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An evaluation of health-related quality of life of patients aroused from prolonged coma when treated by physiotherapists with or without training in the 'Academy of Life' programme

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Abstract

Objective: To evaluate the health-related quality of life (HRQOL) in patients aroused from prolonged coma after a severe traumatic brain injury (TBI) treated by physiotherapists trained in the 'Academy of Life' programme. It was assumed that physiotherapists who acquired this knowledge and experience would create a better therapeutic milieu, and would be more effective than physiotherapists who had not received this training.

Material and methods: 40 patients who had suffered a severe TBI in a motor vehicle accident and had been aroused from prolonged coma were examined. All the patients underwent long-term rehabilitation according to a standard, phased programme. They were divided into two numerically even groups: an experimental group, treated by therapists trained in the 'Academy of Life' programme, and a control group, treated by physiotherapists who were not trained in this programme. The research instruments included an analysis of documentation, a structured clinical interview, and the Quality of Life Scale.

Results: As hypothesized, the experimental group showed significant improvement in HRQOL, whereas in the control group improvement was statistically non-significant.

Conclusions: The patients from the experimental group, treated by physiotherapists trained in the 'Academy of Life', obtained a significantly greater improvement in physical and social functioning, and thus in HRQOL, than patients from the control group.

Key words

social isolation, aphasia, dysarthria, memory, paresis, akinetic mutism

INTRODUCTION

The world literature of recent years has tended to emphasize the ineffectiveness of rehabilitation for patients aroused from prolonged coma after a severe traumatic brain injury (TBI) [1, 2, 3]. Most authors believe that the possibilities of improving their health-related quality of life (HRQOL) [4, 5] are minimal. This results, on the one hand, from the multiplicity of the symptoms that appear as sequelae of a brainstem contusion, and on the other from the consequences of protracted unconsciousness itself [6, 7]. Effective programmes, strategies, and methods of rehabilitation for this group of patients are continually being sought [8, 9, 10, 11, 12]. This is not an easy task, however, especially because over time new symptoms of the brain injury may occur [13, 14].

It results from all this that the patient's complicated problems do not end with somatic complaints, which should mean that the responsibility of the therapeutic team also does not end at the physical level. The patient who is treated in a standard system of rehabilitation, and who does not have a properly organized therapeutic milieu, experiences the course of their own rehabilitation as a random series of visits by various therapists sent to him for otherwise unidentified purposes, and will not be able to make their own essential contribution to the process of their rehabilitation [15]. Each successive specialist often begins rehabilitation all over again, generally knowing very little about the previous or current procedures performed by other specialist, and acting according to their own professional judgment within the framework of their particular specialty. The patient becomes the object of various procedures and therapeutic interventions, which they often do not understand, and for this reason do not appreciate. It is difficult to expect any kind of cooperation in this situation; in the best case, the therapist encounters a passive patient, and in the worst active resistance. This interferes with the rehabilitation programme, resulting in lower HRQOL [16, 17].

The problem raised here affects not only early rehabilitation [18], conducted at the patient's bedside, in the first stage of treatment, the goal of which is to save the patient's life, but also the second phase, the goal of which is to improve the patient's HRQOL. This raises an essential question: how can we increase the effectiveness of rehabilitation in this second phase, when it is already certain that the patient will live, but it is not certain what kind of life it will be?

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At this point it would be useful to review the issue of HRQOL. In the presented study, quality of life will be understood in accordance with the guidelines of the World Health Organization (WHO) [6, 7], which has formulated quality of life as the perceiving of the individual as well as their life position equally within a cultural context as within the value system that surrounds them in relation to their aims, expectations and standards. Cohort studies [6] conducted on individuals with brainstem lesions and coma showed that the most important functions affecting the quality of life are motor functions and social functions. Such variables as life optimism, a happy marriage, and financial stability are ranked somewhat lower. As a result, evaluation of the patient's status should include such parameters as motor activity and social activity.

Meeting this challenge and achieving success in rehabilitation entails certain costs, both material and nonmaterial. This does not mean only the considerable costs associated with acquiring and maintaining the equipment and trained personnel needed for modern rehabilitation, but also the increasing number of 'professional patients' who must live for many years after their injury with disorders of both the peripheral and central nervous systems, with persistent symptoms which render normal daily functioning difficult or even impossible. Many of these patients require constant nursing care, with numerous and protracted stays in different hospitals. The chances that the patient will ever return to professional work remain slight, although much depends on the effectiveness of early rehabilitation, during which the mechanism of spontaneous recovery is utilized and reinforced [18].

The proper organization of the rehabilitation process gives both the patient and the therapist greater certainty that the rehabilitation procedures which are being performed at a given moment are appropriate and should be continued. If this is not the case, they should be stopped or replaced with more effective procedures. Particular emphasis is given to the physiotherapist's ability (along with other members of the therapeutic team) to create a proper therapeutic milieu. However, as many authors have pointed out, such a milieu can only be provided by a properly trained physiotherapist [10] or other members of the therapeutic team, which includes also the patient's family and caregivers [7, 14].

The goal of the presented study was to evaluate the HRQOL of patients aroused from prolonged coma caused by severe TBI who were treated by physiotherapists trained in the 'Academy of Life' programme, in comparison to patients treated by therapists who were not trained in this programme. It was assumed that thanks to the creation of better therapeutic conditions, the trained physiotherapists will be more effective than physiotherapists who had not participated in this kind of training.

MATERIAL AND METHOD

40 patients were examined who were recovering from a long-term coma, treated in the Rehabilitation Clinic of the Jurasz Hospital in Bydgoszcz, Poland, and in the Department of Medical Rehabilitation at the Rehabilitation Centre in Krakow, according to a standard, phased programme of rehabilitation [19]. In the control group (n=20, 11 men and 9 women), rehabilitation was conducted by a team of physiotherapists who had not been trained in the 'Academy of Life' programme, whereas in the experimental group (n=20, 13 men and 7 women), rehabilitation was conducted by physiotherapists who had been trained in the 'Academy of Life', a programme realized by the Reintegration and Training Centre of the Foundation for Persons with Brain Dysfunctions in Cracow.

Exclusion criteria for the experiment were as follows:

0. Speech disorders, such as aphasia or dysartria;
1. severe disorders of memory and/or attention;
2. an acute current clinical condition (such as serious cardiovascular disease, poorly healing wounds, or skin ulcerations) that would render participation in the experiment impossible.

Training for physiotherapist in the 'Academy of Life' programme. A team of physiotherapists working in the Rehabilitation Clinic of the Bydgoszcz Medical Academy took part in 60-hours of training conducted as part of the 'Academy of Life' programme [14]. The training was undertaken in three phases:

1. 20 hours of lectures devoted to the diverse consequences of coma. The lectures were conducted by professors, specialists in the areas of neurosurgery, orthopaedics, traumatology, medical rehabilitation, neuropsychology, and the sciences of cognition and communication, who possessed not only theoretical knowledge but also clinical experience in the treatment of TBI and the problems associated with coma. At the end of these lectures the therapists took a competence test.
2. 20 hours of workshops involving comprehensive analysis of the current life situation of particular patients in rehabilitation and the preparation of an inventory of strengths, weaknesses, opportunities, and threats for particular patients. The patients' capacity was measured with respect to adaptation and compensation in the present situation, in which disturbed or lost functions can be supported and complimented by means of special equipment, training of caregivers, and environmental adaptation (adaptation mechanism) and which functions the patient will be able to perform in a different way (compensation mechanism). One hour was set aside for each patient and their caregiver for purposes of drawing up the inventory.
3. 20 hours of panel discussion devoted to the choice of an overall goal for rehabilitation, subordinate goals, and developing a strategy for coping with problems. The steps involved the following:
   - the selection of an overall goal for the period of at least one year, and subordinate goals by means of negotiation with the patient, the family, and caregivers. After the patient had been familiarized with the results of the analysis, the form was corrected in the light of realistic possibilities. What will the situation be in one year? What can change and what cannot? An effort was made to avoid two fundamental, opposite errors which can bring about failure: overestimating one's own possibilities, and a total lack of confidence in oneself.
   - the selection of subordinate goals which should lead systematically to the realization of the primary goal. Successive steps were identified leading from the current situation to the target situation.

Research methodology. In order to evaluate rehabilitation outcome the following research instruments were used:

- analysis of documentation (medical histories and test results, including MRI and CT scans);
- clinical interview focused on the purpose of the research, with particular emphasis on the means used by the patient to cope with the limitations imposed by the TBI, and the patient's attitude (including self-image and sense of the future), value system (especially life goals), and the patient's personality, including any available information on the premorbid personality;
- the Quality of Life Scale for TBI patients [20].

Two subscales from the Quality of Life Scale were used to evaluate quality of life: functional motor capacity and social functions. The combined score for motor capacity was based on the following five activities:

4. transfer from bed to chair or wheelchair;
5. walking with or riding in the wheelchair;
6. using the toilet;
7. getting into the bathtub or shower;
8. using stairs.

Social functions were evaluated on the basis of performance of the following four activities:

- initiating contact;
- Shopping;
- running errands;
- maintaining correspondence.

The evaluation included three to five activities in terms of the estimated percentage participation of the patient in the performance of the activity. The level of assistance required by the patient was specified in points according to the following scale, adapted from the wildly-used ASIA Scale for the neurological and functional classification of spinal injuries [21]:

- 1 or 2 points – complete dependence (patient's participation: 0 to 25%);
- 3 to 5 points – limited independence (patient's participation: 50–75% or independent performance under immediate supervision);
- 6 to 7 points – independence (patient's participation: 100% with or without adaptational devices).

The evaluation was performed by a physician specializing in rehabilitation on the basis of a physical examination and a clinical interview. Points were awarded by a team of three competent judges (a physician specializing in rehabilitation, a physiotherapist and a neuropsychologist).

All patients gave their consent to participate in the experiment, which was approved by the local Bioethics Committee.

RESULTS

Functional motor capacity. The results obtained by both research groups at baseline and follow-up are presented in Table 1.

In the experimental group, a large differentiation in results can be observed between baseline and follow-up. The differences are especially noticeable in the number of scores from the lower end of the scale (1 or 2 points) and the upper end of the scale (7 points). At baseline, there were 57 scores of 1 or 2 points, while at follow-up the number of such scores had dropped to 14. At baseline, on the other hand, there were two scores of 7 points, whereas at follow-up there were 22. The differences between the distributions of scores at baseline and followiup were statistically significant (χ^2 = 43.993; p=0.0005), which means that rehabilitation conducted by trained therapists had a significant impact on the functional motor capacity of the patients in the experimental group. However, even this high statistical significance of the differences between baseline and follow-up does not fully explain the strength of the association between the rehabilitation process and the magnitude of the improvement in functional motor capacity of these patients. In order to specify the strength of the association, the value of coefficient φ was then calculated for the highest (7 points) and lowest (1–2 points) point scores. The result, φ =0.63, points to a strong association and significant correlation between the rehabilitation and the magnitude of the improvement in functional motor capacity in this group of patients.

Table 1. Results from the Functional Motor Capacity subscale in both research groups

Group	Exam	Scores							Total*	Significance
		1	2	3	4	5	6	7		
Experimental	I	35	22	7	8	13	13	2	100	χ^2 = 43.913
	II	10	4	12	17	17	18	22	100	p = 0.0005
	Δ	–25	–18	5	9	4	5	20		
Control	I	16	6	15	12	17	22	12	100	χ^2 = 5.514
	II	10	6	9	14	14	32	15	100	p = 0.480
	Δ	–6	0	–6	2	–3	10	3		

* Analysis was based on the number of questions in the Functional Motor Capacity subscale multiplied by the number of subjects.

Analysis of the results from the control group at baseline and follow-up shows that the number of very low scores (1 or 2 points) dropped from 22 at baseline to 16 at follow-up, a decrease of 6. The number of highest possible scores (7 points) went up from 34 at baseline to 47 at follow-up. An analogous statistical analysis of the results from the control group shows only a slight differentiation in the number of scores at either end of the scale at follow-up and baseline, and the differences were statistically non-significant (χ^2 =5.514; p=0.480). This result means that the rehabilitation had no significant impact on the improvement in functional motor capacity in this group of patients. The coefficient φ was 0.15, which indicates a very slight association between the rehabilitation and the magnitude of the functional improvement obtained by the patients from the control group.

The slight and non-significant improvement observed here may have resulted from the lack of motivation to participate in rehabilitation exercises, caused by the lack of a clearly specified rehabilitation plan.

Social functions. The results for social functions from both research groups at baseline and follow-up are presented in Table 2.

Analysis of the results from the experimental group shows considerable differentiation between the results obtained at baseline and at follow-up. These differences are especially marked in the number of scores at the low end of the scale (1 or 2 points) and at the upper end of the scale (7 points). Comparison of the results obtained at baseline and follow-up shows a reduction in the number of scores at the lower end of the scale. The number of 1-point scores went

Table 2. Results from the Social Functions subscale in both research groups

Group	Exam	Scores							Total*	Significance
		1	2	3	4	5	6	7		
Experimental	I	47	12	2	1	8	7	3	80	$\chi^2 = 22.253$
	II	24	8	7	5	13	9	14	80	p = 0.001
	Δ	–23	–4	5	4	5	2	11		
Control	I	27	3	16	12	18	4	0	80	$\chi^2 = 1.146$
	II	24	3	13	14	20	6	0	80	p = 1.000
	Δ	–3	0	–3	2	2	2	0		

* Analysis was based on the number of questions in the Social Functions subscale multiplied by the number of subjects.

down from 47 to 24, a difference of 23, whereas the 2-point scores went down by 4. The total number of low scores thus went down from 59 to 32. Attention should be drawn to the increased numbers of 7-point scores, which went up from 3 to 14 – a 470% increase. The differences between the results at follow-up and baseline were statistically significant (χ^2 =22.253; p=0.001). The coefficient C_{sk} was 0.43, which indicates a strong association and significant correlation between the rehabilitation and the patients' improved social functions.

Analysis of the results from the control group found no significant differences between the results at baseline and at follow-up. There was a slight reduction in the number of low scores. The number of 1-point scores went down from 27 to 24, while the number of 2-point scores did not change. The total number of low scores went down from 30 to 27. There were no 7-point scores at all, either at baseline or at follow-up. This indicates that the patients from the control group were not initiating contact and were highly dependent in their social functioning in such activities as shopping, running errands and maintaining correspondence. The differences between the number of high and low scores at baseline and follow-up were statistically non-significant (χ^2 =1.146; p=1.000). The value of p=1.000 rules out any association between rehabilitation and improved social functioning in this group of patients. This suggests that it would be advisable to develop a separate programme focused on training these functions.

DISCUSSION

The rehabilitation of patients aroused from prolonged coma after a severe TBI is a relatively new problem [22]. Very few rehabilitation centres in the world take on such cases, which means there is little scientific documentation of the problem. As a result, the research presented here, evaluating the effectiveness of rehabilitation using the methods described, cannot be fully compared with the research of other authors.

As often stated in the literature on QOL, no significant correlation was found in the presented study between the declared (i.e. subjective) level of quality of life and the severity of the patient's objectively measured disability. No one expresses satisfaction, for example, with complete quadriplegia (this would give reason to question the patient's mental status), but there were cases in the presented material when a person with less severe bodily injuries indicated a higher level of discontent in a given domain of functioning than did another person who had experienced a complete loss of this function.

Atrice et al. [23] have identified three successive phases in the process of the collapse of the quality of life:

- **helplessness** – in the face of catastrophic changes affecting locomotion and other essential functions; the patient does not know what to do and falls into a mental state that resembles the state of physical paralysis (in the case of a patient recovering from coma, this is the phase of akinetic mutism);
- **hopelessness** – when the patient becomes aware (correctly or not) that there will probably not be any major improvement; the patient does not believe that he/she will ever be healthy and either accepts the existing state of affairs, or not;
- **uselessness** – at this stage the patient no longer sees any purpose in further treatment, and perhaps even in continued living.

In neuropsychology this state is frequently combined with executive dysfunction. Worthington [24] states that the executive functions (or executive control functions) control the processes necessary to assemble relatively simple concepts, movements, and activities into complex, goal-oriented behaviours.

Pachalska [14] emphasizes that an efficient executive system enables the individual to designate a goal, formulate an appropriate plan of action, and take steps to realize the plan. The efficiency of the executive functions is thus dependent on both cognitive processes (especially perception and mediating processes) and emotional and behavioural processes.

Of course, patients aroused from prolonged coma after severe TBI experience a breakdown of executive functions, and accordingly they manifest difficulties in initiating, inhibiting, or re-directing their actions [25].

A physiotherapist who has been trained in the 'Academy of Life' programme, and therefore better understands these problems, can increase the quality and effectiveness of the rehabilitation programme being applied by providing the appropriate help in this respect (e.g. in initiating or inhibiting the performance of a given activity). In this way, greater effectiveness in rehabilitation can be achieved when functional motor capacity and social functions are particularly important. The patient's HRQOL can thus be improved.

CONCLUSIONS

1. The patients from the experimental group, treated by physiotherapists who had been trained in the 'Academy of Life' programme, achieved significantly higher improvement with respect to functional motor capacity and social functions, and therefore HRQOL, broadly understood, than did patients from the control group treated by a team of therapists without such training.
2. It would be useful to make training of this sort widely available to physiotherapists, based on the 'Academy of Life' programme, by introducing this subject to the university curriculum or through postgraduate courses.

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