

Vortrag zum Dritten Weltkongreß für Neurologische Rehabilitation, 2.-7. April 2002 in Venedig (3rd WCNR):

The role of relatives in the treatment of apallic syndrome patients

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During the last ten years knowledge about the importance of the relatives in the management of apallic syndrome patients has increased significantly[1]. A person remaining in apallic state after severe brain damage causes stress to the entire family due to the inability to reciprocate in interpersonal relationship and the loss of communication. Relatives' reactions, their burdens, needs, possibilities and limitations for helping the patient have been studied profoundly[2]. This paper focusses on the different roles of the relatives for the management of the patient beginning at the earliest possible stage, including the intensive care unit and the early rehabilitation ward[3]. Through the daily dialogue with relatives of more than 100 apallic syndrome patients within the clinical context the role of the relatives was extrapolated, including counselling and practical training of team staff and family members, in accordance to the recent literature[4].

Relatives' reactions and attitudes depend on the rate and level of recovery of the patients. Regarding their emotional stability relatives can be involved in the observations and activities of the clinical team. Relatives can provide attractive stimuli, which can be useful for sensory regulation of the patient's environment. Because of their familiarity with the patient relatives often are able to discover the primary subtle responses to interpersonal dialogue and to encode these responses as a form of body language and self-actualization, i.e. biosemiology of coma, signaling emerging from the apallic state into the first or second remission stage[5,6]. This way simple yes/no codes can be established with the help of relatives[7]. Accordingly, practical training of fundamental nursing skills and mobilization play a most decisive role for the future quality of life in long-term management and for social participation. These efforts include decision making for the sake of the patient's living will and the right to social integration especially when the patient becomes exhausted and moribund.

The great human potential of relatives participating in treatment, rehabilitation and care should be used through all stages of the management but it requires professional help and social support of the entire society.

References

1. Andrews, K.: International Working Party on the Management of the Vegetative State: summary report. *Brain Injury* 1996; 10 (11): 797-806
2. Allen, K., Linn, R.T., Gutierrez, H., Willer, B.S.: Family burden following traumatic brain injury. *Rehabilitation Psychology*, 1994; 39 : 29-48
3. Zieger, A.: Early Rehabilitation in the Neurosurgical Clinic. In: Engberg, A. (Ed.): *Proceedings of the European Conference on the Rehabilitation after Severe Brain Injury at Copenhagen, on September 6-9, 1998*. Copenhagen: 2000, pp. 22-41

4. Crispi, F., Crisci, C.: Patients in persistent vegetative state ... and what of their relatives? *Nursing Ethics*, 2000; 7 (6): 533-535
5. Zieger, A., Hildebrandt, H., Engel, A.: Early autonomous and electrocortical reactivity during "coma stimulation" and "dialogue construction" as a prognostic indicator for the outcome in early rehabilitation. *Neurologie & Rehabilitation*, 2002 (in prep.)
6. Zieger, A.: [Neuropsychology and body semantics with regard to apallic syndrome patients] (in German). In: Documentation of the Annual Meeting of the German Society of Medical Psychology at Greifswald, on June 7-9, 2001. Lengerich: Pabst Science Publ. 2002 (in press)
7. Zieger, A.: [New research results and considerations for the management of apallic syndrome patients] (in German) *Rehabilitation*, 1998; 37 (4): 167-176

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