DEVELOPMENT OF A STANDARDIZED REGISTRATION AND FOLLOW-UP SYSTEM FOR DOC PATIENTS

Belgian Federal Project

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PhD in Medical Sciences

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Liège, Belgium

www.comascience.org
Background

- **2001**: Working group on acquired brain injury
- **2004**: Pilot Project – Network of care for DOC patients
- **2007**: Clinical practice guidelines for DOC patients

Harmonize the chronic cares and the rehabilitation needs
Background

Health care circuit:

- Collect quantitative/qualitative epidemiologic, clinical, medical data

- Provide information about available vacancies

  - Avoid to leave the circuit

  - Optimize the patient flux
Belgian Federal Network

16 expertise centers
(80 beds)
Belgian Federal Network

- 16 expertise centers (80 beds)
- ≥5 beds
- Physicians/nurses monitoring
- Multidisciplinary team
- Functional rehabilitation department
- Hospital referent(s) – external liaison
- Adapted equipment
  - Suction bronchial device
  - Pulse oximeter
  - Mattresses against pressure ulcers
  - Rehabilitation equipment
  - Lift-system
  - Adapted bathtub/bed
  - Wheelchair
Belgian Federal Network

16 expertise centers (80 beds)

30 accredited convalescent home (165 beds)
<table>
<thead>
<tr>
<th>Patient</th>
<th>Date</th>
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</thead>
</table>

**AUDITORY FUNCTION SCALE**
- 4 - Coherent Movement to Command *
- 3 - Reproducible Movement to Command *
- 2 - Localization to Sound
- 1 - Auditory Startle
- 0 - None

**VISUAL FUNCTION SCALE**
- 5 - Object Recognition *
- 4 - Object Localization: Reaching *
- 3 - Visual Pursuit *
- 2 - Fixation *
- 1 - Visual Stare
- 0 - None

**MOTOR FUNCTION SCALE**
- 6 - Functional Object Use *
- 5 - Automatised Motor Response *
- 4 - Object Manipulation *
- 3 - Localization to Noxious Stimulation *
- 2 - Reaction Withdrawal
- 1 - Abnormal Posturing
- 0 - None/Tactile

**COMMUNICATION SCALE**
- 2 - Functional Auditory
- 1 - Non-Functional Intentional
- 0 - None

**AROUSAL SCALE**
- 3 - Attention
- 2 - Eye Opening with Stimulation
- 1 - Eye Opening with Stimulation
- 0 - Inappropriate

**TOTAL SCORE**

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[Coma Recovery Scale-Revised](comascience.org)
<table>
<thead>
<tr>
<th>A</th>
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<th>C</th>
<th>D</th>
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Case Report Form

<table>
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<th>Centre d'expertise</th>
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## Case Report Form

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www.comascience.org
# Case Report Form

## Function Vision
1. Reflexe of alignment to threat
2. Fixation
3. Pursuit vision
4. Localization of objects: inattention
5. Recognition of objects

## Table

<table>
<thead>
<tr>
<th>M</th>
<th>N</th>
<th>Date de transfert</th>
<th>Diagnostic donné par le référant</th>
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<th>Statut lors de 6 mois</th>
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Epidemiologic data – 2009

- 16 expertise centers
- 187 admissions (60% men)
- Age: 52 18y, min 14 – max 91 (3 patients < 18 ans)
- Etiologies: 65% non-traumatic

- Clinical status on admission:
  5% coma
  34% VS/Unresponsive Wakefulness Syndrome
  42% MCS
  6% Exit MCS
  2% Locked-in syndrome
  11% unknow
Epidemiologic data – 2009

- 16 expertise centers
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- Age: 52 18y, min 14 – max 91 (3 patients < 18 ans)
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Clinical status on admission:

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- 34% VS/Unresponsive Wakefulness Syndrome
- 42% MCS
- 6% Exit MCS
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- 11% unknown
### Flux/Cost-benefit analysis

<table>
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<tr>
<th>Expertise center</th>
<th>Beds (N)</th>
<th>Admission (N)</th>
<th>Occupancy rate Mean±SD (min, max)</th>
<th>% rate Mean (min, max)</th>
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<tbody>
<tr>
<td>Center 1</td>
<td>19</td>
<td>38</td>
<td>15±3 (8-20)</td>
<td>79% (42%-105%)</td>
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<tr>
<td>Center 2</td>
<td>6</td>
<td>17</td>
<td>6±1 (4-8)</td>
<td>100% (66%-133%)</td>
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<td>Center 3</td>
<td>6</td>
<td>9</td>
<td>5±1 (2-8)</td>
<td>83% (33%-133%)</td>
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<tr>
<td>Center 4</td>
<td>6</td>
<td>12</td>
<td>2±1 (0-4)</td>
<td>33% (0%-66%)</td>
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Flux/Cost-benefit analysis

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<td>12</td>
<td>2±1 (0-4)</td>
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Waiting time admission expertise center
- Mean 26 34 days (median 13; range 0-10 months)
- 26 days * cost per day in acute care hospital (xxx €) = xxx € / patient

Waiting time admission nursing center
- Mean 67 99 days (median 34; range 0-2 years)
- 67 days * cost per day in rehab hospital (xxx €) = xxx € / patient
OUTCOME

Emergence from the minimally conscious state

- Functional recovery
- Recovery of consciousness
- Arousal

Minimally conscious state

Vegetative state

Coma

Functional communication
Functional object use

Appropriate smiling/crying
Localization to noxious stimulation
Visual pursuit
Command following

Eye opening
Reflex movements
**OUTCOME**

Vegetative state (n=296)

- Traumatic: **N=107**
- Non-Traumatic: **N=94**
- Anoxic: **N=95**

Minimally conscious state (n=271)

- Traumatic: **N=100**
- Non-Traumatic: **N=128**
- Anoxic: **N=43**

Legend:
- Green: EMERGENCE
- Blue: MCS
- Black: Dead
- Red: VS
Conclusions

- **Centralized database** – Expertise center/Nursing home
- **Inclusion criteria** – Exit MCS/Locked-In syndrome/<18y
- **CRS-R at 1, 3, 6, 12 and 24 post-injury**
- **Fonctional recovery** – Glasgow Outcome-Scale Extended
- **Optimize the patient flux**
- **Admission/discharge criteria** – Expertise center/Nursing home
**CRF* - Epidemiology**

- **Unique patient identifiers**: ID number
- **Date of birth**: extract this number thanks to the ID number
- **Date of the causative incident**: mm/dd/yyyy
- **Age at onset**: before the onset
- **ZIP code**: before the onset
- **Marital status**: Worker, Pupil/student, Unemployed, Housewife/husband, Other, Unknown
- **Level of education**: primary education (primary schools), secondary education (secondary schools/high schools), tertiary education (university and/or TAFE colleges)
- **Nationality**
- **Insurance status**: Complementary insurance policy: yes/no

*Ethic committee*
CRF – Clinical information (1)

Etiology
Traumatic
- Subdural hematoma
- Epidural hematoma
- Contusion
- Diffuse axonal injury

Non-traumatic
- Subarachnoidal hemorrhage
- Hemorrhagic stroke otherwise
- Ischemic stroke
- Anoxia during circulatory arrest
- Anoxia due to other cause
- Infection of the central nervous system
- Intoxication
- Metabolic disorder
- Combination

Date of arrival at the expertise center: mm/dd/yyyy – Unknown
Expertise center: Belgian list

Vegetative state/unresponsive wakefulness syndrome: date of eye opening - mm/dd/yyyy
Coma duration: xx days

Date of MCS: clinical criteria (non-reflex movement) - mm/dd/yyyy
Duration of VS/unresponsive wakefulness syndrome: xx days
Date of Exit-MCS: clinical criteria - mm/dd/yyyy
Duration of MCS: xx days
CRF – Clinical information (2)

Date of the dead: mm/dd/yyyy
Age at the time of the dead:
Cause of death:
  - Natural death
  - Diseases of the circulatory including ischemic heart disease with cerebrovascular disease
  - Tumor
  - Respiratory diseases
  - Digestive Diseases
  - Nervous system diseases
  - Infectious and parasitic diseases
  - Suicides
  - Traffic accidents
  - Violent death
  - Accidental falls
  - Other
  - Discontinuation of treatment
  - Treatment uninitiated
CRF – Clinical information (3)

CRF-R expertise center admission:

AUDITORY FUNCTION SCALE
4 - Consistent Movement to Command
3 - Reproducible Movement to Command
2 - Localization to Sound
1 - Auditory Startle
0 - None

VISUAL FUNCTION SCALE
5 - Object Recognition
4 - Object Localization: Reaching
3 - Visual Pursuit
2 - Fixation
1 - Visual Startle
0 - None

MOTOR FUNCTION SCALE
6 - Functional Object Use
5 - Automatic Motor Response
4 - Object Manipulation
3 - Localization to Noxious Stimulation

CRS-R 3 months post-injury
CRS-R 6 months post-injury
CRS-R 12 months post-injury
CRS-R at the time of the release from the expertise center

OROMOTOR/VERBAL FUNCTION SCALE
3 - Intelligible Verbalization
2 - Vocalization/Oral Movement
1 - Oral Reflexive Movement
0 - None

COMMUNICATION SCALE
2 - Functional: Accurate
1 - Non-Functional: Intentional *
0 - None

AROUSAL SCALE
3 - Attention
2 - Eye Opening w/o Stimulation
1 - Eye Opening with Stimulation
0 - Unarousable

TOTAL SCORE

Admission status (linked with the CRS-R score):
VS/UWS
MCS
EXIT-MCS
LIS
Dead

Status at 3 months post-onset (linked with the CRS-R score):
VS/UWS
MCS
EXIT-MCS
LIS
Dead

Status at 6 months post-onset (linked with the CRS-R score):
VS/UWS
MCS
EXIT-MCS
LIS
Dead

Status at 12 months post-onset (linked with the CRS-R score):
VS/UWS
MCS
EXIT-MCS
LIS
Dead

Status at the time of the release of the expertise center:
VS/UWS
MCS
EXIT-MCS
LIS
Dead
CRF – Medical information

Tracheotomy
- had (yes / no)
- on admission (yes / no)
- at the release (yes / no)

Gastrostomy
- had (yes / no)
- on admission (yes / no)
- at the release (yes / no)

MRSA, infection
- had (yes / no)
- on admission (yes / no)
- at the release (yes / no)
CRF – Hospitalization flow

Date on injury: mm/dd/yyyy
Hospital: List of hospital

- EXPERTISE CENTER
  Date hospitalization request in the expertise center: mm/dd/yyyy
  Date admission in the expertise center: mm/dd/yyyy
  Expertise center name: List of expertise centers

- NURSING HOME
  Date hospitalization request in the nursing home: mm/dd/yyyy
  Date admission in the nursing home: mm/dd/yyyy
  Nursing home: List of nursing home

- HOME
  Date hospitalization request at home: mm/dd/yyyy
  Date admission at home: mm/dd/yyyy