REVISED

S1B-3 Prolonged Coma, Apallic Syndrome/Vegetative and Minimally Conscious State, Medico-legal Aspects

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The dilemma with the complex "Prolonged Coma, Apallic Syndrome/ Vegetative and Minimally Conscious State"(PC, AS/VS, MCS) begins with the interpretation of the diagnosis. Vigouraux et al. (1964) described the details and course of "Coma prolongé" develops after an acute coma ("Coma carus") and is followed by "coma avec stabilisation des phénomènes végétatifs", a state described 1940 and 1967 as Apallic Syndrome and 1972 as persistent vegetative state (PVS). PC and AS/VS have the possibility of remission. K. Andrews confirmed, that some of patients with PVS are misdiagnosed with some of them showing remission even after years. In the detailed description of the remission course of an AS/VS symptoms of a Minimally Conscious State can be recognized. The attempts to describe detailed symptoms and the neuro-pathological basis of MCS are not finished till now.
A clear differential diagnosis, accepted all over the world would give every patient the chance to be treated according to the clinical need. This would reduce the second dilemma, which is the necessity to start the treatment of PC, AS/VS, MCS as soon as possible and with all modern possibilities using special treatment centres.
It is necessary to differentiate two forms of a AS/VS, the form after an severe acute brain damage with the possibilities of a remission and the second form of AS/VS after a progressive diffuse or multilocular brain damage (CJD, Alzheimer Desease etc.). as an end state.
The case of Terri Schiavo and the fate of other patients around the world indicate the third dilemma. These patients have to receive all the modern possibilities in treatment and care available in a nursing home even if there are no signs of a remission. Intensive discussions were initiated involving physicians, relatives and political as well as religious opinion leaders, however this discussion occurred mostly in western countries. From the ethical point of view neither economic factors nor a persons desire can be the basis for medical decisions to continue a life under the special conditions of an AS/VS.
According to the Helsinki-Declaration (1964) and the UNESCO Bioethics-Declaration (Paris, 2005) a patient with AS/VS has to be classified as a human being with all the rights to be treated and to be cared for. In the industrial society enough place must be reserved to continue a special care of a human being which is fully dependent on support by caregivers. To liquidate a patient in AS/VS by withdrawing nutrition and liquid brings to the mind the middle ages and primitive cultures and last not least the methods of the so called "forced euthanasia" (Zwangseuthansie).

S6A-1 Creating an Environment in Brain Injury Rehabilitation to Allow People to Return to Work

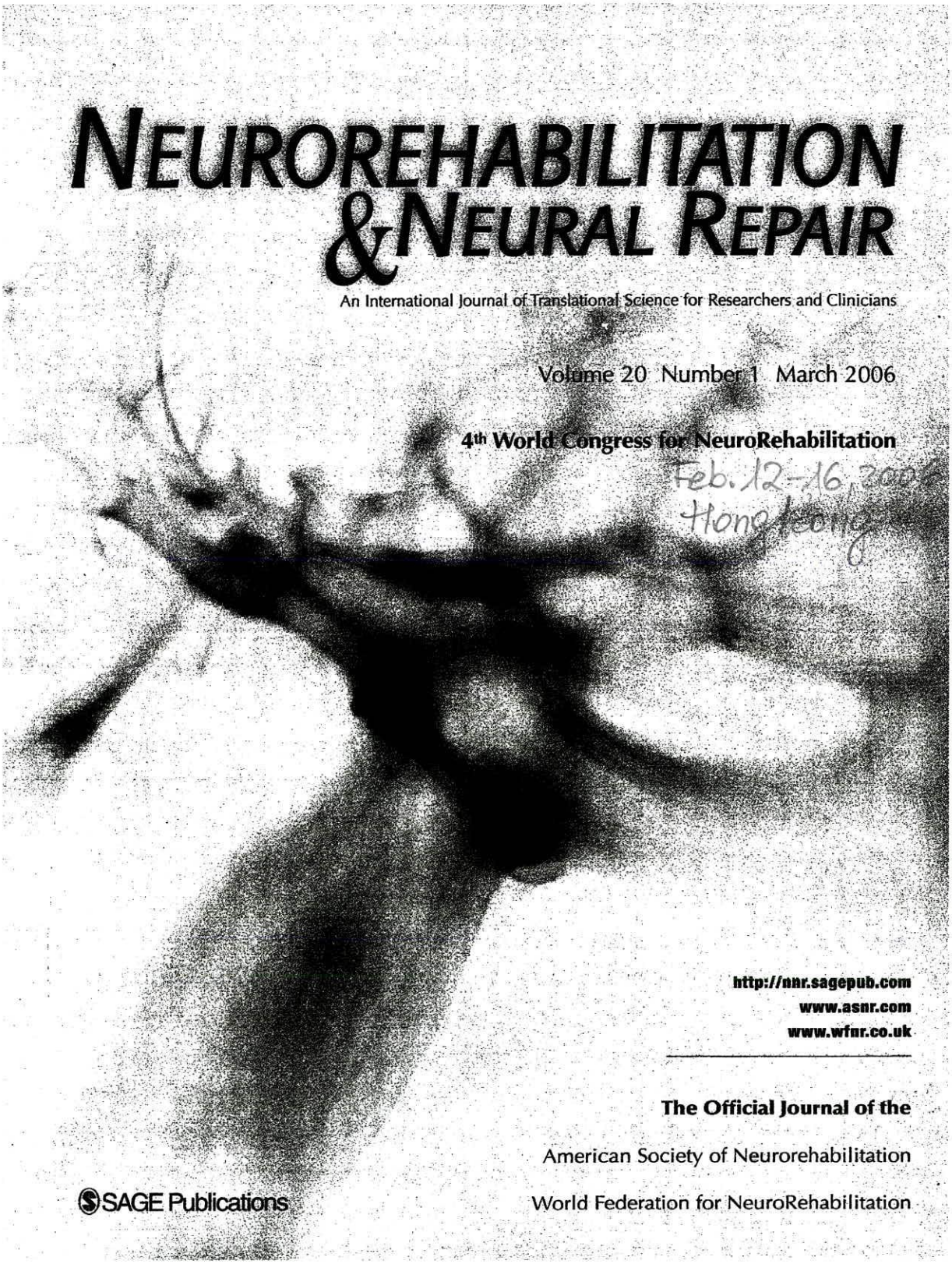
John Olver, Jo Siketa and Pam Ross
Epworth Hospital, Australia

The effects of traumatic brain injury on the ability to return to work have been well documented in the literature. There are many factors that contribute to the typically poor vocational opportunities that are observed in this population, including psychosocial, physical, cognitive and behavioral among others. Studies that discuss rates of return to work vary from 10% to 78%. One of the difficulties has been in defining employment. This varies from volunteer/unpaid work to competitive employment.
Modifications of the environment beyond just the physical are imperative. Addressing psychosocial concerns, behavioral responses, cognitive demands, and executive function such as motivation, attention, memory, etc. is imperative in order to create an environment that enables individuals to return to work. The relationship between self-awareness and employability are well documented. The work setting, paid or unpaid, requires significant changes in attitude, expectations, training and individualizing the environment.
This presentation describes an environment necessary for individuals to return to work that contributes to improving the quality of life for the individual. Various components of rehabilitation to address handicaps after TBI will be explored to assist in developing a framework for successful return to employment.

S8B-2 Addressing the Long-Term Needs of People with Acquired Brain Injury Principles and Methods of Intervention

Charles Durgin
The Kennedy Krieger Institute, Baltimore, Maryland, USA

Successfully adapting to the long-term impact of an acquired brain injury (ABI) is a highly individualized process that often poses considerable challenges for the person who sustained the injury, his or her family, as well as the overall support system. Furthermore, achieving positive and durable outcomes is complicated by the fact that as progress is made and time passes people with ABI typically experience a significant or complete reduction in services despite having continuing needs. Without meaningful supports many of these individuals experience persistent problems that can compromise their health and wellbeing, thereby placing them at risk in a number of critical areas (i.e., socially, vocationally, emotionally, legally, medically, financially, etc.). This in turn can significantly reduce the individuals potential to experience an acceptable quality of life, and further, can place substantial burdens on the family and support system, respectively.
Although the model of supporting the key stakeholders many years post onset is dramatically different than those found in the initial phases of neurorehabilitation, the need for a sensitive, insightful, accessible, and capable support system still remains.
To address these issues the goals of this presentation will be to: 1) identify the various long-term risk factors associated with ABI, 2) briefly review how the broad paradigm of neurorehabilitation still applies to these individuals, and 3) discuss a variety of best practice principles and methods that can offer support to the individual and guidance to those who are in helping roles long after intensive rehabilitation has been discontinued. The emphasis of this model is to help the individual to go well beyond simply adapting to environmental demands. It strives to build an enhanced sense purpose in life, to offer meaningful opportunities for personal growth and community participation, and encourages the use of strategic approaches to facilitate healthy risk taking (which is often central to living a dignified existence and necessary



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4th World Congress for Neuro-Rehabilitation
Hong Kong, February 12-16, 2006

Parallel session 1B

Medico-legal aspects in PC, AS/VS, MCS 3 main problems

- No consistent diagnosis/terminology
- No consistent guidelines for special treatment
- End of life discussion

Basic principles in diagnosis of PC

- "Prolonged unconsciousness", French, 1952
- "Coma prolongé", a prolonged "coma type"
  - by Fau, 1956
  - Le Beau et al, 1958
  - Leson, 1960
- "Coma prolongé", Vigouroux et al. 1964, three states:
  - "coma carus" – acute midbrain syndrome/upper pons stage
  - "coma avec stabilisation des phénomènes végétatifs" – apallic syndrome/vegetative stage
  - "coma, phase sortie de l'état comateux" - apallic syndrome/ vegetative state in remission

Apallic syndrome/vegetative state

Development in three different ways

- acute brain damage
  - traumatic, hypoxic, post-encephalitic, etc.
    - remission principally possible
- Progressive brain process
  - CJD, Alzheimer Disease, etc.
    - final stage, no remission possible
- Chronic intoxications
  - Exogen (Minamata disease, etc.)
  - Endogen (hepatic, renal, etc.)
    - partial remission possible

Symptoms of AS/VS

- Coma vigil
- No recognition of the surrounding
- No contact to the surrounding
- No reaction to external stimuli
- Sleep-wake-rhythm fatigue regulated
- Optomotoric disturbances
- Flexed-stretched position of the extremities and trunk
- Rigido-spasticity
- Primitive motor patterns (oral, grasping, etc.)
- Dysregulation of the vegetative system

Epidemiology of AS/VS

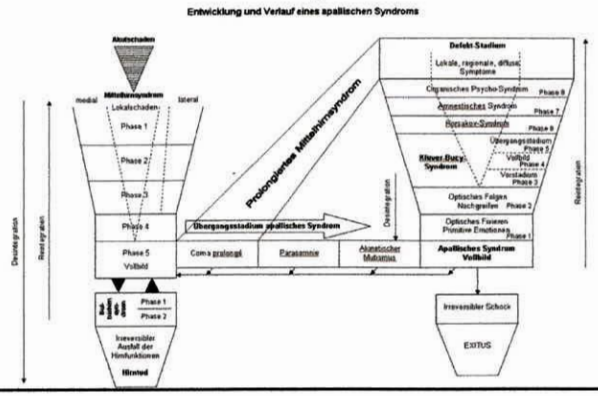
Prevalence of 200 new patients/ year in Austria

Prevalence of 2.500-3.000 new patients/ year in Germany

Prognosis of AS/VS

- Can't be made in the first 6 weeks after an acute brain damage
- Within the first 6 months there cannot be made any decisions about ongoing of active treatment program
- 80% of the patients with an traumatic apallic syndrome develop remission, the same proportion with post-encephalitic AS/VS
- 60% of the patients with a hypoxic apallic syndrome show remission, mostly with severe defects

The course of apallic syndrome after acute brain damage



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

No modern treatment

Irreversible tertiary lesions, complications

Exitus after 14 months

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

Modern treatment program in 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, contact with the surrounding

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

- Emotional reaction
- Optic fixation to her mother
- Turn towards
- Contact reaction
- Well-balanced body state
- Vegetative system regulated
- No artificial respiration
- Nutrition by PEG

Maria Korp, 50ª (AUS)

Parallels to „T. Schiavo Case"

Source:
Sydney Morning Herald, Online News

Maria Korp had been in a "vegetative state" after hypoxia due to strangulation February 13rd 2005

Her husband's lover tried to kill her, allegedly under instruction from him.

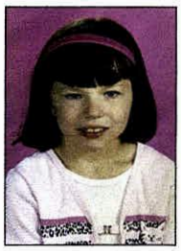
It is unclear, in which condition the patient has been.

Mr. Gardner, Public Advocate, took the responsibility to withdrawal the feeding tube on July 27th. Her family was devastated about this decision.

Maria Korp died in The Alfred Hospital in Melbourne, August, 5th 2005.

Haleigh Poutre, 11ª (USA)

Apallic syndrome/vegetative state



Haleigh was hospitalized in September 2005 after the stepfather allegedly burned her and beat her nearly to death with a baseball bat.

Haleigh was feeded by tube – the diagnosis was "persistent vegetative state".

The stepfather didn't agree to end of life decision – in the case of Haleigh's death he will be charged with murder.

Decision by state's Supreme Court on 20th January 2006 to withdraw life support, one day after Haleigh started to breathe on her own and showed other signs of remission.

The case of Haleigh has a second dimension – she was diagnosed to be virtually "brain dead" after three weeks, termination of life support was discussed.

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

- Traumatic brain injury, August 2003
- late onset of remission
- Defect state with neurological deficits and orthopedic deficits

Patient could hear noises of the surrounding and felt pains and physical contact. Deep desperation.

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

- Car accident 1995 with 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 rehabilita-tion center for apallic patients
- Continued rehabilitation with stepwise improvement
- Full integrated in family life, father of a 3 years old daughter
- Only partially handicapped
- Strict aim to build up a normal professional living conditions

Minimally Conscious States

(Giacino et al, 1997)

- Crude consciousness: alertness
- Phenomenal consciousness: registration of external and internal phenomena
- Access consciousness: directed attention, cognitive awareness, decision making

- Critics:
  - No detailed neurological symptomatology
  - Only phenomenological description
  - In some cases to compare with a remission phase AS/VS
  - Etiology generally open

Treatment and outcome of AS/VS

Remission with modern rehabilitation program for 60 – 80% patients with AS/VS possible

- As fast as possible special treatment in intensive care centers for patients with AS/VS
- Transfer in special rehabilitation centers for AS/VS
  In Austria: 5 (44 beds)
- Activating long term nursing
  In Austria: 2 (28 beds)
- Nursing home
  In Austria: 38 (200 beds)

Similar situation in Italy, Germany

Legal basis for the treatment of patients with AS/VS

Patients
in the full stage of AS/VS,
in remission stages I – V,
in certain defect stages
(severe dementia, Wernicke Aphasia, etc.)
are unable to give consent
for treatment and care as well as to participate in research programs.

A solicitor is necessary.

Decisions to make during the treatment of patients with AS/VS

- Decide, whether an active rehabilitation program has to be continued in a special center, or a patient with a supposedly hopeless prognosis can be transferred to a nursing home with long term activating program, but with the possibility for a control examination and in upcoming signs of an improvement to continue the special rehabilitation program
- Decide to minimize special medical treatment during the active rehabilitation
- Renunciation of MAXIMAL THERAPY in upcoming complications during the stay in the nursing home and continuation in nursing care

„End of life decision", realization in Austria and in some other European countries not possible, equivalent to active euthanasia, regulated by criminal law.

Active euthanasia in patients with AS/VS

Willful neglect of medical care

- Withdrawal of medical treatment, artificial nutrition and hydration (ANH)
- Nursing care has to be continued
- Analgetics have to be continued
- Active euthanasia regulated by criminal law

Active, assisted, passive euthanasia

- Regulated by criminal law in civilized countries
- Euthanasia in each form bioethically not acceptable
- Euthanasia not conform to Helsinki Declaration (1964), Declaration of Paris (2005),
- Hippocratic Oath allows a partial acceptance
- Forced euthanasia (Zwangseuthanasie) unacceptable at no means

Active euthanasia = homicide
§ 75 StGB (Austrian criminal law)

assisted suicide, killing on request:
§ 77 und 78 StGB

passive euthanasia:
conform to Hippocratic Oath

renunciation of maximal therapy:
a medico-legal decision

Regulations for patients with AS/VS in special nursing home, without prospect of remission

- Continuation of basic medication
- Continuation of nursing care
- Continuation of long term activating program
- Withholding of maximal therapy in case of complications

Decision to withhold „maximal therapy"

- Decision is made by treating physician considering certain facts:
  - Objective criterias: diagnosis and prognosis
  - Living will of the patient
  - How the patient himself would decide in this situation
  - Solicitor and family

Summarizing I

- Every human being has the right to live.
- Every human being has the right to most modern medical treatment and best nursing care.
- A patient in AS/VS has to be cared according to the base right and medical principles.

Summarizing II

- Economic consideration are not acceptable following the Hippocratic principles and Universal Declaration on Human Rights (December 10th, 1948).
- According to Hippocratic principles patients in AS/VS have to be treated in dignity but not to be "over-treated" by all modern possibilities.
- Maximal therapy has to be renunciated in states of severe complication occurring in patients with AS/VS without hope of remission (hopeless prognosis).

Summarizing III

- The renunciation of maximal therapy is a directive following the Hippocratic principles.
- According to medical rules a decision for end of life by legal institutions, Supreme court, etc. is not acceptable.
- Such decision has not to be realized by a physician (→ danger to be accused for active euthanasia).

End of life decision

Errare humanum est

(To err is human)

Judges are human, too, (and can err) !

Greetings from Vienna!

Stephansdom by night

Wolfgang Amadeus Mozart
1756 – 1791
„Eine kleine Nachtmusik"