

“Social networking” as a strategy for adequate long-term care and participation of severely brain-injured “apallic” people.

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Background:

In the past two decades the medical treatment, rehabilitation and long-term care for severely brain-injured patients has improved impressively in some European countries (Zieger 1998a).

Since the report of the Multi-Society Task Force on Persistent Vegetative State (1994) we know about the prognosis is worse in cases with hypoxic origin than with traumatic. Complete recovery with regaining consciousness is very seldom however, prognosis of individual cases can not be made accurately (International Working Party Report on PVS 1996).

In Germany, due to modern neurosurgical and nursing technologies about 5000 people per annum will survive severe and severest brain injuries living within an prolonged comatose state or an apallic syndrome state (Gerstenbrand et al 1990; Zieger 1998a,b). Severe brain injuries often occur in young adults who nowadays can survive for several decades.

In the past 15 years we made some experiences with an integrated system of intensive medical care, early rehabilitation, long-term care and social participation for severely disabled “apallic” people and their families (The German Federal Self-help Association 1997; German Association of Rehabilitation 2000; Zieger 1998a,b; 2002a-c).

On the one side, with the help of a comprehensive and structured interventional program during early rehabilitation many cases can recover successfully. We know that about 6 to 8 per cent of the worst cases can achieve a remission stage I or II according to Gerstenbrand (1967), i.e. minimal responsiveness to external stimuli for establishing Yes/No-codes (Zieger 1998a,b).

But, on the other side, the ongoing socio-economical crisis within the European countries due to chronic unemployment and reduced financial resources of the health insurances has made the social support for the severest disabled people worsened. Therefore, oppression of the solidarity community might have been increased alarmingly.

In addition, recent legalizing of active euthanasia in The Netherlands and in Belgium should be considered a severe suppression of the human rights and the human dignity within the centro-European culture due to an misanthropic bioethical and neo-utilitarian philosophy and practice.

Purpose:

The aim of this paper is to develop “social networking” as a strategy for qualified treatment, long-term care, integration and social participation of severely brain-injured, disabled and “apallic” people who require life-long complete assistance, and

¹ Paper to the 8th European Regional Conferenz, Rehabilitation International, November 11-16, 2002 at Aachen/Germany (Conference Proceedings in press, 2003)

for their families (WHO 2001). In this way discrimination, social isolation and active euthanasia might be overcome successfully.

Method:

In order to get a solid data-base several sources are evaluated: the Multi-Society Task Force on PVS (1994), the International Working Party Report on PVS (1996), the Expert Meeting of the German Federation of Rehabilitation of the Disabled (1996), the Report of the European Biomed Programme of the London King's College (1997), the declaration of the German Federal Self-help Association (1997), the German Federal Association of Rehabilitation (2000), the Declaration of the Austrian Coma Vigile Society (2000), especially the memorandum "The coma vigil patient as a fellow-citizen" (Zieger 2002a), some special studies and questionnaires about the attitudes of family members (EU-study 1993, 1995; Käsbach 1999; Kleen 2000; Mwaria 1990; Redecker & Sonntag 1994/1995; Tresch et al 1991), and finally, some reports about the experiences of those patients who regained consciousness after they have been in an apallic syndrome state for several months or years (Zieger 1998b, 2002b) have been evaluated.

Results:

Over all, there is a lack of research on this field. Some results can be reported from the literature:

- In Germany, with the help of an integrating care system 70 per cent of the "apallic" people can be reintegrated into their families if sufficient nurses, doctors, therapists as well as emotional, psychosocial, and financial support are provided, and if the family members were trained and taught sufficiently
- 30 per cent of the people must be integrated into nursing homes if a family network can not be established. However, only for 10 per cent out of this group special nursing homes are provided, and 20 per cent have to live within residential homes although people often are young, and their life-expectation might last several decades.
- The life-span of all the people living within special nursing homes have increased twice, i.e. from 2 to 4 years average. But, survival-time of more than ten years can happen in many cases, if sufficient assistance and social support are available.

Reactions and attitudes of physicians dealing with apallic syndrome state patients differ impressively among both the Anglo-american and the Centro-european countries:

- While, in a survey of 319 American physicians almost half considered homogenously vegetative patients to be already dead (Payne et al 1996), questionnaire of European doctors revealed heterogenous attitudes within different countries: In Great Britain, The Netherlands and Belgium withhold of treatment and withdrawal of artificial nutrition and hydration were refused only in about 20 to 30 per cent however; in Germany, Austrian, Italy and France in about 60-80 per cent (Grubb et al 1997; Jennett 2002).
- These heterogenous attitudes changed and adapted to one another if the patients have been emerged from a vegetative or apallic syndrome state to a so called minimally conscious or responsive or to a severely disabled state. Now,

homogenously, the physicians refused withhold of treatment as like as withdrawal of artificial nutrition and hydration in about 70-90 per cent (Grubb et al 1997; Jennett 2002).

Throughout the past 10 years in Germany, Austria, Switzerland, Denmark and elsewhere well-organized self helping associations have been formed to improve their situation and to protect the rights of the apallic syndrome patients. The most striking experiences the relatives report about are that they get only insufficient information about the prognosis. Although they were initially told by the physicians that their patient is a “hopeless case” and that it would be better for the patient “to let him die” some relatives have witnessed their patient to have recover successfully. Relatives consider their patients’ life to be worth living whether the patient is unconscious or not. They consider their efforts to be meaningful because they have learnt much about their own lives. They demand life rights and the right to rehabilitation.

However, relatives not always are aware of the necessity of some distance in order to balance the presumed quality of life of the patients and their *own* desires of what might be beneficial for the patient (Käsbach 1999; Kleen 2000; Zieger 2002a-c).

The following needs and clames have been reported frequently:

- Relatives want to get understanding information from the physicians. They want to be treated with appreciation and empathy. They claim informed consent in decision making. They want to be integrated into the activities of the whole team. They want to be advised, instructed, and trained for interaction and assistance with their patient. They want to be prepared for the long-term care of their family members at home. They claim emotional, social and financial support of the community and society (Austrian Coma Vigile Society 2000; German Federal Self-help Association 1997, German Federal Assioaction of Rehabilitation 2000).

There are only some studies dealing with the attitudes of relatives directly. The questionnaire of 33 family members of vegetative state patients done by Tresch and colleagues in 1991 showed that

- 90 per cent of patients were considered to have some awareness of pain, taste, light or darkness, food, verbal conversation, or the relatives’ presence.
- Concerning the initiation and continuation of tube feeding 87 per cent of the family members, retrospectively, agreed with the initial decision to insert the tube.

Relatives often claim the poor quality of life of the patients and their families. These claims are substantiated well:

- From 1993 to 1995, an EU-study of about 1.500 families taking care of severely brain injured patients after car accident revealed that about 90% suffer from social isolation, existential problems and financial down fall.

A German survey on the life situation of 154 families of apallic syndrome patients placed in nursing homes revealed that

- 60 per cent of the people never had a chance to be treated in a rehabilitation centre. 84 per cent did not get any therapeutic support, and 80 per cent of the nursing staff complained not to be trained adequately for the special nursing care (Redeker & Sonntag 1994/1995).

On the opposite, a “Coma vigile study” has outlined recently that

- by relatively simple and inexpensive but, creative life-forming concepts, advices and procedures concerning the daily living activities within the nursing homes and the families the life-situation and quality of life for many people and their surrounding can be improved impressively (Bienstein & Hannich 2001).

Another study has demonstrated that,

- by therapeutic procedures improvements of the functional outcome and level of independence was available successfully even in a special in-patient long-term nursing home (Binder et al 1999).

Discussion:

There are three central aspects concerning “social networking”:

First, from a socio-ethical viewpoint it is crucial whether an vegetative state / apallic syndrome patient is considered to be living integrated within the society or whether the patient is considered to be excluded from community and social life. In the first case life-long emotional, financial, and social support is provided independently of the state of deficiency or remission. Medical treatment, nursing care, and personnel assistance is required for 24 hours a day, i.e. complete social integration and participation.

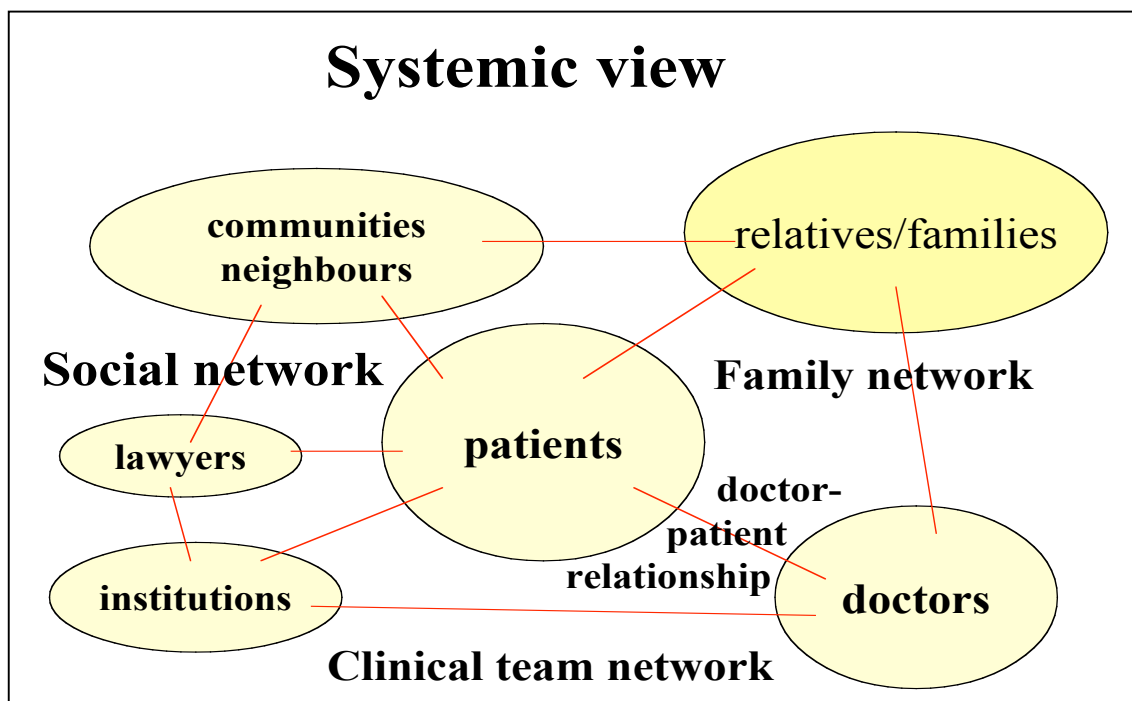


Figure.1: Systemic view of the social networks surrounding severely brain-injured people (adopted from Zieger 2002b).

In the second case, those patients who have not recovered sufficiently within given time-limits can be refused medical treatment, and they should be disconnected from the feeding tube in order to make them dying (Jennett 2002). The dispute has been pushed forward in the past few years relating to these both ethical controversial positions: bioethical “utilitarianism” vs christian-ethical “humanism” (Zieger 2002c).

Second, one should be aware of the complexity of the problem (fig. 1). The social network surrounding the patient and his or her partners is built up by some little social, clinical and family networks, most important to be connected cooperatively. The doctor-patient relationship seems to be as important as ever because it provides the care of the main principles of medical ethics like beneficence, informed consent, autonomy, and prevention of maleficency. Therefore a systemic view is necessary for our understanding of the special life-situation of the people, and for methodological reasons.

Third, “social networking” within the local community should be considered the most adequate human strategy for treatment, long-term care, reintegration, and social participation as well as to protect the human life-rights of these people and their families. In proceeding from “coma to community” both kinds of long-term care integration within the nursing home or within the family network can be successfully managed even in “worst” cases, i.e. phase “F” of the German neurologic rehabilitation phase-model (VDR 1995). Working together with the relatives is very important to evoke the potentials and resources of the relatives as much as possible. Relatives can learn assistance in all activities of daily living, especially Yes/No-communication, verticalization, mobilization, and transfer into a wheelchair. These activities are decisive for the patients’ future quality of life. Relatives can be prepared on probatory vacation and long-term care with their patient at home within the family. They can learn case management and guardianship according to the patient’s living will. After all they might have become experts of “living with liminality”. The decisive point is that all these activities have to be an integral part of the whole teamwork (Zieger 2002b).

Establishing “little social networks” within the local community the following basic principles are crucial for success and have to be kept in mind during the whole process:

- Connecting all partners of the patient: relatives, family, nurses, therapists, doctors, medical specialists, pastors, friends, and neighbours in a cooperative way (team-work).
- Providing 24-hour care with nursing help for the relatives at night
- Providing individual case management
- Providing qualified physician’s service including “special finances” in cases who require medical treatment.
- Providing physiotherapy and occupational therapy with regard to the individual medical necessity, three to seven times per week, or logopedics/speech therapy, neuropedagogics, music of recreation therapy, and neuropsychology with regard to the individual medical necessity, one to three times per week.
- Undertaking some therapeutic units by trained nurses and relatives, for instance at weekend.
- Financing the high costs in a mixed way, i.e. all kinds of patient’s insurances (health, pension, unemployment, welfare) have to take part in.
- Addressing the highest level of support oth the nursing care insurance (i.e. degree IIIa, in the German nursing insurance system) by the medical service of the health insurance to these severely brain-injured and assistance-dependend patients.

The aims of “social networking” can be outlined as follows:

- Connecting all partners in the surrounding of the severely brain-injured people
- Effective use of the medical treatment, early rehabilitation, nursing care system
- Effective allocation of the financial resources of the health care insurances in a “mixed cost-model” way.
- Prevention of social isolation, emotional burn-out and financial ruin
- Prevention of social neglect and active euthanasia.
- Improvement of quality of life for both the “apallic” people and their families
- Providing integration from coma to community, and social participation in a solidarity community (WHO 2001; Zieger 2002a-c).

Conclusions:

Obligatory guidelines for constructing “little social networks” for severely brain-injured “apallic” people and their families with the help of connecting partners are an imperative humanistic demand on social communities and modern European solidarity societies (WHO 2001; Zieger 2002a). However, there should be no doubt that living in a vegetative/apallic syndrome state might be as like as “living with liminality” (Mwaria 1990). This extreme dilemma of a human life-form can be tried to be overcome in a solidarity community only (Zieger 2002a,c).

In a given society the level of humanity will be measured by the efforts of life support and human care. To protect the ill and weakest people constitutes the dignity of the healthy. Each society has the laws it deserves!

References:

- Bienstein, Ch., & Hannich, H.-J.: Förderungs- und Lebensgestaltungskonzepte für Wachkoma- und Langzeitpatienten. Abschlussbericht. Dorsten: Verlag Ingrid Zimmermann, 2001
- Binder, J., Griese, J., Schaible, W., Harms-Ensink, G., Netz, J., & Hömberg, V.: Therapieeffekte in der neurologischen Langzeitrehabilitation. Methodik und erste Ergebnisse einer Interventionsstudie. In: Wild, K.R.H.v, Hömberg, V., Ritz, A. (Eds.): Das schädelhirnverletzte Kind. Motorische Rehabilitation. Qualitätsmanagement. (pp. 281-284). München: Zuckschwerdt, 1999
- Bundesarbeitsgemeinschaft für Rehabilitation [German Federal Association for the Rehabilitation] (Ed.): Wachkoma und danach. Langzeitrehabilitation schwer und schwerst schädel-hirngeschädigter Menschen. Frankfurt am Main, 2000
- Bundesverband Schädel-Hirnpatienten in Not e.v. [German Federal Self-help Association] (Ed.): Rund ums Koma. Amberg, 1997
- Deklaration der Österreichischen Wachkoma Gesellschaft Wien, 2000 [Austrian Coma Vigile Society at Vienna, 2000] www.wachkoma.at
- Deutsche Vereinigung für die Rehabilitation Behinderter [German Association for the Rehabilitation of the Disabled] (Ed.): Empfehlungen zur Rehabilitation und Pflege von Menschen mit schwersten neurologischen Schädigungen. Standards der Langzeitbehandlung in Phase F. Bericht über die Experten-Klausurkonferenz in Maikammer/Pfalz am 10./11. Mai 1996. Heidelberg: Eigenverlag, 1996.
- EU-study - Europäischer Verband der Straßenverkehrsunfallopfer (Ed.): Befragung von 1500 Familien von Verkehrsunfallopfern (1993), Schlußbericht (1995). Auswirkungen von Unfalltod und Verletzung im Straßenverkehr. Genf: Eigenverlag, 1993 und 1995 (German edition)
- Gerstenbrand, F.: Das traumatische apallische Syndrom. Wien: Springer 1967
- Gerstenbrand, F., Pfäusler, B., & Rainer, J.: Das apallische Syndrom. Diagnose – Frührehabilitation – Prognose. In: Wild K.v., Janzik H.-H. (Eds.): Neurologische Frührehabilitation. (pp. 175-180). München: Zuckschwerdt 1990
- Gerstenbrand, F., Matulla B., Baumgartner, H., & Kalchschmid, G.: The legal basis in the treatment of apallic/vegetative state, an ethical view. (6th Congress of the European Federation of Neurological Societies, Vienna, Oct. 26-29, 2002). European Journal of Neurology, 2002c; 9(Suppl. 2): 246 (Abstract)

- Grubb, A., Walsh, P., & Lambe, N et al.: The moral and legal issues surrounding the treatment and care of patients in persistent vegetative state. Report to European Biomedical and Health Research Programme, 1997 (on file in the library of the Centre of Medical Law and Ethics, King's College, London)
- International Working Party Report on the Vegetative State. Republished "Copyright document" from The Royal Hospital for Neurodisability, London. Coma Recovery Association Inc., 1996 (<http://comarecovery.org/pvs.htm>)
- Jennett, B.: The vegetative state. Medical facts, ethical and legal dilemmas. Cambridge: Cambridge University Press, 2002
- Käsbach B.: Eine Untersuchung an Angehörigen von Patienten mit erworbenen, schweren Schädel-Hirnverletzungen. Diplomarbeit, Fachbereich Psychologie, Universität Hamburg, 1999
- Kleen, K.: Bewältigung belastender Ereignisse von Angehörigen schwerst-hirngeschädigter Menschen. Diplomarbeit, Psychologische Fakultät, Carl von Ossietzky Universität Oldenburg, 2000
- Multi-Society Task Force on PVS: Medical Aspects of the persistent vegetative state (Second of two parts). New England Journal of Medicine, 1994; 330(22): 1572-1579
- Mwaria, C.B.: The concept of the self in the context of crisis: A study of families of the severely brain-injured. Journal of Social Science Medicine, 1990; 8: 889-893
- Payne, K., Taylos, R.M., Stocking, C. et al.: Physicians' attitudes about the care of patients in the persistent vegetative state: a national survey. Annals of Internal Medicine, 1996; 125:104-110
- Redecker, C., & Sonntag, A.: Ergebnisse einer Umfrage zur Lebenssituation von Menschen im apallischen Syndrom in Norddeutschland. Mitteilungen der Luria-Gesellschaft e.V., 1994; 1(2) und 1995; 2(1): 32-44.
- Tresch, D.D., Sims, F.H., Duthie, E.H., Goldstein, M.D.: Patients in an persistent vegetative state. Attitudes and reactions of family members. Journal of the American Geriatric Society, 1991a; 39: 17-21
- VDR – Verband Deutscher Rentenversicherungsträger [German Association of the Pension Insurance] (Ed.): Phasenzuordnung n der Neurologischen Rehabilitation. Rehabilitation, 1995; 34: 119-127
- WHO – International Classification of Functioning, Health and Disability (ICF). Genf, 2001
- Zieger, A.: Neue Forschungsergebnisse und Überlegungen zum Umgang mit Wachkoma-Patienten. Rehabilitation, 1998a; 37(4): 167-176
- Zieger, A.: Grenzbereich der Wahrnehmung. Über die ungewöhnliche Lebensform von Menschen im Koma und Wachkoma. Behinderte (Linz), 1998; 21(6): 21-40
- Zieger, A.: Early Rehabilitation in the Neurosurgical Clinic. In: Engberg, A. (Ed.): Proceedings of the European Conference on the Rehabilitation after Severe Brain Injury, Copenhagen, September 6-9, 1998. (pp. 22-41). Copenhagen, 2000
- Zieger, A.: Der Wachkoma-Patient als Mitbürger. Lebensrecht und Lebensschutz von Menschen im Wachkoma und ihren Angehörigen (Memorandum 2002). Wachkoma und danach, 2002a; 11(2): 12-15
- Zieger, A.: The role of relatives in the treatment of apallic syndrome patients. In: Battistin, L., Dam, M., & Tonin, P. (Eds.): Neurological Rehabilitation. Proceedings of the 3rd World Congress of Neurological Rehabilitation, Venice (Italy), April 2-6, 2002. (pp. 165-166). Bologna: Monduzzi 2002b
- Zieger, A.: Ethical guidelines for the treatment and care of vegetative state/apallic syndrome state patients. (6th Congress of the European Federation of Neurological Societies, Vienna (Austria), Oct. 26-29, 2002). European Journal of Neurology, 2002c; 9(Suppl. 2): 246 (Abstract)

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