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Neurorehabilitation for people with disorders of consciousness: an international survey of health-care structures and access to treatment, (Part 1)

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ABSTRACT

Aims: The provision of rehabilitation services for people with disorders of consciousness (DoC) may vary due to geographical, financial, and political factors. The extent of this variability and the implementation of treatment standards across countries is unknown. This study explored international neurorehabilitation systems for people with DoC.

Methods: An online survey (SurveyMonkey®) was disseminated to all members of the International Brain Injury Association (IBIA) DoC Special Interest Group (SIG) examining existing rehabilitation systems and access to them.

Results: Respondents ($n = 35$) were from 14 countries. Specialized neurorehabilitation was available with varying degrees of access and duration. Commencement of specialized neurorehabilitation averaged 3–4 weeks for traumatic brain injury (TBI) and 5–8 weeks for non-traumatic brain injury (nTBI) etiologies. Length of stay in inpatient rehabilitation was 1–3 months for TBI and 4–6 months for nTBI. There were major differences in access to services and funding across countries. The majority of respondents felt there were not enough resources in place to provide appropriate neurorehabilitation.

Conclusions: There exists inter-country differences for DoC neurorehabilitation after severe acquired brain injury. Further work is needed to implement DoC treatment standards at an international level.

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Introduction

Disorders of consciousness

Severe acquired brain injury (sABI), either from TBI or nTBI etiology, can lead to prolonged DoC (PDc). DoC encompasses vegetative state (VS), more recently named unresponsive wakefulness syndrome (UWS) (1), wherein the person displays only reflexive behavior, and minimally conscious state (MCS) (2), a clinical state characterized by inconsistent but reproducible purposeful behavior. The research focus for these conditions over the past 10 years has been on diagnosis and assessment techniques, in part due to the prevailing high rates of reported misdiagnosis in this population (3,4). Therapeutic interventions aiming at improving levels of consciousness have been increasingly reported in the literature (5), and the importance of early intervention, in helping to promote recovery has been identified (6). While knowledge and research on the neurorehabilitation of DoC increases, there

remains a dearth of available data on care structures and the rehabilitative management of this clinical population worldwide.

Current clinical recommendations

In the US Practice Guidelines Update Recommendations (7), it was proposed that all people with DoC (>28 days) should receive rehabilitation and specialized care to enable timely treatment of medical complications, accurate diagnosis, prognostication, rehabilitative care, and family counseling. In 2020, recommendations for the structure and process of these rehabilitation services (8) were published. Recommendations regarding care and treatment at different time points, in addition to program components, staff training, family counseling, and ethical issues were outlined.

In the UK, national clinical guidelines for DoC were updated in 2020 by the Royal College of Physicians (9). The US and UK guidelines, alongside European guidance (10)

recommend active healthcare management with ongoing assessment and treatment. They include recommendations for stimulation programs, multidisciplinary goal-orientated programs, 24-hour programs of care, medical management of complications, and formal structured assessments of the level of responsiveness. For long-term care, regular re-assessments, adequate nursing care and a “revolving door policy“ with the possibility of re-admission to inpatient treatment and family involvement and support are recommended.

These guidelines have important implications for service provision and program development. However, there have not been any efforts as of yet to assess international compliance with the existing guideline recommendations.

Existing treatment structures and systems of care – geographical aspects

Description of treatment systems for people with DoC has been published very sparsely. Germany has had systems for care in place since the ‘70s with advocacy efforts contemporaneously aimed at legislating appropriate medical treatment for people with severe brain injuries (11). For the US, treatment systems were partially described (12). It was noted that there is limited access to and insufficient length of intense multidisciplinary rehabilitation for part of the affected population, especially when progress is slow in the acute phase (13). An analysis of data of the Traumatic Brain Injury Model Systems (TBIMS) National Database shows that many people with DoC are discharged directly from acute care to nursing care facilities with insufficient expertise in specialized care (14).

While there have been some reports on the development of systematic treatment protocols for people with DoC within specific health-care structures (15), for most countries the systems of care have not been described and/or published. The results of recent surveys on diagnosis and prognosis in the adult and pediatric population (16,17) show that internationally, there are a lot of differences with regard to institutions’ admission criteria and procedures, testing and the use of prognostic criteria. Economic, cultural, and political factors can influence the availability and duration of treatment given to this population.

Importance of timing and duration of neurorehabilitative treatment

Studies have demonstrated the importance of neurorehabilitation in the acute and post-acute phases after sABI, especially in regard to outcome and cost-savings (18–21). Multidisciplinary care and rehabilitation of people with severe brain injury can lead to improvements in mobility, cognition, and functional independence; it can also lead to a reduction of caregiver distress and decreases the length of stay and the likelihood of re-hospitalization (6,22). Data from the TBIMS database (14) reported that approximately 30–40% of people with DoC after TBI admitted to inpatient rehabilitation after the acute phase recover relevant functions like speech or following commands that are important for independence and quality of life. Clinical factors should be taken into account to ensure adequate transfer criteria from intensive care unit (ICU) to post-acute neurorehabilitation facilities (21).

Some authors suggest that treatment is justified in all cases of severe brain injury (10). In the post-acute phase, available literature has reported the types and effectiveness of therapies provided to people with DoC (23–25). Some people with DoC receive long-term interventions at home or in specialized centers with a variety of interventions including but not limited to formal home-based treatment, sensory stimulation/regulation and family support/engagement. The efficacy of such interventions has not as of yet been documented (24). The training and education of staff that are responsible for providing care has not been clearly outlined. Clinical challenges from the perspective of health-care professionals have also not been investigated, but there is some evidence for significant psychological burden on both clinicians and caregivers (26–29).

In summary, the research focus has not been on the implementation of existing guidelines or the description of systems of care and treatment. Also, little is known about the underlying regulations and facilitating factors in regard to health-care systems and payment issues. Though studies suggest that intense inpatient rehabilitation, both acute and post-acute, has a positive effect on the person’s potential to recover, no consensus or guidelines exist for the duration of inpatient rehabilitation for DoC. Timing and duration of rehabilitation for people with DoC, and its relationship to patient outcomes is still an important subject of debate and an area where further controlled, prospective research is necessary to guide clinical care as well as care reimbursement.

Study aims

The treatment subgroup of the IBIA DoC-SIG was interested in assessing the extent to which specialized treatment facilities are available and what types of treatment approaches are actually being used in adults and children with DoC in the countries represented in the SIG. Due to the complexity of the topic, an internationally distributed survey consisted of two parts:

Part 1: Structures of care, availability, duration and payment of treatment

Part 2: Therapies being implemented

This article details the results of part 1 of the survey for the adult population. Results of part 2 and results relating to the pediatric population will be published separately. The goal was to examine the availability and accessibility of neurorehabilitation services for people with DoC (resulting from TBI and nTBI) from acute to long-term care within international geographical regions and countries.

Methods

A descriptive, cross-sectional, online survey was selected due to its ability to target international participants, cost effectiveness and ability to be disseminated and responded to in a timely fashion. Members of the DoC-SIG (n = 116), working in both clinical and research settings in relation to DoC, were invited to participate. The survey explored differences in clinical structures and processes between countries in the treatment of people with DoC. Treatment was defined as the availability of specialist multidisciplinary neurorehabilitative care, from acute

to long-term care, to improve and/or regularly assess arousal and awareness levels for people with DoC, facilitate neurorecovery, and minimize neuromedical morbidity.

Participants were asked to answer questions based on their own geographical area which could represent a regional district thereby allowing for within and between country comparisons.

Survey development

The survey had three stages of development. The first stage entailed reviewing all relevant literature (PKM and AMM) to identify potential areas of investigation surrounding treatment for people with DoC. Using this information, a draft survey was developed. In the second stage, the survey underwent two rounds of consultation and amendment. Consultation was undertaken with DoC-SIG members from different countries and also a multi-disciplinary team currently working with people living with DoC. In the third stage, the survey was piloted. The survey was piloted with two clinicians (who were ineligible to be in the recruitment sample) before being finalized and disseminated using SurveyMonkey®. It was decided to separately explore adult and pediatric DoC after both TBI and nTBI. The survey consisted of 124 questions in total with options to skip sections if the respondents did not have experience or did not currently work in a particular area of practice. Time to complete varied depending on number of responses with an approximate completion time of 20 minutes. The questions explored the available specialist and rehabilitative services from initial treatment following the brain injury, to inpatient treatment, to medium-long-term care and outpatient care. This paper reports on responses in relation to adult services only.

Survey dissemination

All members of the IBIA DoC-SIG (n = 116) were eligible to participate in the study and the online survey was disseminated via e-mail in March 2017. A reminder e-mail was sent after 4 weeks of data collection and the survey closed 8 weeks after initial dissemination.

Data analysis

Responses from Survey Monkey were uploaded into IBM Statistical Package for the Social Sciences Version 23 (SPSS-23). Data checks ensured each respondent only completed the survey once. Descriptive, rather than inferential, statistics were run due to the exploratory nature of the survey and the limited response rate.

Results

Demographics

Thirty-five out of 116 members completed the survey, representing a response rate of 30%. Respondents represented geographical areas within 14 countries across four continents with the majority coming from Europe (n = 27) followed by North America (n = 5), Asia (n = 2) and Australia (n = 1) (see Table 1).

Table 1. Country of origin of participants.

Location	N	%
Europe		
UK	6	17.14
Denmark	1	2.86
France	2	5.71
Belgium	6	17.14
Ireland	2	5.71
Italy	4	11.43
Netherlands	4	11.43
Germany	1	2.86
Spain	1	2.86
North America		
USA	4	11.43
Canada	1	2.86
Asia		
China	1	2.86
Indonesia	1	2.86
Australia		
New Zealand	1	2.86

Around 95% of respondents (94.29%, n = 33) had experience working with people with DoC in both clinical and research capacities, two participants had a clinical-only role with no respondent having a research-only role. The majority of respondents (62.8%, n = 22) had more than 5 years of work experience with people with DoC. 28.6% (n = 10) had between two- and five-years experience and only 3 participants (8.6%) had less than 2 years experience working with people with DoC in their role. In addition to working in research (n = 18) and academic institutions (n = 11), respondents had clinical roles across ICU/acute hospital (n = 19, 54.3%), rehabilitation hospitals (n = 16, 45.7%), and long-term care (n = 12, 34.3%). Professional backgrounds varied and included researchers (n = 13), medical doctors (n = 17), allied health professionals (speech and language therapy, occupational therapy, physiotherapy, dietician, neuropsychology) (n = 17), neuroscientists (n = 3), and a nurse (n = 1).

Initiation of rehabilitation

Commencement of specialized multidisciplinary rehabilitation (answered by 16 respondents) varied among geographical areas, averaging 3–4 weeks for TBI (n = 5) and 5–8 weeks for nTBI (n = 4). Rehabilitation initiation after more than 2 months was reported by four respondents (50%) for nTBI etiology and 3 respondents (18.8%) for TBI etiology. Nineteen respondents did not answer this question with some stating it depended on available resources and medical status of the person.

Access to rehabilitation services across the care continuum

Tables 2 and 3 summarize the findings in relation to the percentage of people with DoC who get access to specialist interdisciplinary neurorehabilitation services from acute to outpatient care. The data for TBI (Table 2) and nTBI (Table 3) etiology are noted separately.

Table 2. Access to specialist interdisciplinary neurorehabilitation services across the care continuum for DOC resulting from TBI.

Estimate of percentage of Patients with access to treatment	Acute(n = 33)			Rehab (n = 28)			Outpatient (n = 24)		
	% of Respondents	N	By country	% of Respondents	N	By Country	% of Respondents	N	By country
> 75%	27.3	9	UK (n = 2), Denmark (n-1), France (n = 1), Belgium (n = 2), USA (n = 2), Indonesia (n = 1)	28.6	8	UK (n = 1), Denmark (n = 1), Belgium (n = 2), Italy (n = 1), Germany (n = 1), Indonesia (n = 1), New Zealand (n = 1)	12.5	3	China (n-1), Germany (n = 1), Denmark (n = 1)
> 50%	9.1	3	Belgium (n = 1), Italy (n = 1), China (n = 1)	7.1	2	UK (n = 1), Italy (n = 1)	4.2	1	Italy (n = 1)
> 25%	3	1	USA (n = 1)	14.3	4	Belgium (n = 1), Italy (n = 1), USA (n = 1), Canada (n = 1)	8.3	2	Indonesia (n = 1), USA (n = 1)
< 25%	6.1	2	France (n = 1), Canada (n = 1)	21.4	6	Spain (n = 1), The Netherlands (n = 3), USA (n = 2)	37.5	9	UK (n = 2), Belgium (n = 2), Spain (n = 1) Italy (n = 1) USA (n = 2) Canada (n = 1)
None	15.2	5	Italy (n = 1), The Netherlands (n = 3), Germany (n = 1)	0.00	0		8.3	2	The Netherlands (n = 2)
I don't Know	33.3	11	UK (n = 3), Ireland (n = 1), Belgium (n = 2), Italy (n = 2), Spain (n = 1), The Netherlands (n = 1), New Zealand (n = 1)	21.43	6	UK (n = 2), France (n = 1), USA (n = 1), Italy (n = 1), China (n = 1)	29.1	7	New Zealand (n = 1), The Netherlands (n = 1), Italy (n = 1), Belgium (n = -1), France (n = 1), Ireland (n = 1), UK (n = 1)
Other	6.1	2	Belgium (n = 1), USA (n = 1)	7.14	2	Ireland (n = 1), The Netherlands (n = 1)	0.00	0	

Table 3. Access to specialist interdisciplinary neurorehabilitation services across the care continuum for DOC resulting from nTBI.

% of Patients	Acute			Rehab			Outpatient		
	% of Respondents	N	By country	% of Respondents	N	By Country	% of Respondents	N	By country
More than 75%	16.1	5	UK (n = 1), Denmark (n = 1), Belgium (n = 1), USA (n = 1), Indonesia (n = 1)	33.3	9	UK (n = 1), Denmark (n = 1), Belgium (n = 2), Italy (n = 1), Germany (n = 1), USA (n = 2), Indonesia (n = 1)	12.5	3	Denmark (n = 1), Germany (n = 1), China (n = 1)
More than 50%	16.1	5	UK (n = 1), France (n = 1), Belgium (n = 2), Italy (n = 1)	7.4	2	UK (n = 1), France (n = 1),	8.3	2	Italy (n = 1), Indonesia (n = 1)
More than 25%	3.2	1	USA (n = 1)	7.4	2	Belgium (n = 1), Canada (n = 1)	4.2	1	USA (n = 1)
Less than 25%	9.7	3	France (n = 1), Canada (n = 1), China (n = 1)	22.2	6	The Netherlands (n = 3), Italy (n = 1), USA (n = 2)	37.5	9	UK (n = 2), Belgium (n = 2), Italy (n = 1), Spain (n = 1), USA (n = 2), Canada (n = 1)
None	16.1	5	Italy (n = 1), The Netherlands (n = 3), Germany (n = 1)	0.00	0		8.3	2	The Netherlands (n = 2)
I don't Know	32.3	10	UK (n = 3), Ireland (n = 1), Belgium (n = 1), Italy (n = 2), Spain (n = 1), The Netherlands (n = 1), New Zealand (n = 1)	22.2	6	UK (n = 2), Ireland (n = 1), Italy (n = 1), China (n = 1), New Zealand (n = 1)	29.2	7	UK (n = 1), Ireland (n = 1), France (n = 1), Belgium (n = 1), Italy (n = 1), The Netherlands (n = 1), New Zealand (n = 1)
Other	6.5	2	USA (n = 2)	7.4	2	Spain (n = 1), The Netherlands (n = 1)	0.00	0	

Table 4. Average length of inpatient rehabilitation.

Average length	TBI (n = 28)	nTBI (n = 27)
1–3 months	N = 12 The Netherlands (n = 2), Italy (n = 2), USA (n = 2), Denmark (n = 1), Ireland (n = 1), China (n = 1), New Zealand (n = 1), Indonesia (n = 1), Germany (n = 1)	N = 9 The Netherlands (n = 2), Denmark (n = 1), Ireland (n = 1), Italy (n = 1), USA (n = 1), New Zealand (n = 1), Germany (n = 1), UK (n = 1)
4–6 months	N = 5 UK (n = 3), France (n = 1), Canada (n = 1)	N = 10 UK (n = 3), Belgium (n = 2), France (n = 1), Canada (N = 1), China (n = 1), The Netherlands (n = 1), Italy (n = 1)
7–9 months	N = 2 Italy (n = 1), Belgium (n = 1)	N = 1 Indonesia (n = 1)
>9 months	N = 3 Belgium (n = 2), Italy (n = 1)	N = 1 Italy (n = 1)
Other	N = 4 Only available to under 25 year olds (The Netherlands, n = 1), <1 month (USA, n = 1), not transferred to rehab (Spain (n = 1)	N = 5 Only available to under 25 year olds (The Netherlands, n = 1), <1 month (USA, n = 1; Belgium n = 1), not transferred to rehab (Spain (n = 1), Variable (USA, n = 1)
I don't know	N = 2 UK (n = 1), USA (n = 1)	N = 0

Generally, access to services decreased when the person moves from rehabilitation to outpatient services. Both TBI and nTBI groups received the most access when in specialized rehabilitation settings when compared to acute care and the least access for both groups in outpatient care.

Average duration of rehabilitation

Out of 35 respondents, 28 answered the question about duration of inpatient rehabilitation for people with DoC from TBI etiology and 27 answered regarding rehabilitation services for nTBI etiology. The duration of inpatient rehabilitation varied across geographical areas within and between countries. Respondents reported that for inpatient rehabilitation the most common length of stay for TBI etiology was 1–3 months (n = 12) and 4–6 months for nTBI (n = 10) (see Table 4 for a comparison of rehabilitation duration across countries for both TBI and nTBI etiologies). Rehabilitation beyond 9 months was reported by three respondents from Italy and Belgium. Two respondents were not aware of the average duration of rehab in their geographical region, while one respondent from the Netherlands reported that only people with TBI up to 25 years receive rehabilitation.

Ending inpatient rehabilitation

The rationale for ending inpatient rehabilitation was reported by 15 out of 35 respondents, who could select more than one rationale (Table 5). Eleven respondents were from Europe, two from the USA and two respondents from outside of these two continents. A lack of functional improvement and good functional recovery were the most common criteria for ending inpatient rehabilitation (both 86.67%, n = 13). Financial reimbursement limitations were the third most common reason to end inpatient rehabilitation (53.33%, n = 8), followed by a surrogate decision (n = 5), demand for beds (n = 4) and other (n = 3). Twenty respondents chose to skip this question.

Table 5. Reported reasons for ending inpatient rehabilitation.

	Lack of functional recovery	Good functional recovery	Surrogate decision	Financial reasons	Demand for beds
EU	10	10	4	4	3
USA	2	2	0	2	0
Other Region	1	1	1	2	1

Outpatient and long-term care

Participants were asked to identify the most common care locations for adults with long-term DoC within their geographical areas with the option to select more than one location. Twenty-two respondents answered this question. The most common long-term care locations were reported to be at home with family (72.73%, n = 16), specialist nursing home for DoC (50%, n = 11), general nursing home (45.45%, n = 10), community living facility with other people with DoC (13.64%, n = 3), and other (9.1%, n = 2). Other included a local community hospital and a community living facility for people with neurological conditions. The questionnaire also contained a question regarding the extent to which people with DoC (as the result of both TBI and nTBI) retain access to rehabilitation services once discharged from inpatient rehabilitation (24 respondents answered this question). The most common reported ways in which people with DoC retain access to specialist DoC teams is by the person traveling to a specialist center for outpatient appointments (41.67%, n = 10) and through individual therapists visiting the person with DoC in their local care facility (n = 10). Less commonly, the specialist rehabilitation team would visit the person with DoC at their care facility (25%, n = 6) or the person with DoC would travel to a specialist center to receive individual therapy (n = 3). Four respondents reported that no outpatient services were accessible for people with DoC.

Depending on available services there was a discrepancy in who the respondents felt was responsible for long-term outpatient care of the person living with DoC. Half of respondents who answered this question (n = 9, 42.9%) reported that the consultant in rehabilitative medicine was responsible while the other half felt it was the local general practitioner's role. Of the respondents, 90.9% (n = 20) reported they felt there were not adequate resources in place to provide regular re-assessment of the person's clinical diagnosis.

Funding of Rehabilitation across Treatment Phases

Twenty-two respondents answered questions in relation to funding of rehabilitation. The majority of rehabilitation and treatment was reportedly sustained by state funding across the three treatment phases (acute, rehabilitation, long-term care/outpatient). Insurance was also an important source of funding for this clinical population. Private funding accounted for the

minority of funding sources and funded more outpatient services (18.2%) than acute or inpatient rehabilitation (both 4.6%). Variation in funding sources varied between countries with both Belgium and the USA reporting within country differences (see Table 6 for a summary of funding streams for rehabilitation of DoC as reported across all countries).

End-of life care

Eighteen respondents answered the question regarding end-of-life care. Around 67% (66.6%, $n = 12$) reported that the treating physician is responsible for initiating a conversation about end-of-life decisions. Four respondents (22.2%) reported that the family is responsible, one respondent reported it was the multidisciplinary team's responsibility, and one respondent was unsure.

Clinical challenges

Twenty-one respondents answered the question regarding clinical challenges they face working with people with DoC. Of the respondents, 90.91% ($n = 20$) reported that they felt there were not enough resources in place to provide appropriate rehabilitation for this clinical population. The most commonly reported clinical challenges faced by respondents were follow-up and re-assessment ($n = 16$) followed by access to specialist services ($n = 13$). Completing diagnostic assessments in addition to limited time and resources were both identified as the third most challenging issue ($n = 9$). Access to therapy services was also identified as challenging by respondents ($n = 8$).

Discussion

This survey explored the available treatment structures, systems of care and challenges associated with providing neurorehabilitation to people with DoC. The data present new insight into current treatment structures and practices for this clinical population from the perspective of experienced clinicians.

Table 6. Funding of rehabilitation.

Europe	
UK ($n = 6$)	State Funded ($n = 3$), (missing, $n = 3$)
Ireland ($n = 2$)	Privately and publicly funded ($n = 2$)
Denmark ($n = 1$)	State Funded ($n = 1$)
France ($n = 2$)	State Funded ($n = 1$), Missing ($n = 1$)
Belgium ($n = 6$)	State Funded ($n = 1$), State Funded and Insurance ($n = 1$) Privately and Publicly Funded ($n = 1$), (missing $n = 3$)
Italy ($n = 4$)	State Funded ($n = 3$), missing ($n = 1$)
Spain ($n = 1$)	Mix of State Funded, Insurance and Privately and Publicly Funded ($n = 1$)
Netherlands ($n = 4$)	Insurance ($n = 1$)
Germany ($n = 1$)	Insurance ($n = 1$)
North America	
USA ($n = 4$)	State Funded and Insurance ($n = 1$), Privately and Publicly Funded and Insurance ($n = 1$), Missing ($n = 2$)
Canada ($n = 1$)	State Funded ($n = 1$)
Asia	
China ($n = 1$)	Insurance ($n = 1$)
Indonesia ($n = 1$)	Privately and Publicly Funded ($n = 1$)
Australia	
New Zealand ($n = 1$)	State Funded ($n = 1$)

Most respondents to the survey had many years of work experience with this population and respondents represent a wide range of professions.

Access to specialized rehabilitative services

Based on the responses collected, specialized neurorehabilitative infrastructures for people with DoC are available in all participating countries, but with varying availability and degree of access during different phases in the clinical continuum after brain injury. Respondents mostly reported that access to services decreased when the person moved from inpatient rehabilitation to outpatient services.

Many respondents were not aware of the extent rehabilitative treatment was available in the acute phase. Among those who could give an estimate, less than 30% of respondents think that the majority of people with DoC have access to neurorehabilitative treatment in the acute phase, with a higher percentage of people with TBI having access to services than those with non-traumatic etiologies. For the post-acute phase, all participating countries have facilities in place for inpatient rehabilitation for people with DoC. For those who get access to these rehabilitative systems, specialized multidisciplinary treatment structures with focus on improvement of consciousness and prevention of complications seem to be available, but to a varying extent. Less than half of all respondents stated that the majority of people with DoC get access to this type of specialized treatment. Respondents from some countries (Spain, Netherlands, and US) even reported that less than 25% of all people with DoC get access to such neurorehabilitative programs. In some countries or regions more than 50% of people with TBI and nTBI have access to inpatient rehabilitation according to the majority of respondents.

In addition to the national and international differences in regard to degree of access to specialized rehabilitative services, some respondents noted that access was also dependent on the age of the person affected. Respondents from the Netherlands reported that only people up to 25 years of age with TBI were being treated based on national policies. After the conclusion of this survey, access to rehabilitative services improved for this population due to the activities of a group of clinicians from the Netherlands (30). The role of the person's age in the admission process was not studied in this survey, but should be included as part of further inquiry, especially considering the increasing average age of persons with brain injury (31).

These findings show that treatment structures are not available to all people with DoC. Thus, recommended diagnostic procedures, therapeutic attempts, and counseling of relatives have not been implemented as guidelines in many countries suggest.

Start of inpatient rehabilitation and duration

For those who get access to rehabilitation, time to rehabilitation is longer for nTBI compared to TBI (5–8 versus 3–4 weeks). This might be due to the fact that in general there is a higher average age and a higher percentage of multimorbidity in the population of people with nTBI (32). That might lead to an increased need for a longer acute care treatment stay

and with that a later onset of rehabilitation referral (19). For both groups, major differences could be seen between countries and regions, with rehabilitation commencement after more than 2 months in some places.

We found that duration of rehabilitation is also longer for nTBI compared to TBI. This finding is important considering that in general people with DoC after nTBI are considered to have poorer outcomes than people with TBI and are considered to be in a chronic phase after 3 months (8). One explanation might be that the nTBI group is very heterogeneous; many people, especially after anoxic brain injury, might have a longer recovery period and show the first signs of reactivity only after weeks of rehabilitation. In countries in which health care and payment systems allow for an extension of stay in case of apparent progress, the overall treatment time could be longer due to this. In general, most countries reported a length of stay that allows for a thorough diagnostic process and initiation of treatment, but major discrepancies in duration of treatment of DoCs could be seen across countries, but also within countries, ranging from 1 to more than 9 months. Many respondents (nTBI: $n = 9$; TBI: $n = 12$) reported that the average duration of rehabilitation is less than 3 months, and with that below the recommended minimum time for treatment and evaluation for this population.

Long-term treatment

Not all countries reported dedicated structures for medium and long-term treatment and care for this population. For people with TBI and nTBI, access to specialized neurorehabilitation in the outpatient treatment phase seems to be limited, with the majority of respondents reporting that less than half of all people with DoC get continued treatment. This finding raises the concern that long-term follow-up and expert treatment do not seem to be available for most people with DoC.

After discharge from inpatient rehabilitation, most people with DoC (73%) are being cared for at home by their families and in nursing homes. In the last 20 years, some European countries like Belgium, the Netherlands, and Germany even have developed specialized nursing homes, living communities specialized for long-term treatment and care of this population as well as cooperation between inpatient rehabilitation facilities and long-term facilities (32). This shows that it is possible to develop and maintain the necessary structures for long-term treatment and care as called for in the clinical guidelines for this population (8).

Relatives or health-care professionals who provide long-term care for this population and thus have a role in evaluating changes to clinical and behavioral status. As suggested by existing clinical guidelines (9) they should receive special training as part of neurorehabilitation. As this survey reports limited availability of specialized out-patient therapies, this training should be provided within existing inpatient structures.

Questions around end-of-life and neuro-palliative care were included as this is considered an important part of treatment and intervention for people with DoC. In regard to the question who initiates a discussion on end-of-life care, there seem to be major differences between countries and regions. End-of-

life discussions do not seem to be routinely integrated in the care pathway of people with DoC. This very sensitive topic that may be related to ethical and socio-cultural attitudes, local policies, and national health-care systems.

Funding of treatment

Financial reimbursement limitations seem to play a major role in treatment duration to varying degrees depending on the country. The role of financial reimbursement impact on the setup of clinical infrastructures and access to services should be examined further. A lack of treatment funding seems to be the third most common reason for ending inpatient rehabilitation (53.3%). In general, state-funded rehabilitation is most common, though payment through insurance companies seems to play a major role as well. In regard to the financial reimbursement question, major differences seem to exist between countries, certainly due to major international differences in health care and insurance systems. An international collaboration of clinical experts, payers, governmental agencies/representatives, family members, and ethicists could help in setting up the groundwork for providing adequate financial resources for the rehabilitation of people following severe brain injury. That might be an important step toward implementation of the international treatment and management practice guidelines (8,9).

Perceived challenges

Many respondents reported a lack of resources and availability of treatment as major challenges for this population. Among the most important treatment challenges perceived by experienced clinicians/researchers was the lack of opportunity for follow-up and difficulties in re-assessment due to a lack of availability of outpatient treatment and long-term care services. This is a clear evidence supporting the fact that best practice guidelines have not been implemented to date in many locales. In many cases general practitioners are responsible for managing the long-term care of this population, with the question remaining if they are trained and equipped to provide specialized assessment and guidance.

Study limitations

The response rate was low with 35 respondents in total. The survey was only answered by IBIA DoC-SIG members who had an interest and expertise in this area of practice. It was likely that all respondents had at least some experience with this population and that their countries had some form of treatment and care structures. Therefore, the survey results cannot be considered representative, especially for other countries not represented in the DOC-SIG. The majority of respondents were from Western, developed countries. Thus, findings may be based on health-care systems with some form of stable financing. While discrepancies and limited resources were reported for these more developed countries, there is a need for further research to explore care and treatment in other countries not represented in this study, in particular developing countries which may be even more impacted by financial constraints.

Many respondents skipped a number of important questions and the reasoning for this is unclear. This could be attributed to uncertainty regarding care and treatment of people with DoC outside their own institution/in other parts of their own country. This rationale is likely due to the fact that there are no central databases in most countries and hence no exact data on these questions are available. With that, the available data can be interpreted as expert clinical judgments rather than representative statements regarding the care of this population.

Due to the level of missing data and also the low response rate, in addition to the exploratory nature of the study only descriptive statistics could be presented. There is a need for more research and larger data sets to build upon these findings.

Conclusion

To conclude, the results of this survey highlight the variability in treatment initiation, length, availability, and resources for people with DoC. Neurorehabilitation for people with DoC is likely dependent on geographical location, age, and etiology, among other factors. The results also show the decreasing likelihood of inpatient rehabilitation as time progresses. Financial issues have been found to be a major limitation to access rehabilitation services. Finally, the majority of respondents found that there are a lack of resources and availability of treatment for this clinical population. Clear care trajectories should be developed and implemented by health-care systems worldwide based on the recent guidelines from the United States (8).

This study confirmed the notion that many clinical challenges remain in regard to providing treatment internationally as Zhao et al. (15) previously concluded. Having a better understanding and awareness of the treatment systems and limiting factors can provide the basis for achieving improvements of care and treatment of this population. Further work and research are needed to implement best practices at an international level.

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