End of Rehabilitation Decision in Severe Traumatic Brain Condition, Apallic Syndrom/Vegetative State, Locked-In-Syndrome

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Apallic Syndrome/Vegetative State (aS/vS) and the Locked In Syndrome (Lis) are the most severe neurological conditions. The patients are fully depending of the care of the surrounding. The Apallic Syndrome/Vegetative State can be caused by a severe acute damage of the brain (hypoxia,trauma, exogenous/endogenous intoxication) having a high percentage of remission, but with the possibility of a remission interruption in the first three phases (8 phase remission scale). The second form of an aS/vS is caused by a progressive diffuse brain process (Huntington's Disease, Alzheimer's Disease, chronic intoxication etc.), remaining in a finale state without any chance of improvement. The Lis occurs mostly after a circulatory accident in the basilaris artery but can be the sequence of trauma etc. too. Every Apallic patient after an acute severe brain damage as well as every Locked-In patient needs a treatment in an intensive care unit (ICU) in the initial state, followed by a consequent programme in a special centre using an individual treatment programme (activating medicaments, sufficient circulatory support, stimulation methods). Secondary neurological symptoms (polyneuropathia, posterior tract symptoms, pontine myolinolysis, encephalopathy), mainly caused by a Bed Rest Syndrome and by insufficient treatment activities but sometimes by a negative therapeutic resonance (Vegetables) have a freezing influence to the remission course.

During the treatment of a patient with aS/vS as well with Lis important decision are necessary. At first, the decision for the transferation from the ICU to the special centre in the right time, depending from the earliest possibility, but without artificial respiration and an intensive monitoring. The demand for an individual rehabilitation programme and the adaptation of the programme during the further course is an

important obligation. The most difficult decision is the question for the end of the active rehabilitation programme with the knowledge consequence to stop all future possibilities for an improvement of a patient. This judgement needs a consilium of experienced specialists.

The decision to interrupt the basic care for a patient with the consequence to withdraw nutrition and hydration in most parts of Europe is out of discussion. It would be accused as active euthanasia. In contrast to this basic ethical obligation the renunciation for maximal therapy in severe complications like intestinal tract haemorrhage etc. is acceptable and based on the Hippocratic principles.

For patients in a chronic neurological condition the International Society for Amelioration of Quality of Life has introduced a new system to organize special centres in cooperation with the relatives. This organization is backed by the Orthodox Church and builds up a new field in neurology "the care for untreatable neurological conditions" .

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End of Rehabilitation Decision in Severest Neurological Conditions

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Session for Young Neurologists

5th World Congress for NeuroRehabilitation
Brasilia, Brasil
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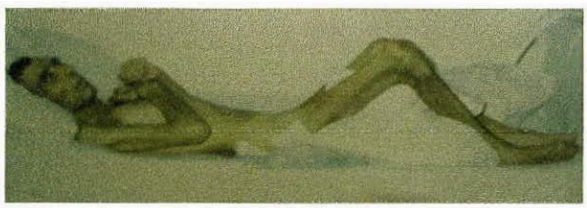
Severest neurological conditions and neurorehabilitation

- Apallic syndrome/vegetative state (hypoxic, traumatic, etc.)
- Locked-In syndrome
- Minimally Conscious State (different origin)
- Severe traumatic brain injuries
- Encephalitis (viral, bacterial, parasitic, etc.)
- Cerebrovascular diseases
  - Stroke, severest form
  - Vascular dementia
  - Subarachnoidal hemorrhage

Apallic syndrome, pat. G.B., 36a traumatic brain injury, 1975



Full state, untreatable condition

Irreversible primary and tertiary lesions, complications

Exitus after 14 months

Apallic syndrome, pat. E.S., 19a traumatic brain injury, 1992

Modern treatment program in a special center for apallic syndrome patients

No tertiary lesions, minimal complications

Remission after 5 months to minimal defect state

Terri Schiavo (USA)

Apallic syndrome/vegetative state, remission state II-III, Full contact to the surrounding

End of life decision by court, withdrawal of liquid and nutrition.

- Optic fixation to her mother
- Turn towards
- Contact reaction, positive
- Positive emotional reaction
- Well-balanced body state
- Vegetative system regulated
- No artificial respiration
- Nutrition by PEG
- **No perspective of improvement under local conditions**

Apallic syndrome – sindrome apallico (traumatic), Salvatore C., 38a (Italy)

- Traumatic brain injury, August 2003
- Long time classified as untreatable
- Late onset of remission
- Defect state with neurological and orthopedic deficits.

During long time patient could hear noises of the surrounding. Pains and physical contact have been registered, patient was not able to react and felt deep desperation.

Successful rehabilitation after AS, traumatic, Fred A., 39ª (A)

- Car accident 1995 at 30 years
- Apallic syndrome in full stage in a special center for apallic patients over 6 months
- Remission phase over 2 years
- Treated in special rehabilitation center for apallic patients
- Continued rehabilitation with stepwise improvement
- Full integrated in family life, father of a 3 years old daughter
- Only partial handicapped
- Strict aim to build up a normal professional condition

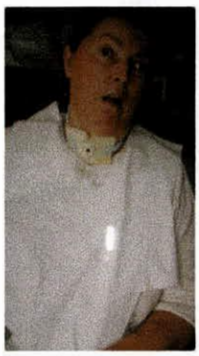
Apallic syndrome, Alzheimer's Disease, end state

Patient A.S., 67a

Untreatable end-state in need of permanent care during 18 months

Exitus: heart infarction

Locked In-Syndrome 45ª, female



Post traumatic etiology

Severest defect state

Hippocratic oath

Obligation to heal
Not do anything to harm the patient
No continuation of therapy in untreatable disease
No therapy in advanced physical and mental destruction
No continuation of life prolongation for hours or days
No prolongation of suffering during dying
Not to tell anyone the details of patients
No admitting of lethal poison, even as advice

Will to respect the teacher like own parents, sharing one's life support with teacher and his successors, treated as own brothers
Medical teaching to own sons and the sons of the teacher
or to pupils bound by physicians rules and oath

World Medical Association, Helsinki Declaration, 1964 Medical Research Involving Human Subjects Ethical Principles

- Medical progress is based on research which ultimately must rest in part on experimentation involving human subjects
- In medical research on human subject, considerations related to the well-being of the human subject should take precedence over the interest of science and society
- International Code of Medical Ethics : A physician shall act only in patient interest when providing medical care which might have the effect of weakening the physical and mental condition of the patient
- Ethical Principles to provide guidance for physicians and other participants in medical research involving human subjects

Including identifiable material or identifiable data

UNESCO Bioethics Declaration on Human Rights

Paris, September 2005
Aims – Article 2

- Universal framework of principles and procedures to guide States in bioethics
- to guide the actions from individuals as well as communities, public and private
- to promote respect for human dignity and protect human rights
- to recognize the importance of freedom in scientific research
- to foster multidisciplinary and pluralistic dialogue
- to promote equitable access to medical, scientific and technological development
- to safeguard and promote the interest of the present and future generations
- to underline the importance of biodiversity

UNESCO Bioethics Declaration on Human Rights

Paris, September 2005

- Art. 3: Human dignity and human rights
  - Fundamental freedoms: fully respect
- Art. 4: Benefit and harm
  - Applying and advancing scientific knowledge, medical practice and associated technologies, direct and indirect benefits to patients including research participants
- Art. 5: Autonomy and individual responsibility
  - Persons to make decisions while taking responsibility for those decisions and respecting the autonomy of others
- Art. 6: Consent

Informed consent generally

... is necessary for each human being (patient and healthy volunteer) involved in:

- any preventive, diagnostic and/or therapeutic medical intervention
- scientific research (basic research, clinical studies) according to
  - ICH-GCP (Good Clinical Practice)
  - GMP (Good Manufacturing Practice)
- For implementation of every new diagnostic and therapeutic methods clinical trials are indispensable and required

Declaration of Paris, 2005

Article 7

Persons **without** the capacity to consent – I concerns medical practice and research

a) authorization for **research and medical practice** should be obtained in accordance with the best interest of the person concerned and in accordance with domestic law. However, the person concerned should be involved to the greatest extent possible in the decision-making process of consent, as well as that of withdrawing consent.

Patients unable to consent

Decision making on behalf of patients

- Presumed consent in emergency situations
- Proxy consent by an authorised person (legal representative)
- Living will
  - Advanced directives
  - Previously expressed wishes

Activities of Daily Living – ADL

after Nancy Roper,
developed by Liliane Juchli, 1993

- Contains:
  - Being awake and sleeping
  - Moving
  - Dressing/undressing
  - Eating and drinking
  - Maintain continence
  - Regulation of body temperature
  - Respiration
  - Care for safety
  - Keeping busy
  - Communication
  - Feeling as woman/man
  - Sense of life

Basic Activities of Daily Living - BADL

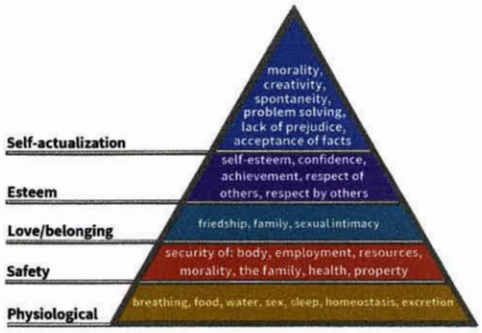
after I. McDowell, C. Newell, 1996

- The basic activities of daily living consist of these self-care tasks and should be aim of any rehabilitation program:
  - Bathing
  - Dressing and undressing
  - Eating
  - Transferring from bed to chair and back
  - Voluntarily control urinary and fecal discharge
  - Using the toilet
  - Walking (not bedridden)

Instrumental Activities of Daily Living- IADL after A. Bookman, et al, 2007

- Instrumental activities of daily living are not necessary for fundamental functioning, but enable the individual to live independently within a community:
  - Light housework
  - Preparing meals
  - Taking medications
  - Shopping for groceries or clothes
  - Using the telephone
  - Managing money

Maslow's hierarchy of needs



Quelle: http://en.wikipedia.org/wiki/Maslow%27s_hierarchy_of_needs

Quality of medical care

Three factors will determine the quality of medical care:

- individual clinical expertise
- Individual clinical experience
- scientific evidence

Best available medical care & quality of scientific evidence – 1

Providing the best possible medical care to an individual patient depends on the responsible physician's

- ability and willingness to
  - integrate individual clinical expertise
  - and the best external evidence
  - "true" evidence-based medicine

Best available medical care & quality of scientific evidence – 2

- The practice of contemporary medicine depends crucially on the quality of scientific evidence
- Experienced based medicine has to be taken in consideration even without EBM background

General regulation for neurorehabilitation of severe neurological conditions - 1

- Initial state treatment in ICU, optimal neurological ICU
- Every patient with a severe neurological condition has to be transferred in a special neurorehabilitation center with all modern therapeutic possibilities
- Transfer to a special neurorehabilitation center has to be executed as soon as possible
- Individual neurorehabilitation program based on the recent neurological symptoms and additional examinations
- Procedure of individual therapy program without restriction and with all possibilities
- Continuing of neurorehabilitation program till 6 months concerning to existing rehabilitation potential

General regulation for neuro-rehabilitation of severe neurological conditions - 2

- Decision to interrupt rehabilitation in any case not before 3 months, consilium necessary
- End of rehabilitation only after consilium
- In any step of the rehabilitation program detailed information of the relatives
- Transfer to a special care centre with "activating long term nursing care"
- Transfertohome care only with the possibility of "activating long term nursing care"
- In home care and in special nursing care reevaluation after 6 weeks, obligatory
- In case of signs of further remission retransferation to the special neuro-rehabilitation department

Different decisions to make during the rehabilitation program in severe neurological conditions

- Decision to continue the active rehabilitation program in the special center
- Decision to transfer patients with a supposed negative prognosis to a nursing care center with long term activating program or to transfer patients to home care, both with long-term activating program
- In upcoming signs of an improvement retransfer to the special rehabilitation center

A minimizing of the individual neurorehabilitation program (medicaments, physiotherapy, etc.) is ethically not acceptable.

Regulations in neurorehabilitation program for patients with severe neurological conditions without chance of further improvement

- Transfer to a special nursing care center only after medical decision (rechecking, consilium)
- Requirements:
  - Continuation of basic medication
  - Continuation of nursing care
  - Long term activating program
  - Continuous neurological controls

Summarizing -1

- Every human being has the right to most modern medical treatment, best nursing care and the right to take part in rehabilitation programs.
- Every neurological patient has the right to an individual neurorehabilitation program adjusted to the special condition.
- Economic consideration is not acceptable in acute treatment, (neuro-)rehabilitation and life decision (Hippocratic principles and Universal Declaration on Human Rights (December 10th, 1948).

Summarizing -2

- The individual neurorehabilitation program has to be continued till rehabilitation potentials are exhausted.
- The decision of end of rehabilitation program is only possible by a consilium with specialists.
- In occurrence of remission signs the patient has to be re-transferred to the special rehabilitation center for severest neurological condition.
- According to Hippocratic principles patients have to be treated in dignity but not to be "over-treated" by all modern possibilities.