THE QUALITY OF LIFE IN APALLIC PATIENTS AND PATIENTS WITH LOCKED-IN SYNDROME-WHAT CAN BE DONE FOR AMELIORATION?

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In apallic Syndrome (AS) the brain functions are reduced to the midbrain niveau. Patients resemble newborns with the need of external support. An AS can emerge following an acute brain damage (traumatic, encephalitic, hypoxic, etc.) or after severe Intoxications (Minamata disease, etc.). In 80%, remission (8 stages) is possible, but can discontinue during the first two stages. An apallic patient not only in the fullstage, but even during the first 5 remission stages is totally dependent upon the surrounding. 20% of all apallic patients need continuos care. During the remission course, parallels to the physiological development of an infant can be observed. The incidence of AS, following acute brain injury, is 2500-3000 in Germany, 250-300 in Austria.

An AS can depict a final stage, following a progredient brain process (CJD, M.Alzheimer, etc).

Locked-in Syndrome (LIS), caused by a lesion in the ventral pons region, is less frequent. Because of a total loss of motor functions (except vertical eye-movements), these patients are fully dependent on others too. Sensory functions being intact, make it possible to have contact with the environment. A remission, mostly to a defect stage is possible in 70% of the cases.

For both patient groups, the AS and LIS patients, being totally dependent on their surrounding, there is not only a legal but also an ethical need for a solicitor.

In the treatment of these patients, beside artificial nutrition (high-caloric), special medication and particular physiotherapy, stimulation-therapy plays a main part. Stimulation-therapy consists of visual, acustic and haptic stimulation-programs and vibration therapy. The basal stimulation-concept has to be included in nursing care. The neurorehabilitation program has to be adapted to the patients abilities concerning the stage of remission already reached.

Quality of life is affecting not only the patient, but also the family and associates. The apallic patient is widely uncoupled from the environment and problems concerning the severe impairment. In contrast, patients in LIS fully realize their situation. That is why in apallic patients primarily the somatic state is to fully concentrate on, in LIS additional psychological support is of high importance.

Both syndromes are characterized by entirely helplessness, concerning the patients and his sorrounding. Misunderstanding consists in AS, when family members misinterpret reflexes to be motor reactions, in LIS to think the patient to be comatous. In both severe neurological disorders patients need a special care and treatment for months, even years. Two groups have to be supported on this way. The patients with their severe neurological deficits and the possibility of remission and the group of family members, associates, nurses, etc. with the need for psychological assistance.

The possibility for family members to receive psychological, moral and religious assistance and to frequent self-help groups has to be augmented.

FRIDAY 31 JANUARY 2003

Plenary Lectures

Chairmen: A. Minas, N. Robakis

09:00-09:45 ***F. Gerstenbrand, B. Matulla***
The Quality of life in apallic patients and patients with Locked-in Syndrome-What can be done for amelioration?

09:45-10:30 ***E. Giacobini***
Do cholinesterase inhibitors improve the quality of life of Alzheimer patients ?

10:30-11:00 **Coffee Break & Poster viewing**

Plenary Lectures

Chairmen: F. Gerstenbrand, A. Portera

11:00-11:45 ***M. Emre***
Management of the behavioral problems of Dementia and Parkinson's disease

11:45-12:30 ***D. Schiffer***
Apoptosis in chronic neurological disorders

12:30-13:15 ***R. Ihl***
Psychological parameters in frontal chronic neurological disorders

13:15-17:00 **Break & Poster viewing**

Plenary Lecture

Chairmen: M. Emre, A. Korczyn

17:00-17:45 ***A. Portera***
Frontal Cortical functions in degenerative Dementias

HELLENIC SOCIETY FOR AMELIORATION
OF THE QUALITY OF LIFE
FOR CHRONIC NEUROLOGIC PATIENTS

1st International Congress on the Improvement of the Quality of Life on Dementia, Epilepsy and MS

BOOK OF ABSTRACTS

İstanbul 30/1 - 1/2 2003
HOTEL HILTON

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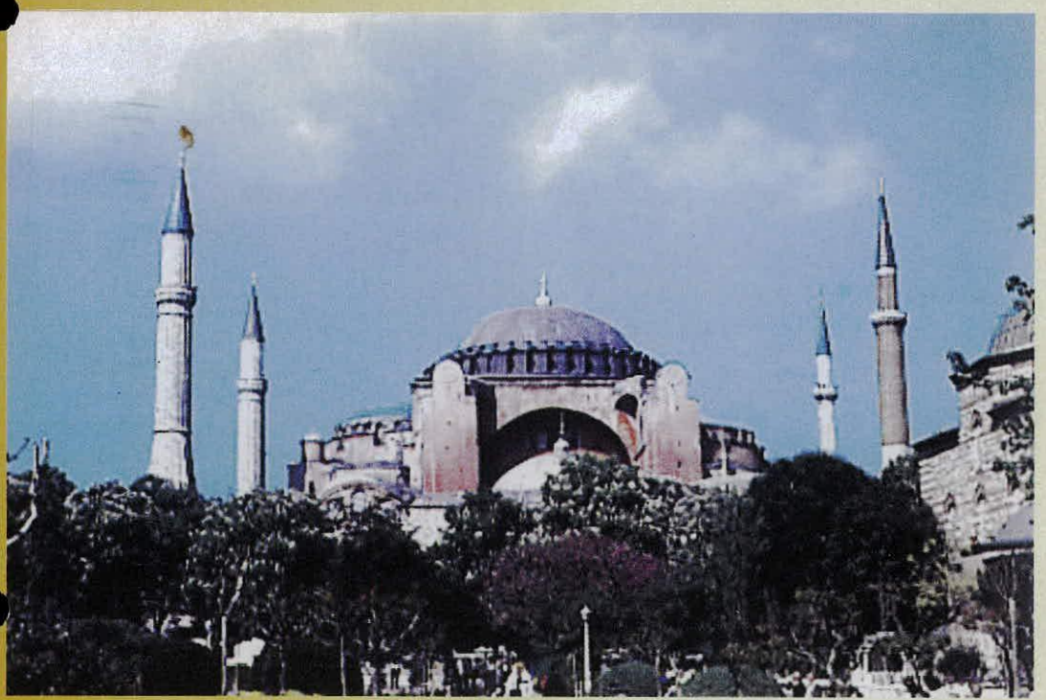

Book of Abstracts

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Istanbul, Turkey

Symptoms of AS/VS

- Coma vigile
- No recognition of the sorrounding
- No reaction to external stimuli
- Reaction on internal stimuli
- Optomotoric disturbances (divergent position of the eyes, gaze disturbances)

Symptoms of AS/VS continued

- Motor disturbances of extremities and trunk (flexed-stretched position of the extremities with fist, rigidospasticity, hyperreflexia, pyramidal signs)
- Primitive motor patterns (oral, grasping)
- Dysregulation of the vegetative system

Etiology of apallic Syndrome

- after acute, severe brain damages (TBI,encephalitis,hypoxia,malignant stroke etc.) possibility of remission
- after progredient, diffuse brain processes (CJD, M.Alzheimer, M.Pick, Chorea Huntington etc.)

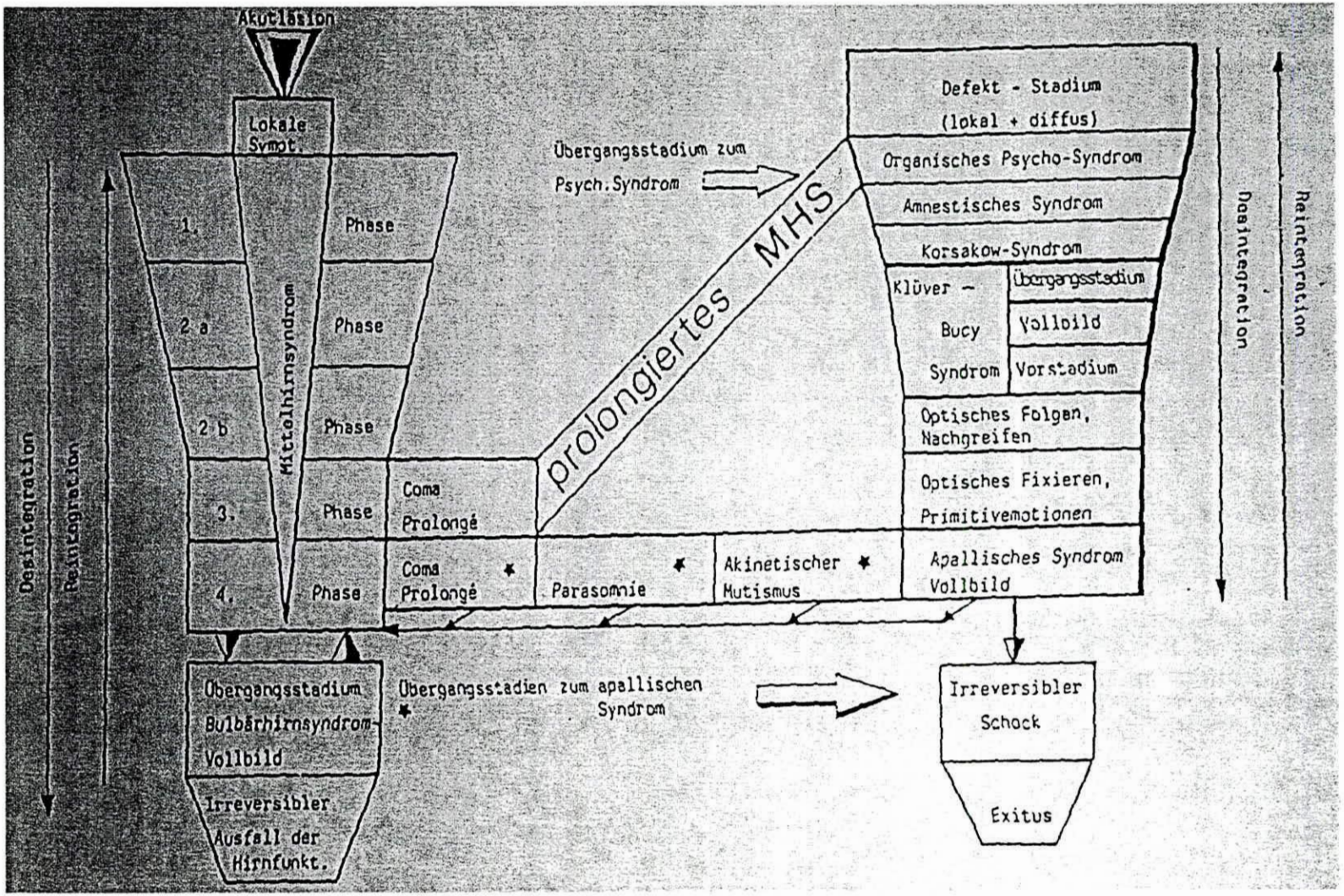
  final stage, no remission possible
- Intoxication-acute (exogenous-neuroleptics etc., endogenous-hepatic,uremic etc.)

  full remission possible

  -chronic (exogenous-Minamata disease etc., endogenous-hepatic,thyreotoxic etc.)

  partial remission possible

Course of apallic syndrome after acute, severe brain damage



Apallic Syndrome after progredient, diffuse brain processes as final stage

- Desintegration of higher and highest brain function
  Diffuse organic psychosyndrome
- Multilocular cerebral Symptoms
  Aphasia,Apraxia,mot.disabilities, etc.
- Klüver-Bucy Phase
  3 different stages
- Preapallic Phase
  „dementia", motoric primitive patterns, mass movements, decerebrate rigidity, etc.
- Apallic Syndrome, Full Stage
  No remission signs

Symptoms of Locked-in Syndrome

- Total paralysis of all extremities, trunk, neck and motor brain nerves except
  eye opening and vertical eye movements
- Impairment of swallowing
- Spontaneous respiration
- No possibility to communicate with the sorrounding
- Consciousness and perception fully maintained
- Alpha-EEG

Etiology of Locked-in Syndrome

- Lesions in the ventral pons (interruption of corticobulbar and corticospinal tracts bilaterally) due to infarcts or hemorrhages, tumor etc.
- Somatosensory pathways and reticular system usually spared.
- Tectum is not affected (vertical eye movements possible)

Course of Locked-in Syndrome

- 30% are remaining in fullstage, with a letal outcome in 20%
- In 50% Remission to a defect stage is possible
- In 20% Remission to a defectless stage can be found

Therapeutic strategies in A.S

- Causal therapies in the initial phase

- Special drug treatment (antispastics, anticonvulsants, ß-blockers, psychostimulants, etc.)
- Stimulation therapies (visual,haptic,acustic, basal stimulation)
- Verticotherapy
- Physiotherapy, ergotherapy, logopedia, cognitotherapy

- Therapeutic community

Therapeutic strategies in L.I.S

- Causal therapies (hemorrhage, thrombosis, etc.)
- Special drug treatment (antispastics, anticonvulsants, ß-blockers, psychostimulants, etc.)
- Logopedia, physiotherapy and ergotherapy
- Psychological assistance for the patient
- Therapeutic community

Profund differences between apallic Syndrome and Locked-in Syndrome

- A.S

Loss of all brain functions, reduction to the midbrain-level (coma vigile, no voluntary motor action)

temporary or permanent

- L.I.S

Loss of all motoric abilities, except vertical eye movements, undisturbed vigilance, full contact to the sorrounding, normal body sensation

temporary or permanent

Quality of life

- **In healthy situation**

A subjective view

Health

Family

Occupation

Religious faith

Moral and ethical resonance

Satisfaction

- **In illness**

A.S: physically and mentally disabled

L.I.S: physically disabled

Quality of life in relatives of apallic patients

- Experience, the patients fully dependence and their own impossibility to help.
- Unability to communicate with the patient.
- Unawared of the patients feelings.
- Misinterpretation of reflexes (grasping, etc.) as active movements.

Quality of life in relatives of Locked-in patients

- Experience, the patients being totally plegic and fully dependent.
- To know, the patient is realizing everything around.
- Relatives have to learn certain „codes", (eye opening) for communication, in remission using electronic communication devices .

What can be done for patients` and relatives` amelioration?

- Full information about the patients state and possible future outcome and decisions
- Integrate relatives in nursing care under supervision (supporting during feeding, washing, positioning of the patient, etc.)
- Actions to build up contact with previous life situation (presentation of photos, report about family activities, etc.)

What can be done for patients` and relatives` amelioration?

continued

- Integration in the treatment program (physiotherapy, ergotherapy, logopedia, stimulation program-basal stimulation)
- Amelioration of the patients sorrounding (photos, music, flowers, etc.)
- Integration of family members into staff decisions
- Family members should relieve one another
- Psychological assistance for the patient and for the relatives

In ameliorating quality of life not only in patients, but also in their relatives, a summation effect can be seen.