Guidelines and Standards of Rehabilitation for Severely Traumatic Brain Injured

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Twenty years of progress in the knowledge of the problems of the Traumatic Brain Injured (TBI) and of the long-term sequelae, the experience of specific rehabilitation programs and the demonstration of their efficiency (Semlyen J.K. et al., 1998) (4), allow an attempt to derive guidelines for TBI rehabilitation.
We will concentrate our proposals on severely TBI adults (i.e. moderate and severe handicap according to the Glasgow Outcome Scale) who are the concern of the majority of specific programs. Thus, our study will exclude the slightly head injured, vegetative states, children and initial care and early rehabilitation.

We try to answer two questions:

1. What are the individual goals for a severely TBI adult?
2. How to choose a good rehabilitation unit?

I. INDIVIDUAL GOALS:

1. A pertinent evaluation is required to reach individual goals:

The EBIS (European Brain Injury Society) working group, created in 1989, developed a European project on "epidemiology, evaluation and service delivery for TBI", granted by a research contract with the European Commission (1989-1993) (Truelle J.L. et al., 1990) (5).
The main result of this contract was the publication, in 1994 (Brooks D.N. et al., 1994) (1), of the EBIS document for the evaluation of traumatic brain injured people. Its goal is to derive guidelines for a minimal assessment of TBI, following W.H.O. classification of deficiencies, disabilities and handicaps. It is a holistic questionnaire of 175 items, dealing with the most pertinent problems, medical as well as social, validated and leading to second-step investigations. It takes two hours to fill in (Truelle J.L. et al., 1996) (6).
In 1998, we derived from the EBIS document the so-called "EBIS mini-document", composed of 30 items in 4 clusters: physical, cognitive, behaviour handicap. It takes 17 minutes to fill in.
There are few other validated data on TBI holistic assessment. Together with the EBIS documents, we will take into account a few other scales: the neurobehavioral rating scale of H.LEVIN, the functional independence measurement, the community integration questionnaire and the PQVS (protocol for subjective quality of life).

2. A selection of specific problems to be dealt with:

a. Physical state: epilepsy, orthopaedic deficiency through the reduction of movement amplitude in the different joints, neurological motor deficiencies (central more than peripheral paresis, spasticity) gait, visual problems, pain and fatigue.

b. Cognitive state: unawareness, communication troubles, spatial troubles, memory and learning executive functions to assess frontal dysfunction.

c. Behavioural state: emotional self control, avolitional, self-criticism, "mourning", motivation.

d. Handicap:

- activities in daily living:
  - Basic autonomy: eating, toilet, dressing, WC, transfers.
  - Moreover, advanced activities: mobility outside, financial management, third person, legal guardian.
  - Family: relative's distress couple and sexual problems, changing role of patient in the family.
  - Social aspects: drug addiction, creativity, sports and leisure.
  - Resources: money available, "case manager" access to facilities and support groups devoted to TBI.
  - Medico-legal aspects: compensation of prejudice, solicitor, medico-legal expertise process.
  - Vocational aspects: in-company assessment, job coach

e. Quality of life through a questionnaire to be filled in by the patient and a significant other. The unavoidable subjectivity of the concept has to be taken into account. This often leads to a readjustment of the care planning.

II. WHAT SHOULD BE THE CRITERIA OF A GOOD REHABILITATION PROGRAM DEVOTED TO TBI?

1. The only existing model is provided by C.A.R.F. (U.S. Committee for Accreditation of Rehabilitation Facilities):

a. These autonomous and non-profit organisations were born in the U.S. and promoted in Europe for a few years. They are always improving their criteria of accreditation, going from facilities to individual needs and from rehabilitation to brain injury standards.

b. There are two hurdles to get over:

- The standards of accreditation regarding mainly:
  - The leadership of the program
  - The information and the outcomes management system
  - The rehabilitation process

- The nature of the service delivered: is the program devoted to in-patients, community re-entry, case management, vocational rehabilitation… ?

c. The quality criteria of standards are:
   - The standards of accreditation regarding mainly:
   - Goals more than means
   - To be relevant to TBI
   - Efficient - reflecting the "state of the art"
   - Cost effective
   - Practical
   - Consensual
   - And above all, achievable

2. **What are the questions to ask of a program devoted to TBI adults rehabilitation?** (Murrey G.J et al., 1998) (4) (Johnson C., Brooks D.N., 1999) (2)
   - Admission:
     - How are decisions made about who to admit?
     - Are the previous records available?
     - Are the requests of the client and family taken into account?
     - What is the facility understanding of the role of the purchasers of the services.
     - Is there a written contract?
   - Family:
     - How does the facility involve family members?
     - Are families sent copies of reports?
     - How can the family have contacts with the staff? Is there a referent?
     - Does the facility have any family support?
     - Are there facilities for relatives to stay overnight? Group? What are the visiting policies? What arrangements are available for "conjugal visits"?
   - Organisation:
     - Who is responsible ? Is he full time?
     - Who makes up the treatment team?
     - Is there a daily written time-table for each individual?
     - How are the unscheduled times, the week-end timetable (Leisure, etc) organised?
   - Medical services:
     - Is there a medical doctor inside the facility, part or full time?
     - Will the individual General Practitioner be involved and how?
     - How are the routine medical issues and the emergencies dealt with?
     - How does the facility avoid or prevent skin problems?
     - Does the individual have any say in medical or nursing treatment?
     - How are the medication delivery side effects and patient's refusal managed?

- Experience with people with brain injuries:
  - How many people with brain injuries are admitted every year? How many are currently in the units?
  - How many staff does the facility have? Which disciplines?
  - What is the training and experience of TBI? What staff training is provided?
  - How long has the unit been open?
- Unit presentation:
  - Are the facilities clean?
  - Are the residents clean and dressed in an appropriate manner?
  - Is the food appealing?
  - Are the people resident in the facility happy?
- Cognitive treatment:
  - How does the facility assess and treat cognitive strengths and weaknesses?
  - Is neuropsychological testing done and repeated?
  - How is the effectiveness of the treatment measured?
- Behavioural treatment:
  - How does the unit address behavioural concerns and ensure that behavioural treatments are clearly understood by all the staff?
  - How is the effectiveness of the treatment measured?
  - Are medications used?
  - Are physical restraints and a locked unit used?
  - When does the facility decide that a resident's behaviour is unacceptable and necessitates discharge?
  - How are the rights of the patient taken into account?
- Work and social re-entry:
  - Does the facility provide or have access to vocational services?
  - How are work placements conducted? Are job coaches used?
  - Is there any liaison between the facility and the resources of the Department of Employment?
  - Are educational services on offer?
  - Which parts of the treatment are based in the community? What is the interface with community services?
  - Is there a social support and activity groups?
- Discharge planning:
  - Who makes the decision?
  - What are the possible options after discharge?
  - What are the liaisons with the regional network?
  - What kind of follow-up after discharge is provided to the individual and his family?
  - Is there a "case management" in the community?
  - What is the average length of stay?

- What if someone decides to leave the family with or without advance notice?
  - What sort of discharge summary is provided?
- Quality:
  - Does the unit have a quality standard? Which one?
  - Is the standard relevant to brain injury?
  - Is there any other outside means of assessing the unit's quality?
  - Is there an external advocacy service?
  - Who monitors the practice of the facility, its policies and its procedures? How is monitoring done and recorded?

To conclude, a rehabilitation unit which is not threatened by the list and which admits its deficiencies and tries to improve is probably a good unit, ready to engage in the long process of accreditation which includes:

- A staff consensus
- A budget devoted to accreditation and the corresponding resources
- A training course in a CARF organisation and a visit to an accredited centre
- Prepare quality and cost for survey
- The accreditation survey: yes or no?

The benefits concern not only the quality but also the marketing of the unit.
Nowadays, only two European units are CARF accredited, in Torino (Italy), and in Lund (Sweden).

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