functioning of the conscious patients

Figure 2 presents functional outcome of the 19 conscious patients. Concerning ADL, 37% of the patients were completely independent, 21% needed minimal help, 10% were partially dependent, 10% were very dependent and 21% were completely dependent. About 58% of the patients were able to walk independently, one-quarter of them with aids. One patient (5%) was able to walk with assistance, the remaining used a wheelchair (28%) or were dependent of others for transfer (10%). Almost 75% of the patients were able to speak, 16% communicated with some aids, e.g. a speech computer, and 11% could not speak coherently. Thirty-two per cent of the patients lived independently and 32% with some household support. Only one patient lived in a long-term care facility.

Of the two patients who had recovered from MCS into full consciousness, one was totally dependent and lived with the parents. The other patient was very dependent and lived alternately with the parents and in a care facility.



¹TBI=Traumatic Brain Injury; ²VS/UWS=Vegetative State/Unresponsive Wakefulness Syndrome; ³MCS=Minimally Conscious State; †=deceased.

Figure 1. Flow chart of the level of consciousness of all 44 patients who were admitted to the neurorehabilitation programme between 2001–2003.

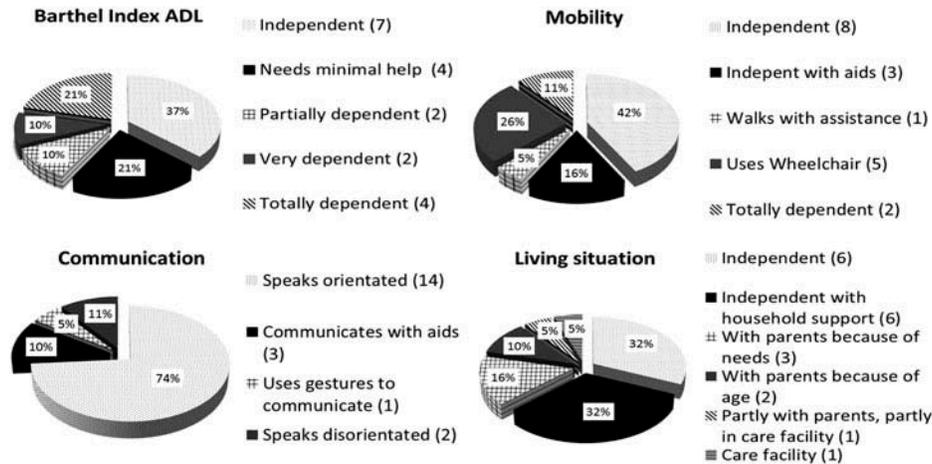


Figure 2. Functional outcome of the conscious patients at follow-up, showing the Barthel Index level of independence on activities of daily living; level of mobility (part of the Barthel Index); level of communication; and living situation.

VS/UWS and MCS patients

All four patients who had not recovered into full consciousness were living with their parents. The patient in VS/UWS was bedridden. The three MCS patients were transferred by wheelchair. One of the MCS patients was able to use a yes/no button occasionally.

Further treatments

All conscious patients had participated in regular rehabilitation programmes after EINP. None of the VS/UWS and MCS patients had undergone any regular rehabilitation other than physical therapy to prevent contractures and to give support in daily care, although some of them were involved in complementary treatments, like hyperbaric oxygen therapy or acupuncture. Eighty-seven per cent of all patients are still receiving some kind of a treatment; this generally consists of physical therapy in a low frequency. Twenty-six per cent of the patients still have speech therapy.

Discussion

This is one of the first follow-up studies that describes the outcome beyond 10–12 years post-injury of prolonged disorders of consciousness (VS/UWS or MCS) due to severe brain injury in young patients, who had previously received a specialized treatment programme (EINP) aimed at recovery of consciousness.

Two outcome patterns can be seen. First, most of the patients who had recovered to full consciousness at the end of EINP have shown further recovery, resulting in partial or even complete functional independence. Second, most (63%) of the participating patients still in VS/UWS or MCS at discharge from EINP died before the follow-up study. Four of the six VS/UWS or MCS patients who survived showed some progress in the level of consciousness; however, none of them demonstrated any functional recovery, i.e. in communication or self-care.

It can be suggested that, at the end of a specialized rehabilitation programme like EINP, the long-term outcome can

be predicted: most of the conscious patients are able to live either partially or fully independent, whereas all other patients will either die within a couple of years or will be 24/7 dependent.

Although the reviewed studies presented in Table I [15,16,18–21] are not completely comparable on variables like the duration of VS/MCS, the length of time since injury or patient characteristics (e.g. adults or TBI patients only), the trend is the same as in this study: the mortality rate is high in VS/UWS, whereas in MCS a greater proportion of patients have recovered to partial or complete functional independence.

In accordance with earlier outcome studies [28], only a small proportion of nTBI patients demonstrated recovery to partial or complete functional independence (1 of 9), compared to 18 of 25 TBI patients. Mortality was also higher in nTBI patients compared to TBI patients. As has been shown earlier, no relationship was found between some other possible relevant patient factors (gender and age) and recovery [21]. In that study, only time between discharge from intensive care and start of EINP correlated significantly with the level of consciousness at the end of the programme and with the level of disability 2–5 years after injury: the sooner patients were admitted to the programme, the greater the chances for recovery. The differences in further (functional) recovery between the fully conscious patients and the VS/UWS or MCS patients at discharge from EINP might be explained by the fact that the fully conscious patients had received further rehabilitation treatments in a rehabilitation facility [29], while most of the VS/UWS and MCS patients did not receive any further rehabilitation treatments. However, they had not shown any recovery during the specialized treatment programme. In addition, although some of them have been involved in other ‘treatments’ aimed at recovery, like hyperbaric oxygen therapy or acupuncture, no significant progress is seen in the level of consciousness or the functional abilities. It can be assumed that the injuries of these patients were too severe to establish any significant recovery.

Previously, a long-term (2.4–15.7 years) retrospective study was conducted by the first author (HE) with a group of patients who had received an early version of EINP

between 1987–2001 [13]. Since a difference exists in the level of consciousness at admission (75% VS/UWS in the current study against 51% VS/UWS in the retrospective study) and the length of time since admission to the programme, proper comparison cannot be drawn between the groups. Nevertheless, the two main outcome patterns found in the retrospective study, with only a small proportion of the patients remaining totally or largely dependent, has been replicated in the current study.

One can conclude that a considerable number of the DOC patients, even in VS/UWS 1–6 months post-injury, can recover to a(n) (semi-)independent life in the long-term following specialized rehabilitation. As recently argued by Seel et al. [12], it can be presumed that specialized intensive multidimensional care, at least within the first 3–4 months post-injury, can contribute to recovery.

The level of functional independence in the conscious patients varies substantially. Most of them are largely or even fully independent, but some need 24/7 support. In this study, it was not possible to search for critical factors that can predict the level of recovery of independent functioning, It would be of interest to search for neurological, personal or social factors that contribute to recovery, besides the possible differences in treatments in the different phases in the hospitals and rehabilitation facilities to which the patients were admitted to.

Strengths and limitations

A strength of this study is the long-term follow-up—more than 10 years after injury. In this context, a response rate of 72% over such a long period of time, a period during which no regular contacts occurred, can be seen as satisfactory. This is perhaps especially so since no differences have been found in any relevant factors between participants and non-participants. In some of the other long-term studies, a smaller loss of participants has been reported, albeit over a shorter period of time (i.e. Skandsen et al. [16], Luauté et al. [18]).

The sample size may seem rather small. It is, however, comparable to other studies performed in a single facility, as can be seen in Table I. Moreover, taking into account the age of the studied cohort, this is a rather large group; to the best of the authors' knowledge no other study only includes children and young adults. Besides, a study in all major Dutch hospitals about the incidence of children and young adults up to 25 years of age with severe TBI, who were still in VS/UWS or MCS 1 month after trauma, showed that 71,4% of these children had been admitted to the specialized programme of this study [30]. Also, in 2003, Lavrijsen et al. [31] only found 32 patients in VS/UWS across all Dutch nursing homes. This is the lowest number in the world according to a recent systematic review [32]. At of these, only five patients were under the age of 30. A recent prevalence study including all Dutch care facilities confirmed the lowest prevalence of VS/UWS [33]. Taking this context into account, the cohort involved in the current study can be regarded as a significant portion of all potential participants.

A limitation of the current study is the way in which the outcome data were collected: only by means of a questionnaire, filled in by a representative or the patient himself,

without independent assessment. The advantage of this method of data collection is that the thoughts and opinions of the patients or their relatives have been described without third party interpretation. Furthermore, this method of data collection is generally less stressful than an interview or assessments. However, one cannot rule out that (some) answers are attributable to wishful thinking rather than a reflection of reality, for instance regarding the amount of help that is needed with ADL. With the limited resources available, the use of a structured questionnaire is the next best method to collect data to get a first impression about the situation such a long time, 10–12 years, post-injury. The fact that the questionnaire has not been fully validated may raise some question marks regarding the results, although the contribution of the expert clinicians in developing the questionnaire might have helped to ensure sufficient construct validity and good enough understanding by the participants to provide valid answers. Probably the main limitation in the questionnaire is the description of the levels of consciousness. It was chosen not to fully use the diagnostic guidelines, as formulated by Giacino and Kalmar [34], but instead to limit the descriptions to clearly observable and indisputable behavior, e.g. fixating and following with the eyes are not used, to avoid positive interpretations by relatives. This could have led to misdiagnosis of MCS patients as VS/UWS. Another, related, limitation is the fact that the level of consciousness was confirmed by a professional in only half the VS/UWS and MCS patients (three confirmed out of six). However, given the small numbers, this flaw in the follow-up study does not impact the main results regarding the outcomes of the conscious patients.

The aim of this study was to gain a first global insight in the long-term outcome of unconscious patients who previously were treated with a specialized early neurorehabilitation programme aimed at recovery of consciousness. In further studies it is important to search for more detailed information in order to get more insight in cognitive and functional possibilities and difficulties of the former DOC-patients and the perceived quality-of-life. This will contribute to making adequate long-term prognoses.

Conclusions and recommendations

This study suggests that the level of consciousness in young patients in prolonged DOC can predict the long-term outcome, after they had received an early intensive neurorehabilitation programme. Fully conscious patients at discharge seem to have reasonable opportunities for further recovery of the level of functioning, most of them ultimately living and participating in the community. On the other hand, two-thirds of the VS/UWS patients and more than half of the MCS patients died within 10 years, while those who survive probably do not show any recovery in their level of functioning. This knowledge may help care providers to inform and advise family members during an intensive and uncertain period post-injury and to make decisions about the most appropriate treatment options.

In order to gain more insight into long-term outcomes, recovery processes and treatment possibilities, future research is recommended that tracks DOC patients regularly over time following their completion of similar, specialized, treatment

programmes. The current lack of knowledge and misdiagnosis in clinical practice, published recently as 39% in the Netherlands [33], can be resolved by systematic assessing patients quantitatively and qualitatively with valid measures by specialized professionals on all relevant aspects, such as level of consciousness, functional skills, cognitive skills, social participation and perceived quality-of-life. This can be done, for instance, by using a specific International Classification of Functioning (ICF) checklist for patients with disorders of consciousness (ICF-DOC) [35], as recently has been done by Willems et al. [36], together with reliable diagnostic tools like the Coma Recovery Scale-revised [37] and/or the WNSSP [27]. This study underlines the importance of very long-term outcome studies for gaining insight into different outcome patterns, different scenarios for patient treatment and different options for family counselling, in young patients with disorders of consciousness.

Note

As part of the study, a documentary has been made in which three of the patients and/or their relatives have been interviewed to show the progress they have made (or the lack of it) and to show the possibilities and difficulties of their situation. The documentary can be seen on: <http://www.libranet.nl/vin>.

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Declaration of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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