Patients with Disorders of Consciousness in India: Preliminary Results from a Pilot Survey

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Abstract

The epidemiological data of Indian patients with disorders of consciousness (DOC), specifically vegetative state and minimally conscious state, have not been investigated. The present study sought to explore the current state of the art in India for patients with DOC promoting a pilot survey. An *ad hoc* questionnaire was sent to a total of 400 Indian professionals who are affiliated to various centers; 59 professionals completed the questionnaire and 52 of them declared that their centers hospitalized patients with DOC in the last year for rehabilitation/medical treatments. The majority of the professionals were from Maharashtra region. The main preliminary findings showed that the prevalence rates of traumatic and nontraumatic etiologies were equally distributed, that the rate of use of the coma recovery scale-revised was low, and that the rehospitalization was always or frequently possible in neurological and rehabilitation units. The extrapolated estimated rate of patients with DOC hospitalized in the centers involved in 2017 was equal to 4 per million of population in Maharashtra region. More than 50% of the professionals declared that there were neither sufficient nor adequate services for caregivers' support. Even if the present pilot survey has some limitations, the present article offers the first preliminary data on patients with DOC in Indian country.

Keywords: Disorders of consciousness, epidemiology, India, survey, vegetative state

Introduction

There is an increasing number of patients who survive after severe brain damage and enter into a vegetative state (VS) or minimally conscious state (MCS), generally defined as disorders of consciousness (DOC).[1,2] Organization of healthcare services for those patients requires different information, among which epidemiological and clinical ones are fundamentals. However, available epidemiological data are mainly from the US or some European countries (classified as high-income countries) whereas, for the Asian continent, there is only an old study about the epidemiology of DOC in Japan that reported a prevalence rate around 18.8 persons/per million of population (pmp) at the moment.[3]

Given this lack of data, it is very important to develop studies that try to unveil the condition of the patients with DOC in countries that are highly populated and that are increasing the health systems performance, such as India. To our knowledge, studies on hospitalization rate for persons in VS and MCS in India are still lacking, although this a middle-income country is the second most populous nation in the world and is also going through a period of rapid economic growth.[4]

The present pilot study aims to collect preliminary information about Indian patients with DOC, as well as to provide a first raw estimated hospitalization rate of this clinical condition in the country.

Subjects and Methods

This survey was developed through collaboration between Italian and Indian members of the World Federation of Neurorehabilitation (WFNR) from December 2017 to February 2018. Considering the limited funding available, authors opted for a pilot study to collect preliminary data on the complex reality of patients with DOC in different areas of India. An *ad hoc* questionnaire [Questionnaire 1] was developed by Italian and Indian researchers according to previous explorative surveys made in European countries.[5,6] The questionnaire was implemented online using Google Forms by the Indian team, and its link was sent to a total of 400 members who are affiliated to various centers in India through e-mails. In detail, participants are members of the Indian Federation of Neurorehabilitation (IFNR), of the Indian Academy of Neurology (IAN) and/or the Neurological Society of India. Fifty-nine professionals (each one from different centres) completed the questionnaire. Several centers from different regions of India are represented in this survey, but majority of the responses are from the Maharashtra

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region (120.68 millions of people in 2017).[7] Considering that India has approximately 51 physicians per 1,000,000 persons according to the WHO,[8] this pilot survey covered a wide percentage of centers in Maharashtra region.

Only aggregated data were collected. Consent was obtained from each participant that accepted to answer the form.

Statistical analysis

Continuous variables are presented as medians and interquartile ranges and categorical variables as numbers and percentages. The calculation of the total number of patients hospitalized in the last year was inferred considering the median value for each category reported in the question B.1 (How many patients with the diagnosis of VS or MCS have you/your unit managed in the last year?) by each center. Raw hospitalization rate estimation was calculated considering the total number of patients hospitalized in Maharashtra centers which declared to admit patients with DOC, divided by the total regional population. Analyses were performed using SPSS 24.0 (SPSS Inc., Chicago, IL, USA).

Results

A total of 59 professionals completed the questionnaire [Supplementary Figures 1 and 2] and 52 of them hospitalized patients with DOC in 2017 for rehabilitation and medical treatments. A total of 741 patients with DOC were hospitalized in these centers involved.

Regarding the instrumental examinations, most used for differential diagnosis between VS and MCS were reported the structural magnetic resonance (25 centers use it in >80% of patients), computed axial tomography (20 centers >80%), and EEG (19 centers >80%). The survey also showed as the most clinical assessment scale used in the respondent centers were the Glasgow outcome scale (48/52 centers used it), then the Disability rating scale (25/52 centers) and the functional independence measures (22/52 centers). Only 9/52 centers used the coma recovery scale-revised (CRS-r) during the assessment procedures for the clinical assessment of patients with DOC

Table 1 reports information on patients' hospitalization by all the centers which completed the questionnaire. Considering only the 52 centers that declared to admit patients with DOC in 2017, 22 centers reported that the most etiology found in patients was nontraumatic brain injury (n-TBI), whereas 23 centers reported that it was TBI. Seven centers reported that the two etiologies were equally distributed.

Considering the features of the pathways of care, at the question "Can patients be hospitalized again for a second, third, etc., hospitalization if they need treatments?," the 75% of professionals reported that it was "always" or "not always possible but frequent" to re-admit a patient in the same center, whereas the other 25%of them that it was "rare" or "very difficult" to hospitalize a patient again. Considering the difference between units, the possibility of readmission declared by professionals ("always" or "not always possible but frequent") was equal to 69.7% in neurological units and equal to 75% for rehabilitation units.

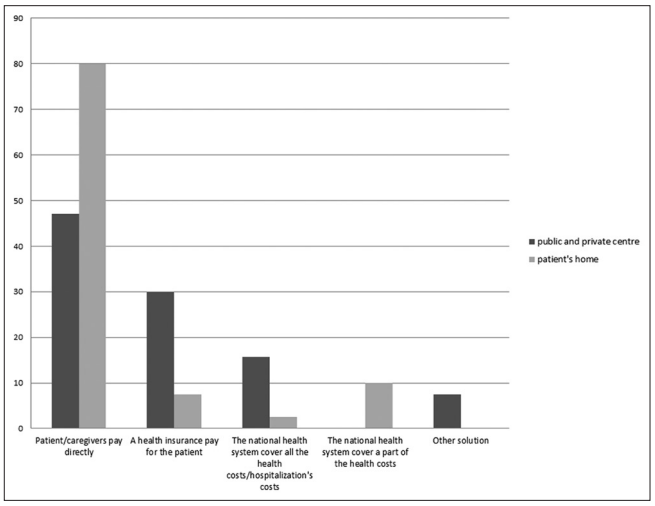

Figure 1: Health care coverage costs. Note: The diagram showed the professionals' answers to the questions "Hospitalization costs in the place where you work are covered by?" and "The health costs for patients in vegetative and minimally conscious state at home are covered by?" The graphical representation must be read considering that the sum of light gray percentages indicates the 100% of professionals' responses for patients at home subdivided for the different types of coverage of costs, as well as for the sum of the lead-gay columns that represent the 100% of the professionals' evaluations for patients admitted in their centers

Table 1: Types of units involved in the survey and data on hospitalization of patients with disorders of consciousness

Type of center/unit	Number of respondent professionals, *n* (%)	Adult patients only, *n* (%)	Pediatric patients only, *n* (%)	Both, *n* (%)	Number of centers that hospitalized patients with DOC in the last year, *n* (%)	Median value (IQR)	
						Number of patients with DOC in the last year	Days that occurs from patient's acute event to the first visit by professionals of the unit
Neurology unit	36 (63.1)	17 (70.8)	1 (50.0)	18 (58.0)	33 (63.5)	8 (12)	2 (4.0)
Rehabilitation unit	14 (24.6)	4 (16.7)	1 (50.0)	9 (29.0)	12 (23.1)	8 (25.7)	4.5 (11)
Surgery/neurosurgery unit	3 (5.3)	3 (12.5)	0	0	3 (5.8)	15 (-)	3 (-)
General clinic unit	2 (3.5)	0	0	2 (6.5)	2 (3.8)	3 (-)	15.5 (-)
Orthopedic unit	2 (3.5)	0	0	2 (6.5)	2 (3.8)	14 (-)	9 (-)
Total	57 (100)	24 (100)	2 (100)	31 (100)	52 (100)	-	-

Percentage must be read in relation to columns. DOC=Disorders of consciousness, IQR=Interquartile range

In Figure 1, we show the descriptive results about the refunding of health costs. In detail, we represent the 57 professionals' answers at two questions as reported in the note of the figure, differentiating the results for patients admitted in centers and patients at home. Direct payment was the most cited refunding method in our pilot survey.

Regarding the results from the other questions of the questionnaire, the evaluation of the health services provided, the sum of "inadequate" + "not sufficient responses" was more than 50% for caregivers' support. Furthermore, neurologists and medical doctors from rehabilitation units are the professionals who showed the higher probability to visit patients with DOC also at home (60% and 24.4%, respectively).

Considering that the total number of patients with DOC hospitalized in centers placed in Maharashtra region was $n = 488$; a raw extrapolated rate of 4 hospitalizations/pmp/year was estimated for this area.

Discussion

This survey, although with several methodological limits, shows preliminary data from professionals working in 52 healthcare centers hospitalizing patients with DOC. Regarding clinical assessment of patients, a very low prevalence of CRS-r use was found, in contrast to international guidelines which indicated the CRS-r as the gold standards tool for behavioral assessment and research purposes.[9,10] Data on etiology did not confirm the trend reported in the scientific literature for the European countries[5,6] in relation to the main prevalence of n-TBI with respect to the TBI ones. The raw estimated hospitalization rate for Maharashtra region is 4/pmp/year.

This final result could underestimate the real prevalence of patients with DOC because the majority of the population resides in the rural areas, and the rural patients are covered by the government health care setup where qualified neurologists or neurosurgeons are not easily available, so patients with DOC are not seen by them (they could be managed by other health care professionals who were not included in this survey).

Moreover, for interpretation of the result, we need to take into account that health insurance in India typically pays for only inpatient hospitalization and for treatment at hospitals. According to La Forgia and Nagpal 2012,[11] >25% of India's population gained access to some form of health insurance by 2010, up from 55 million in 2003–2004. More than 180 million of these were people below the poverty line.[8] Indian population estimate is >1.300 billions in 2017.

This pilot study has some limitations. First, the response rate of professionals involved was very low. It is impossible to estimate how many of them hospitalized patients with DOC, but our estimations of the health coverage were quite good, considering that a lot of professionals who hospitalized patients with DOC in Maharashtra region are members of the IFNR or of the IAN and that the rate of professionals/population seems to respect the numbers reported in the methodological section. This hypothesis lets authors to calculate the hospitalization rate only for Maharashtra region although the original aim was to collect information on a wider area of India.

Despite of these limitations, our study highlighted the high number of centers who offer readmission of patients guaranteeing the access to health services for these patients also after the first rehabilitation phase. However, the relationship between hospitalization rate and outcomes has to be investigated seriously for patients with DOC, also considering the influence of family support, clinical conditions, and healthcare services for rehabilitation outcomes.[12,13]

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Conflicts of interest

There are no conflicts of interest.

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Supplementary Data

Questionnaire

Questionnaire 1

SECTION A

(1) Where do you work (mainly)?*(only one answer is allowed)*

Hospital: Neurology unit
Hospital: Rehabilitation unit
Hospital: Emergency unit
Hospital: Orthopedic unit
Hospital: Surgery/neurosurgery unit
At patients' home
General clinic
Other: Please, specify here

(2) Please insert the address of your work place (street and city)

(3) Do you mainly work with adults or with pediatric patients?

[ ] <18 years old patients
[ ] >18 years old patients
[ ] Both

(4) How many patients do you see every month?*(Mean number considering the last six months)*

(5) Which are the most recurrent diagnosis? Please refer to ICD10 diagnosis if possible

(6) Have you managed patients with a diagnosis of vegetative state or minimally conscious in the last year?

To ensure comparability of responses, we provided a working definition of the vegetative state, adapted from the 1994 report of the US Multi-Society Task Forceand asked respondents to bear this definition in mind when completing the questionnaire. The vegetative state was defined as patients presenting with:

- No evidence of awareness of self or environment
- All responses are reflex in nature
- No meaningful or voluntary response to stimulation (visual, auditory, gustatory, olfactory or tactile).
- No evidence of language comprehension or expression
- Intermittent sleep-wake pattern
- Variable preserved cranial nerve reflexes
- Sufficiently preserved hypothalamic and brainstem autonomic function to permit prolonged survival with medical and nursing care.

Yes
No

If NO, thank you very much for your attention.

SECTION B - Epidemiological information

(B.1) How many patients with diagnosis of VS or MCS have you/your unit managed in the last year (from January 2017 to today)?

1-5
6-10
11-20
21-30
>30

(B.2) How many of those patients are in VS and in MCS? *(indicate percentage)*

VS%
MCS%

(B.3) Please, could you indicate the percentage relative to traumatic and non-traumatic etiologies?

TBI%
n-TBI (postanoxic, hemorrhage, ischemic stroke, etc.,) %
Mixed etiology

(B.4) Please, indicate the average time (mean value) that occurs from patients' acute event to your first visit/clinical consulation? *(days)*

(B.5) How many of the above patients changed their functional and diagnostic level in the last year? Please, indicate a percentage

From VS to Minimally conscious state (MCS)	%
From VS to emerged from MCS/recover of consciousness	%
From MCS to emerged MCS/recover of consciousness	%
From VS or MCS to death	%
Remaining clinically stable	%

SECTION C - Clinical managing information

(C.1) Have you used any of the following examination for making diagnosis in your patients in VS or MCS? *(more than one answer is allowed)*

	Not available	From 0 to 100 (all patients treated made it)
Evoked potentials		
EEG-electroencephalography		
Structural magnetic resonance		
Functional magnetic resonance		
CAT-computed axial tomography		
PET-positron emission tomography		
SPECT-single photon emission computed tomography		

MEG-magnetoencephalography

(C.2) Do you usually use one, or more than one, of these clinical assessment tools? *(more than one answer is allowed)*

Glasgow outcome scale (GOS)
Disability rating scale (DRS)
Level of cognitive functions (LCF)
Coma near coma (CNC)
Functional indipendence Measures (FIM)
Nociception Coma Scale (NCS)
Coma Recovery Scale (CRS-r)
Wessex Head Injury Matrix (WHIM)
Sensory Modality Assessment and Rehabilitation Technique (SMART)
Western Neuro Sensory Stimulation Profile (WNSSP)
Other: Please, specify here

FROM HERE THERE ARE 2 SUB-SECTIONS IN ACCORDING TO ANSWERS PROVIDED TO QUESTION NO 1

(ONLY FOR MEDICAL DOCTORS WORKING IN A HOSPITAL UNIT)

(C.3.1a) Do you have the following specialists for diagnosis treatment and care of patients in VS or MCS in your unit? *(more than one answer are allowed)*

Physician
Neurologist
Neurosurgeon
Physiatrist
Physiotherapist
Neuropsychologist
Speech therapist
Psychologist
None, not necessary
None, nobody is available for caring them
Other: Please, specify here

(C.3.2a) How long do patients stay in your unit? Please indicate mean time considering only first admission in hospital *(days)*

(C.3.3a) Can patients be hospitalized again for a second, third, etc., hospitalization if they need treatments?

Always
Not always, but frequently
Rarely
Very difficult to hospitalize a patients again
Other notes: Please specify

(C.3.4a) **Hospitalization costs in the place where you work are covered by?** *(more than one answer are allowed)*

The unit is in a private center	Patient/caregivers pay directly	Insert [X] here
	A health insurance pay for the patient	
	Other solutions, specify	

No, the unit is in a public center	The national health system cover the costs of hospitalization
	Patient/caregivers pay directly
	Other solutions, specify

(ONLY FOR FAMILY PRACTITIONERS/DOCTOR WORKING IN MEDICAL OFFICES/PATIENTS' HOME)

(C.3.1b) If in your patients' group you have patients in VS and MCS at home, how many times did you manage to see each of those patients in the last year? (Please indicate the mean number of visits made and divided it with the no of patients visited)

(C.3.2b) If a patient needs a medical consultation/expert opinion from specialists is it easy to obtain it?

- Always
- Not always, but frequently
- Rarely
- Very difficult to obtain it

(C.3.3b) How would you rate the health services provided to patients?

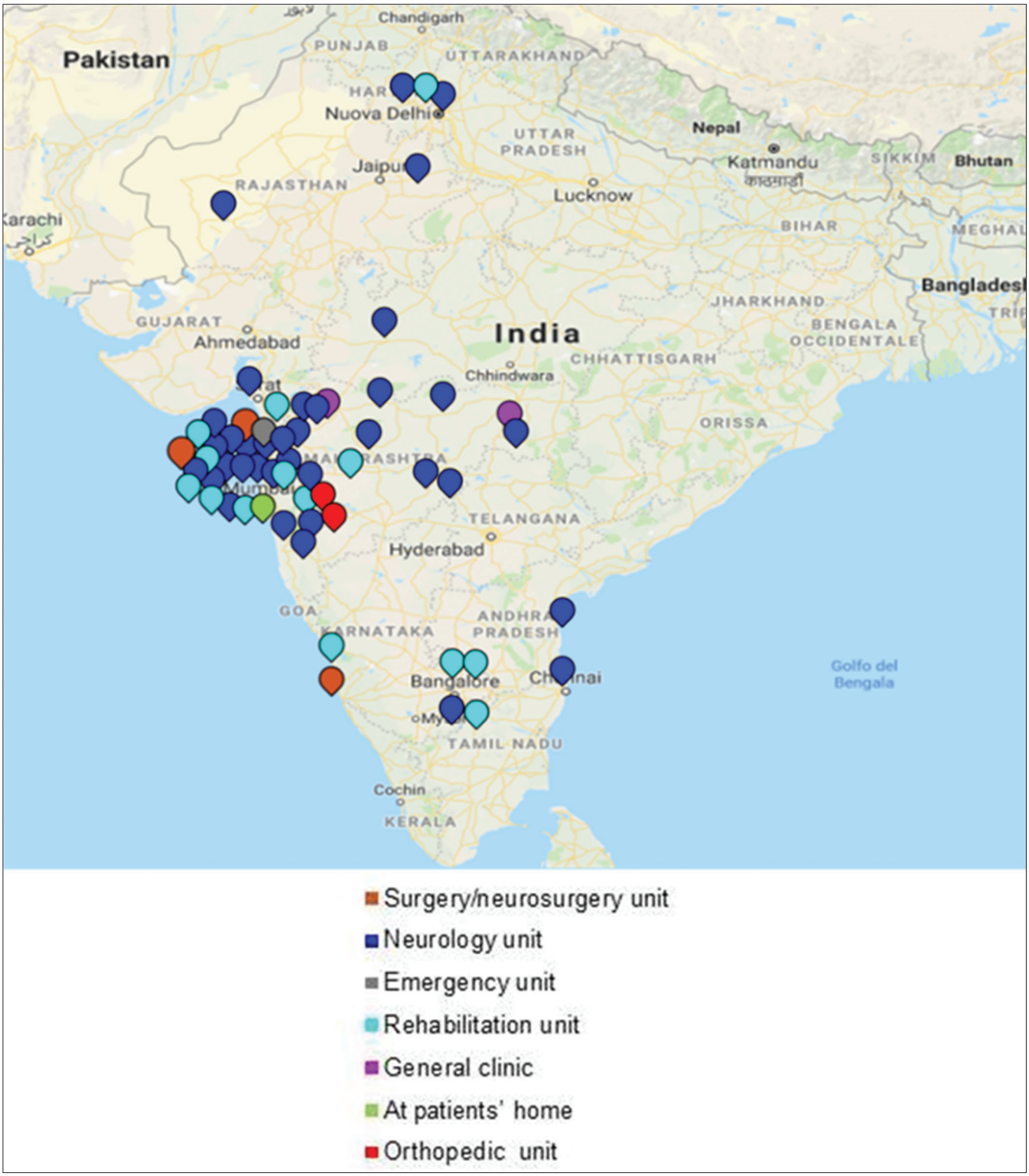
- Optimal
- Sufficient
- Not sufficient
- Inadequate

(C.3.4b) The health costs for patients in VS and MCS at home are covered by? *(more than one answer are allowed)*

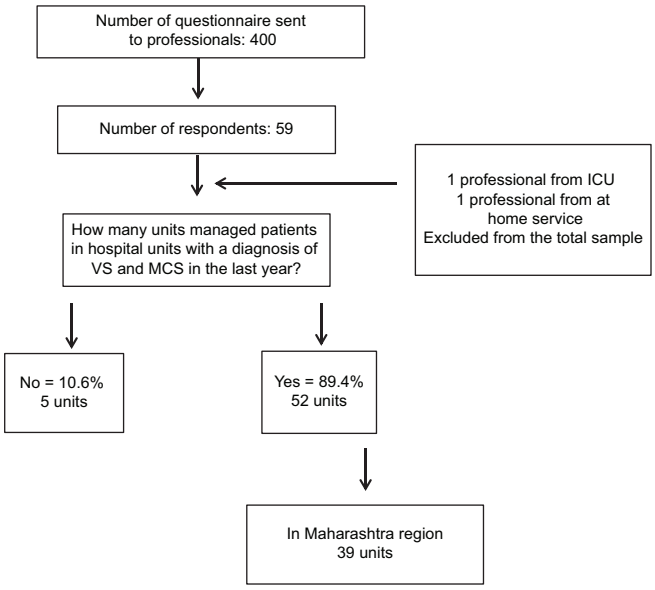
- Patient/caregivers pay them directly
- A health insurance pay for the patient
- The national health system cover all health costs
- The national health system cover a part of health costs
- Other solutions, specify

(C.3.3d) How would you rate the health services provided to family/caregivers of your patients in VS or MCS?

- Optimal
- Sufficient
- Not sufficient
- Inadequate/absent



Supplementary Figure 1: Distribution of participating centers



Supplementary Figure 2: Sampling flowchart