

THE STRATEGIC APPROACH TO THE REHABILITATION OF PATIENTS WITH "LOCKED IN SYNDROME"

**Maria Pąchalska¹, Katarzyna Markiewicz²,
Leszek Buliński³, Magdalena Wilk⁴**

¹ Institute of Psychology, Gdansk University, Gdansk, Poland

² Institute of Psychology, Maria Curie-Skłodowska University, Lublin, Poland

³ Gdańsk South Private Health Clinic, Gdańsk, Poland

⁴ Cracow Rehabilitation Center, Cracow, Poland

Key words: spinal cord injury (SCI), rehabilitation planning, quality of life

SUMMARY

Background. This article presents an evaluation of the strategic approach to managing rehabilitation for patients with cervical spinal cord injuries and "locked in syndrome". Consistent pursuit of concrete and explicit individual goals enables the patient to achieve greater independence, and thus a better quality of life.

Material and methods. We examined 68 patients with tetraplegia subsequent to cervical spinal cord injury (SCI) and "locked in syndrome" under treatment in the Cracow Rehabilitation Center, divided into two groups matched for age and sex: the experimental group (E), rehabilitated according to a strategic plan, and the control group (K) rehabilitated without such a plan. Outcomes were measured by clinical observation, the Functional Independence Measure (FIM), and a Self-Evaluating Scale of Progress in Rehabilitation. The patients were tested once just before beginning rehabilitation, and again 6 months later.

Analysis of results. In both groups similar progress was recorded in certain parameters of the FIM scale; in group E, however, much greater progress was noted in terms of self-help and psycho-social functioning. The patients from group E were much more content with the results they had achieved in rehabilitation.

Conclusions. The results reported here justify the assertion that the strategic approach to the rehabilitation of patients with cervical SCI and "locked in syndrome" makes the most of the procedures applied, without fundamental changes in procedures or additional personnel, new equipment, etc. The

strategic approach helps the patient attain better results in becoming independent, and gives grounds for greater satisfaction with the results obtained in rehabilitation.

INTRODUCTION

In recent years the treatment outcome after acute spinal cord injuries (SCI) in the upper cervical area, once considered invariably fatal, is more and more often favorable, measured in terms of both survival and better functional outcomes. With the progress of medical knowledge and the increasing skills of attending physicians, especially in such fields as anesthesiology, intensive care, orthopedic surgery, traumatology, and neurosurgery (Pachalska et al. 2000), the number of patients discharged from hospital after high SCI is constantly increasing. This success in treatment is also owed in large part to progress in surgical engineering, orthopedic equipment, and technological solutions enabling the disabled to function in society without constantly encountering physical barriers that cannot be overcome.

Though there is every reason for satisfaction with improved outcomes in SCI cases, still, the improvement comes at a certain price. There is also an increase in the number of patients living for many years with serious disabilities. The majority of them are unable to work, very often not even capable of living independently, confined to a bed or a wheelchair for life, sometimes permanently connected to various machines that are needed to keep them alive. For the neuroorthopedic surgeon, the survival of a patient who would have died several years ago is a great success, but for the patient the matter is not always so clear. It is not uncommon to hear these patients say, in moments of breakdown, "Wouldn't everyone be better off if I just died? What good is such a life? I'll go home from the hospital, and then what? Nothing will ever be like it was." The patient hears words of encouragement repeated like a mantra by those near and dear to him, and by the medical personnel attending him: "Don't worry, everything will be OK." But no one can give him a simple answer to his simple question: "Now what? What's to become of me?" And this inclines the patient to believe that all the routine words of encouragement are unnecessary, devoid of value, like a check drawn on an empty account.

This problem is especially acute in the case of "locked-in syndrome," which occurs when the neurological injury is so severe and so high that the patient is unable to move any muscles other than those innervated by one or several cranial nerves. Often eyeblinks are the only way the patient can send messages, though the ability to hear and understand may be entirely unimpaired. Cognitive processes are usually unimpaired, though this can be hard to prove in a situation when the patient is physically unable to perform any tests or give much beyond yes and no answers to questions. In time some minimal proximal movement may be restored in remaining cranial nerves and

even to a very limited extent in the upper limbs, but the patient must learn to do virtually everything with his head - not figuratively, but literally. The cognitive status is usually much better initially than in patients who have sustained severe brain injury, and may seem perfectly normal, but in time the secondary effects of stimulus deprivation, depression and inactivity begin to take their toll.

Popular films in recent years have dramatized this situation very effectively, including the depression and suicidal tendencies that often ensue. Within the last year the Polish news media widely reported the case of such a patient, who attempted to claim a constitutional right to euthanasia in the courts. He lost his suit, of course, but the case prompted considerable public interest in the issue. The problem can be sensationalized, indeed trivialized, as an ethical or legal dispute over an alleged "right to die," but the more interesting questions lie, as usual, just below the surface. What is the real "outcome measure"? Is life always worth living, no matter what the circumstances? Is there an irreducible minimum "quality of life," below which the outcome should be considered the moral equivalent of death?

Thus the physician's victory in the struggle with death after a severe SCI only marks the beginning of the battle for the patient's successful adaptation, both mental and physical. What can we really do to help this patient? In our experience, the best answer is, "More than one might think, and less than one might want." For perhaps obvious reasons the treatment of medical symptoms takes first place, especially pain and the various manifestations and consequences of paresis and plegia. This involves, among other things, well chosen physiotherapeutic interventions, tailored to the patient's present clinical status and individual needs, in order to improve his or her physical condition. Sometimes, but in Polish reality much more rarely, other specialists are also involved: the occupational therapist, art therapist, speech therapist, clinical psychologist, psychiatrist, even more rarely the neuropsychologist, of whom there are not enough even for neurology and neurosurgery clinics, let alone spinal units. For most SCI patients, their families, and their physicians, in theory and in practice "rehabilitation = physiotherapy."

This extremely limited view of rehabilitation does not do justice to the scope of the problems faced by persons recovering from any severe, debilitating illness or injury, or to the range of possibilities offered by other specialties actually or potentially involved in rehabilitation. Having survived the most dangerous moments, the patient is now faced with the challenge of putting some kind of a life together, a task for which she is seldom prepared. Family members, in shock or in full retreat, are seldom in any position to offer real help, and in many cases, sadly, they are simply not present. The few community-based programs that still exist are overwhelmed by needs they cannot meet with the very meager resources available. Not surprisingly, then, many patients arrive home from the hospital with very mixed feelings about what the future may hold.

During this period the role of rehabilitation specialists is extraordinarily difficult, and at the same time decisive, since the lack of proper intervention at this delicate stage of transition from hospital to home can precipitate a crisis, leading to mental and emotional paralysis fully as debilitating as the physical consequences of the accident. In this respect uncoordinated efforts to help, even on the part of the best experts in various fields, are of little avail. What is needed is a well thought out and consistently realized campaign, building forward momentum which will carry through into the weeks, months, and years that follow discharge. Such a campaign in turn requires the development of long-range strategy, based on a comprehensive analysis of the patient's present situation, the establishment of realistic long-term and short-term goals and objectives, and the choice of the best available means to reach these goals and objectives.

The need for strategy in rehabilitation is all the greater in the current situation of steadily rising demand for services accompanied, paradoxically, by constantly shrinking resources. In a word, we must do more and more with less and less. In such a situation waste in any form cannot be tolerated. Procedures and exercises that are not helpful for a given patient are worse than useless, since the lost time and money could have been invested in something that would actually help. Yet as every clinician knows, for each individual patient the array of rehabilitation procedures that may prove useful varies considerably, since effectiveness results from a wide range of variables, not always easy to identify and control. If statistical studies show that exercise A is more effective than exercise B for 80% of patients, then clearly exercise A should be preferred. Yet if exercise B is simply eliminated from the program, what happens to the 20% of patients for whom it is more helpful than exercise A? Would it not be better to offer both exercises, and learn how to distinguish which patients need which exercise?

The rehabilitation program for an individual patient in this situation sometimes reminds one of the menu in some Chinese restaurants: one dish from list A, one dish from list B, one dish from list C, one dish from list D, rice, green tea, and a fortune cookie. Though this may be better than either a fixed menu or complete chaos, it does not guarantee a successful meal, as connoisseurs of Chinese cuisine know very well. Likewise in rehabilitation: neither a lock-step program nor complete improvisation will produce good results. We cannot privilege the protocol and force the patient to fit it, but then again, neither can we be guided exclusively by what the patient herself thinks she needs or wants (or more often, does not need and does not want). The need to negotiate a strategy with the patient, like every successful negotiation, must find a middle ground between excessive rigidity and excessive compliance with patient whims and foibles.

STRATEGIC PLANNING IN REHABILITATION

The theoretical basis for the proposed strategic approach to the long-term rehabilitation of patients with cervical SCI is derived from many sources, including well-tested methods used since the 1980s in managing businesses, such as strategic planning, management by objectives (MBO, Ball 1997), and SWOT analysis (Strengths-Weaknesses-Opportunities-Threats, OECD 1997). Of course, these techniques can be used directly in managing the business affairs of hospitals and rehabilitation centers, but the present article is not about the business dimension of rehabilitation, but rather about an approach to solving problems. In the context of constant limitations and shortfalls in health care in terms of personnel, time, and money, the strategic approach is useful not only for companies struggling to exist and grow on the market, but also for rehabilitation centers striving to fulfill their mission in a constantly changing and very difficult reality. The investments and the payoff in the case of rehabilitation are only partially financial, but the general problem remains the same: how to derive maximum benefit from the available investment.

The standard approach to planning rehabilitation is characterized by:

- **fragmentation**, since in the typical situation, even when all the specialists involved perform their work as well as they can, there is little coordination of effort. The patient and the family, on the other hand, do not know why particular exercises and procedures have been ordered, or what results can be expected.
- **reactivity**, since in the absence of concrete strategic plans problems that require therapeutic intervention are resolved when and if they happen to arise. In other words, the work of rehabilitation is focused on problems, rather than on possibilities, and the health professionals react to the appearance of problems, which determine the course of rehabilitation;
- **rigidity**, i.e. lack of adaptation to the individual situation of the patient, who, since she presents with a particular sort of deficit receives the procedures prescribed for such deficits according to a fixed algorithm. When the financial resources available are inadequate to guarantee the patient access to all the procedures foreseen in the plan (which in today's reality happens very often), particular procedures are crossed out in a virtually haphazard manner (usually beginning of course with the most expensive), and only those which the patient and/or the insurer can afford are continued. The patient's only option is to manipulate the system in such a way as to extract the means to assure those procedures which she believes (rightly or wrongly) to be necessary.

It is not difficult to imagine the consequences of such a situation. The patient, whose sense of self worth is already challenged by the sequelae of cervical SCI, is essentially deprived of any voice in the process of rehabilitation. She becomes the depersonalized object of what appear to be the pure-

ly random ministrations of various specialists, each of whom speaks, as it were, a completely different language. Is the patient in this situation in any position to cooperate effectively with the therapists? How can the patient be motivated to work on self-improvement and maintain a positive attitude towards treatment? This problem can be seen with particular clarity in patients with symptoms of complete severance of the spinal cord, when there is no improvement in the neurological status and a greater or lesser period of locked-in syndrome. Ordinarily it is precisely neurological improvement, and the attendant functional improvement, that best motivates the patient and her family to continue cooperating with the therapist. When this is absent or comes only very slowly, the patient and her family reach the conclusion that there is nothing more to be done, and rehabilitation ends before it has properly begun.

Developing a strategic approach

In response to the problems described above, the present authors, in an interdisciplinary effort, have developed and implemented in clinical practice a set of procedures intended to bring about clearer definition of rehabilitation goals. The proposed method of strategic, long-range planning for the rehabilitation of patients with cervical SCI constitutes a sort of "meta-program," in the sense that it involves making the best possible use of the existing resources, rather than experimenting with new procedures or purchasing new equipment, which the majority of Polish rehabilitation centers at the present moment cannot afford. As soon as the patient is admitted to rehabilitation, before commencing routine procedures, a process of strategic planning is initiated. This perhaps overly military term, "strategic," does not in this case describe the efforts to cope with an enemy on the battlefield, but rather an approach oriented towards using the available resources in such a way as to attain a clearly defined goal. In the consistent pursuit of that goal we choose a series of objectives, whose attainment appears to be:

- realistic, in the light of the existing possibilities and available resources;
- necessary, in order to achieve the overarching goal.

For the present purposes, then, we distinguish between a goal, which defines the purpose of all our activities, and an objective, which is a means or waypoint along the road to achieving the goal.

A particularly important factor in the realization of *goals* is the proper choice and sequencing of *objectives*. It is vital to determine which of the identified objectives must be achieved first in order to make the achievement of further objectives possible. For example, if the goal is to enable the patient mobility in a wheelchair, it is necessary to assure that she is able to sit upright in the chair and in some way propel and steer it, and this defines the objectives.

When the rehabilitation strategy has been clearly identified and well matched to the patient's potential on the one hand, and to the available therapeutic means and the patient's needs, desires, and aspirations on the other (Pa-

chalska et al. 2000), both the patient and the therapist feel greater certainty that whatever they may be doing at a given moment in the process of rehabilitation is fully justified. A well chosen and clearly identified strategy facilitates cooperation between patient and therapist, and also enables specialists from various disciplines to cooperate more effectively with one another in the rehabilitation of a given patient. The strategy also provides a point of reference to define success and failure. When attainable objectives are identified and then achieved, the patient acquires the momentum of success, which in many cases begins to counterbalance the overwhelming feeling of loss with which these patients must deal.

A well-defined strategy, however, is not sufficient. It is also vital to have the consent of all those involved, especially the patient, to the overall shape and direction of the strategy. It is the patient, in particular, who ultimately decides on the overarching goal, though of course the expert advice of the specialists should play a major role in outlining the alternatives. In this context the military metaphor is in fact especially apt. In a democratic state it is not the army, but the elected civilian authorities who decide with whom the state goes to war, and why. The task of the military commanders is to advise the government, before a decision is made, so that the decision-makers have some idea what is easy, what is possible, what is difficult, what is impossible, so that once a decision is made it will be possible to begin realizing sensible military objectives, make the best use of existing and potential resources, and avoid as far as possible incurring irreparable damage. In an analogous manner, the first task of the rehabilitation team is to provide the patient, before the strategic decisions are made, with essential, accurate, and reliable information regarding her state of health and prospects, and then, after the decision is made, to assist her in the choice and application of the best available methods leading to the achievement of the goal established by the patient, with due respect for the first law of medicine: *primum non nocere*.

The purpose of the present article is to describe our experience with such a program for SCI patients, designed and implemented in accordance with the principles and tendencies described here.

MATERIAL AND METHODS

The patients

The effectiveness of the strategic approach was evaluated in a clinical experiment, involving 68 patients with complete tetraplegia subsequent to cervical spinal cord injury (SCI), operated and/or referred for rehabilitation during the period from July 2000 to January 2001 in the Department of Medical Rehabilitation at the Cracow Rehabilitation Center, the Department of Rehabilitation at the Ludwik Rydygier Academy of Medicine in Bydgoszcz, the Department of Spinal Rehabilitation at the Marian Weiss Specialized Re-

habilitation Center in Konstancin, and the Traumatology Clinic of the Jagiellonian University's Collegium Medicum in Cracow. All these patients had experienced at least two weeks of "locked-in syndrome." They were hospitalized during the first portion of the experiment; later, after being discharged from the respective rehabilitation departments, they were supervised by a physician in outpatient rehabilitation.

The patients were divided into two groups matched for age and sex: the control group, K ($n = 34$), which included patients for whom the strategic approach described above was not applied in long-term rehabilitation, and the experimental group, E ($n = 34$), consisting of patients undergoing rehabilitation according to a strategic plan developed as described above. The average age of the patients in both groups was 31.9 years ($SD = 9.3$); the women in this population were somewhat older than the men ($x = 34.2$ years, $SD = 7.8$ vs. $x = 29.6$ years, $SD = 9.4$ for the men). These were primarily young persons of so-called "productive age."

All these patients gave written informed consent to participate in the experiment and submit to testing, while the research project as a whole was approved by the local bio-medical ethics committees in each institution.

Developing a strategic plan

A strategy adapted to the individual needs of each patient from Group E was selected prior to the commencement of rehabilitation procedures in a five-step process:

1) Comprehensive analysis of the patient's current situation

In this phase SWOT analysis was used, consisting in a detailed inventory of not only the patient's problems and limitations, but also his or her preserved capabilities and resources. The patient's existing potential was assessed in terms of adaptation and compensation, e.g. which disturbed or lost functions could be supported and supplemented using specialized equipment, caregiver training, adaptation of the physical environment, etc. (*adaptation*), and which functions the patient might be able to perform in some other way (*compensation*).

The information needed to perform this analysis was gathered from all available sources, including:

- medical documentation;
- interviews with the patient, the primary caregiver, other family members, and medical personnel having contact with the patient;
- clinical observation.

In order to assure that the information thus gathered provided an accurate, realistic picture of the patient's current status, the authors developed a special questionnaire (cf. Annex 1).

2) Establishing the target state (overarching goal) by negotiation

After the rehabilitation team had completed the SWOT analysis, the goals of rehabilitation for at least the next 6 months were established in a series of meetings with the patient, attended by caregivers and family members. The patient was shown the results of the SWOT analysis, and then the operative question was as follows: how should this form look, within the limits of the possible, 6 months from now? What can be changed, and what cannot?

As a result of these discussions the goals were developed, forming a "target state." The effort was made to guarantee that the goals were realistic, bearing in mind two general principles (Pachalska et al. 2000):

- Goals which are set too low, representing very little change from the present situation, do not motivate the patient to action, since the satisfaction gained from achieving such a goal is generally slight and fleeting.
- Overly ambitious goals that cannot be fully realized, though initially they may motivate the patient to extraordinary exertions, most often lead to frustration and psychological collapse, from which it may be very difficult to recover.

As mentioned earlier, the ultimate decision regarding the primary goals belongs to the patient. The therapist's role consists in helping the patient identify goals that are both significant and realistic.

3) Selecting objectives leading systematically to the realization of the overarching goal

During this phase, the rehabilitation team in consultation with the patient establishes objectives, that is, successive steps leading systematically from the present situation to the target situation. At each point in the SWOT questionnaire where there is a visible difference between the patient's present status and the target status, the question becomes, what can and should be done to change the current situation in the direction of the target situation? The effort is made to choose objectives that are concrete and measurable by clearly defined parameters, so that it is possible to state clearly when and how they will be achieved.

4) Setting a schedule for the achievement of objectives

After the goals have been established and the objectives identified, a realistic schedule of exercises and measurements is drawn up. This process also entails designating the person(s) responsible for the particular activities listed in the schedule. In this way it is possible to maintain forward momentum and react quickly and effectively when problems arise.

5) Regular monitoring of performance and goals

The level of performance is monitored in terms of the execution of the plan developed in the course of the first four phases. Testing is performed to determine whether or not the patient is making progress towards realizing the primary goals. If problems in plan performance are detected, the situation is re-analyzed and the decision is made to:

- revise the means used to achieve the objectives (e.g. change exercises or procedures);
- revise the objectives, perhaps choosing an alternative route to achieving the primary goals;
- reconsider the primary goals.

Research methodology

In order to measure the effects achieved by the patients in the process of rehabilitation we used the following instruments:

- clinical observation;
- clinical interview oriented towards issues of strategic planning, with particular emphasis on how the patient presently copes with the limitations caused by SCI, the patient's attitude and self-image, how s/he sees the future, and the hierarchy of values, especially in terms of happiness and contentment.
- the standard Functional Independence Measure (FIM), recommended by the American Spinal Injury Association for the evaluation and description of the impact of SCI on the patient's functioning, and as an outcome measure (Pachalska et al. 2000, Atrice et al. 1995). The FIM makes it possible to evaluate various areas of activity, divided into the categories of self care, sphincter control, mobility, locomotion, communication, and social cognition. Points are awarded by the attending physician on the basis of her own testing, clinical observation, and interview, in large measure according to the degree of help the patient requires to perform the given function: 1-2 points for complete dependence, 3-5 points for modified dependence, and 6-7 points for independence.
- the Self-Evaluating Scale of Progress in Rehabilitation, which includes the same general categories as the FIM. The patient's task is to indicate on a scale from 0-10 her level of satisfaction with her current status in that parameter.

The patients were tested twice, once just before rehabilitation was commenced (baseline) and again six months later (follow-up).

RESULTS

Since the patients were matched by age and sex, there were no statistically significant differences in this respect; accordingly, further analysis will

be conducted without references to these parameters.

The results obtained from the FIM are presented in Table 1, and illustrated graphically in Fig. 1a and 1b.

In the baseline test, significant disturbances occurred in both groups in all 6 categories of functional independence as measured by the FIM. This is shown by the low point scores both in the various kinds of daily life activities, as well as the total score in the areas of self-help, sphincter function, mobility, locomotion, communication, and social cognition. An analysis of the results from both groups in this first test shows that they were quite similar,

Table 1. Percent gains in capabilities measured by the Functional Independence Measure (FIM) obtained during the rehabilitation of patients from groups K and E

Parameters	Max.	Group K			Group E		
		Exam I	Exam II	Δ	Exam I	Exam II	Δ
Self Care							
A. Eating	7	2.3	2.9	26.1%	2.4	6.2	158.3%
B. Grooming	7	1.2	4.8	300.0%	1.4	6.9	392.9%
C. Bathing	7	1.1	2.1	90.9%	1.3	4.2	223.1%
D. Dressing – Upper Body	7	1.5	3.0	100.0%	1.2	5.7	375.0%
E. Dressing – Lower Body	7	1.4	2.2	57.1%	1.7	3.4	100.0%
F. Toileting	7	1.3	2.3	76.9%	1.2	6.7	458.3%
TOTAL	42	8.8	17.3	96.6%	9.2	33.1	259.8%
Sphincter Control							
G. Bladder Management	7	1.0	1.8	80.0%	1.0	2.3	130.0%
H. Bowel Management	7	1.0	1.9	90.0%	1.0	2.6	160.0%
TOTAL	14	2.0	3.7	85.0%	2.0	4.9	145.0%
Mobility							
Transfer							
I. Bed, Chair, Wheelchair	7	1.0	4.3	330.0%	1.0	5.7	470.0%
J. Toilet	7	1.0	2.2	120.0%	1.0	2.6	160.0%
K. Tub, Shower	7	1.0	2.1	110.0%	1.0	2.8	180.0%
TOTAL	21	3.0	8.6	186.7%	3.0	11.1	270.0%
Locomotion							
L. Walk / Wheelchair	7	1.0	5.3	430.0%	1.0	6.8	580.0%
M. Stairs	7	1.0	1.9	90.0%	1.0	3.2	220.0%
TOTAL	14	2.0	7.2	260.0%	2.0	10.0	400.0%
Communication							
N. Comprehension	7	5.9	6.2	5.1%	5.8	7.0	20.7%
O. Expression	7	5.4	6.4	18.5%	5.3	6.9	30.2%
TOTAL	14	11.3	12.6	11.5%	11.1	13.9	25.2%
Social Cognition							
P. Social Interaction	7	1.1	3.4	209.1%	1.3	5.2	300.0%
Q. Problem Solving	7	1.3	2.7	107.7%	1.4	6.1	335.7%
R. Memory	7	3.1	3.6	16.1%	3.2	6.8	112.5%
TOTAL FIM	21	5.5	9.7	76.4%	5.9	18.1	206.8%

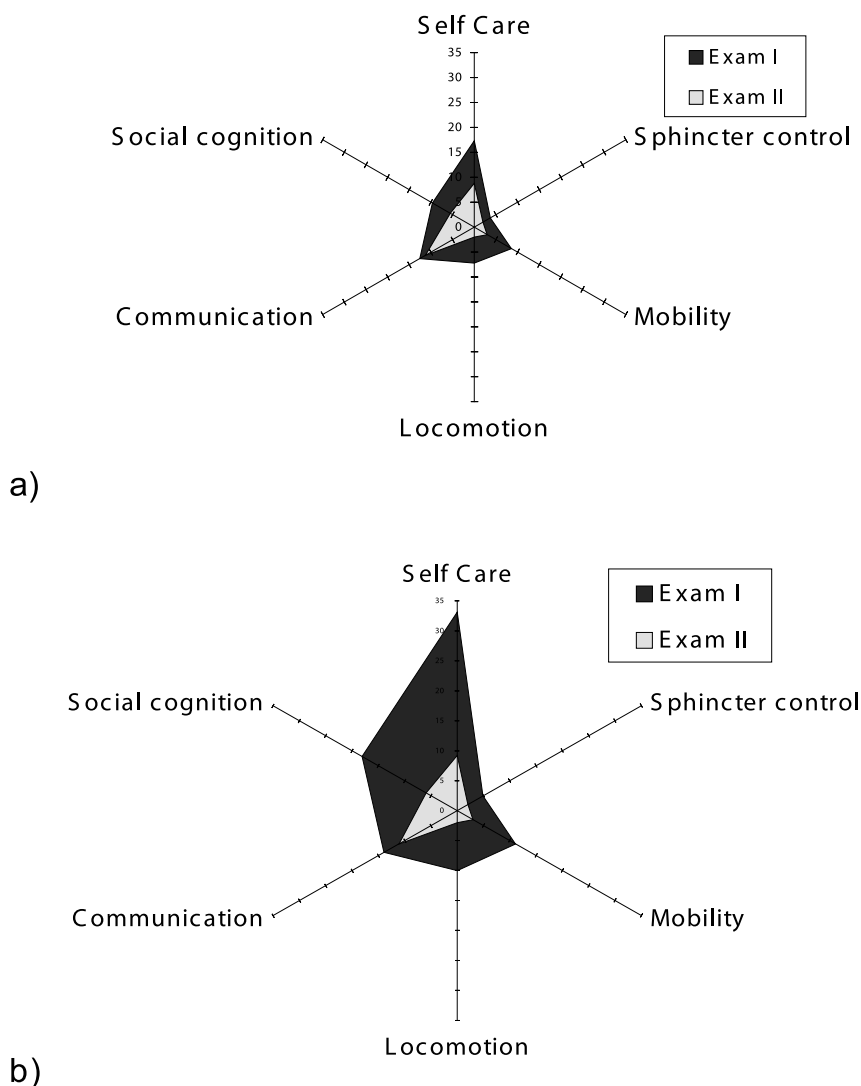


Fig. 1. Point gains obtained by the patients in respect to particular categories of performance covered by the Functional Independence Measure (FIM): a) control group; b) the experimental group

which points to homogeneity at baseline.

In the follow-up test, similar progress was found to have occurred in both groups in respect to sphincter function, mobility, and locomotion. In Group E, however, there was a two-fold higher percentage increase in the areas of self-help, communication, and social cognition (cf. Fig 1a and 1b).

Especially large increases were seen in particular categories, and in particular daily life activities:

- self-help: eating (the improvement in Group E was 158.3%, as opposed to 26.1% in Group K), bathing (improvement of 223.1% in Group E, vs. only

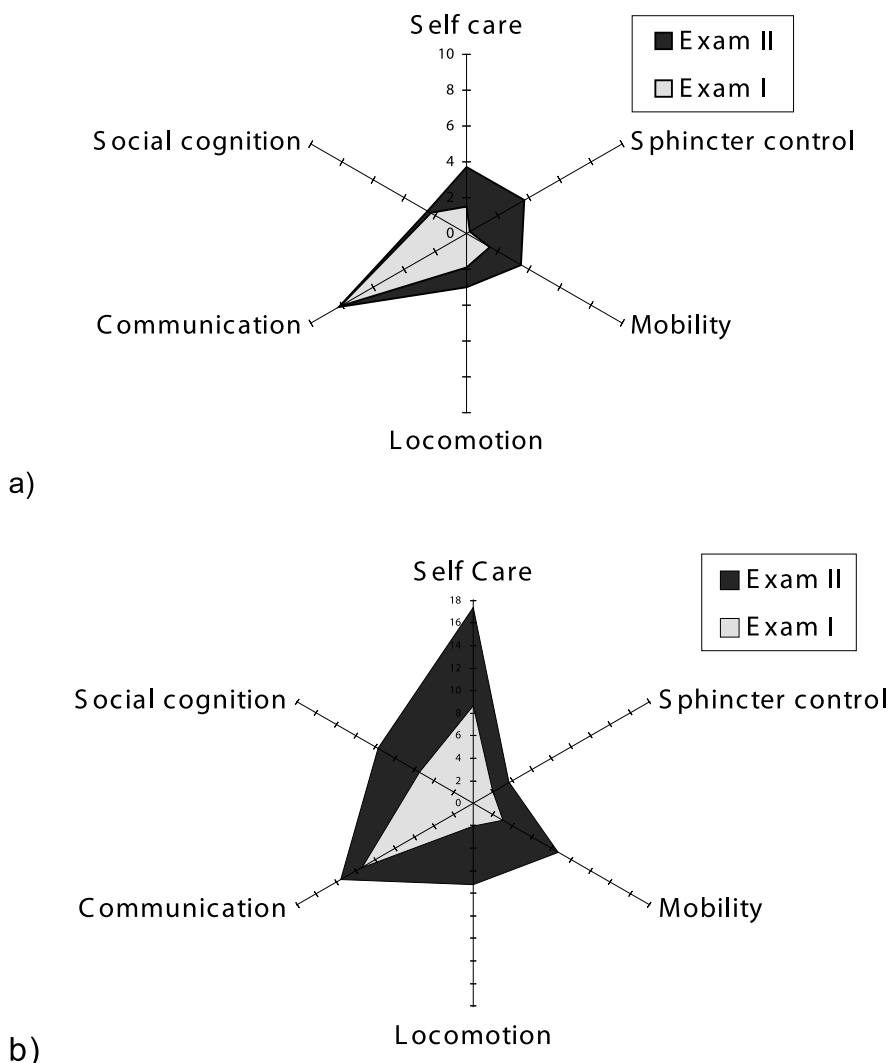


Fig. 2. Point gains obtained by the patients in respect to particular categories covered by the Self-Evaluation of Progress in Rehabilitation): a) control group; b) experimental group

- 90.9% in Group K), dressing upper body (improvement in Group E as high as 375.0%, compared to 100.0% in Group K) and toileting (improvement of 458.3% in Group E, as opposed to only 76.9% in Group K);
- social cognition: problem solving (improvement of 335.7% in Group E, compared to only 107.7% in Group K).

An analysis of the results obtained in the Self-Evaluating Scale of Progress in Rehabilitation indicates that the patients in Group E were much more satisfied with the results they had achieved in rehabilitation than were the patients in Group K, which is a matter of great importance in the positive attitude necessary for further rehabilitation (cf. Fig. 2a and 2b). This pertains

even to those areas in which, despite considerable effort, for purely objective reasons little or no progress was noted, though the highest levels of dissatisfaction were noted in these parameters for both groups.

DISCUSSION

One of the first, most difficult, and at once most important problems in developing a strategic plan for each patient in Group E was to resolve potential conflicts between two imperatives, which are often contrary: the struggle against disability and the need to come to terms with reality. On the one hand, a patient who surrenders psychologically may not achieve as much in rehabilitation as is objectively possible, due to post-traumatic depression, which consists in passive acceptance of the status quo. Depression destroys all motivation to exercise, and causes a lack of openness to new methods of treatment and rehabilitation. Every experienced clinician in any medical field knows what happens when the patient loses all hope. The "what's the point?" attitude becomes a self-fulfilling prophecy.

It is often observed in clinical practice that patients who initially displayed high motivation to exercise, but lack a clearly identified strategy and thus have no foreseeable objectives, fail to show progress in rehabilitation, to a large extent because they invest a good deal of time and effort in procedures that are less helpful at the expense of other exercises that would do them more good. If there is no yardstick to measure progress, the patients have no reason to feel satisfied with their accomplishments. There is a limit to how much can be accomplished by "pep talks." The patient may reach the mistaken conclusion that there is nothing further to be gained from rehabilitation and terminate exercises, which in fact could help him in the future. This may result from either excessive pessimism (when the patient states, "There's no reason to keep trying, even so it'll never be better"), or from exaggerated optimism ("I'm as good as new, so why keep exercising?"). The best way to prevent either of these two mistakes is in fact strategic planning.

To be sure, the patient who stubbornly struggles to increase the range of his/her physical capabilities may at least temporarily inspire admiration, but in some cases, as we showed in a previous publication (Pachalska et al. 2001), this struggle takes on a negative aspect and turns into a denial of reality. The patient "tilts with windmills," may display hysterical reactions, turn into a domestic tyrant, and generally become a burden on the family and ultimately herself. Such a patient often creates completely unrealistic, impossible goals and expectations, leading to inevitable defeat and disaster. The setback in turn causes a breakdown and even deeper depression than in a patient who is resigned to her fate from the beginning and has never believed in any possibility of improving her condition or life situation.

In order to prevent both these extreme situations, a strategic plan should be established at the very beginning of rehabilitation. In the spirit of "21st Century Medicine" (Atrice et al. 1995), the patient is given the role of the "ge-

neral" in the war for a better quality of life. The rehabilitation team does not abdicate its responsibility in this situation, but rather assumes an executive role. In this way the patient's image, both internalized and externalized, changes from that of a person who is helpless, dependent, to a person who is coping with the situation, controlling her own rehabilitation. Moreover, we encourage the patient to think constructively about her future, a subject which inspires mostly anxiety and/or avoidance in most patients with plegia or paresis after locked-in syndrome. Having a realistic strategy and striving consistently to realize it, the patient acquires hope, and along with it motivation to keep working. The strategic plan is also sufficiently flexible to allow for reaction to setbacks, whether minor or major. This is particularly important in the case of cervical SCI patients, since in these cases the process of rehabilitation is long-term, indeed life-long. In this context the loss of hope and motivation may lead to a very unfavorable, even life-threatening situation.

It should be emphasized that the positive results of the strategic approach to long-term rehabilitation are not limited to improving the patient's mood. Focusing on those tasks considered to be the most important, neither the patient nor the rehabilitation team loses valuable time on pointless activity, neglecting essential tasks. In response to the question frequently asked by the patient, "Why do I have to do this?", the answer is no longer, "Because that's what we always do in these cases," but rather, "Because we agreed that we want to achieve objectives x, y, and z, and these exercises are necessary to achieve them." The authors have frequently observed in the clinic that it is much easier to convince patients to exercise by appealing to goals they set for themselves than to recommendations taken from rehabilitation textbooks.

For patients with locked-in syndrome one of the most serious threats to the quality of life is the feeling of having lost control over one's own life, which is symbolized and expressed by the loss of control over one's own body (North 1999). Keeping these patients alive, given the current state of our medical knowledge, is no longer a major problem; it is much more difficult to convince these patients that the life they are living thanks to the miracles of modern medicine is in fact worth living (Gerhart et al. 1999). The role of rehabilitation in these cases essentially consists in finding adaptation mechanisms that are advantageous for the patient, and controlling compensation, which enables her to perform many activities of daily living and work. These sometimes difficult and protracted processes may even help some patients to find within themselves a source of new creativity, which can give life a new sense of purpose.

The very process of developing a strategy focuses the patient's attention on the sequence of tasks in rehabilitation. In this respect there is a hierarchy of needs, corresponding to the hierarchy of goals and objectives, generally flowing from the purely physiological level, through the emotional level, to the mental and spiritual dimension. The patient must first solve particular problems rendering it difficult to satisfy basic needs, in order to develop further, towards the realization of her desires and aspirations. In patients with locked-

in syndrome, frustration caused by the lack of opportunity to satisfy basic needs leads to a situation in which the patient cannot even think about the possibility of realizing her emotional desires and mental or spiritual aspirations, even though, as a human being, she still has them.

When emotional disorders also appear, such as emotional lability, anxiety and depression, or modification of attitude in the direction of passivity, dependence and social isolation, then it likewise becomes a very difficult task to maintain mental composure, hope, self-confidence, faith in other people, in a better tomorrow (Pachalska 1985, Judd & Burrows 1986). These and other modifications in the patient's status cause changes in the value system, often accompanied by a sense of having lost any purpose in life (Tlokinski & Krawczynski 1997). Revaluation in the realization of desires and aspirations is often caused by the fact that the patient does not acknowledge that she still has any right to have desires and aspirations. Ultimately all activity and motivation to exertion and exercise is lost, which leads to a deterioration in physical condition that can even have a fatal outcome (Pachalski & Pachalska 1984).

Cultural traditions, generally prevalent opinions, and accepted hierarchies of values in the environment from which the patient comes are not without importance. Breaking through fallacious beliefs about the reduced value of a disabled person in society and in the family enables real mutual cooperation between the patient and the rehabilitation team. None of this is possible in a patient who is prevented from committing suicide only by his/her physical disability.

An essential role in the process of breaking out of the vicious circle of depression and inactivity is played by the patient's active role in forming the rehabilitation program in the strategic approach (Vilkkki 1995), i.e. active inclusion in the development and choice of a set of planned activities and objectives, leading to the achievement of important goals, which entail the satisfaction of genuine needs, desires, and aspirations (Pachalska et al. 2001). In this way the strategic approach to rehabilitation systematically expands the patient's focus from mere survival to self-realization. The process of creating and shaping a program in turn results from the choice of one's own action strategy (Folkman & Lazarus 1980), with the active, expert assistance of the therapeutic team. If this strategy is well suited to the current situation and goals are set that entail the realization of needs, desires and aspirations the patient feels are genuinely important, then the realization of the plan in accordance with the strategic approach leads to improved quality of life for the patient (Folkman & Lazarus 1980). This is a process built on constantly striving towards the primary goals. In this way we can help the patient concretely and realistically, and yet with full respect for his/her right to self-determination, on which quality of life in large measure depends.

CONCLUSIONS

The results reported here would seem to justify the assertion that the strategic approach to rehabilitation:

- maximizes the advantages to be derived from the application of rehabilitation procedures, without the need to make basic changes in these procedures or increase the number of personnel, equipment expenditures, etc.;
- educates the patient in a broad spectrum of the consequences of spinal cord injury and the role of rehabilitation in the struggle to overcome these consequences;
- supports the patient in achieving greater independence;
- leads to satisfaction with the results achieved in rehabilitation, which in turn increases the patient's motivation to take an active part in exercises and other procedures;
- guarantees the patient's basic right to make important decisions in the process of her own treatment, which is in accordance with the Patient's Bill of Rights and the demands of medicine in the 21st century.

REFERENCES

- Atrice, M.B., Gonter, M., Griffin, D., Morrison, S.A. & McDowell, S.L. (1995). Traumatic spinal cord injury. In: D.A. Umphred (ed.), *Neurological rehabilitation* (pp. 484-534). 3rd ed. St. Louis: Mosby.
- Ball, J.R. (1997). *DNA leadership through goal-driven management*. Reston, VA, USA: Goals Institute.
- Folkman, S. & Lazarus, R.S. (1980) An analysis of coping in a middle-aged community sample. *Journal of Health and Social Behavior*, 21, 219
- Gerhart, K.A., Weitzenkamp, D.A., Kennedy, P., Glass, C.A. & Charlifue, S.W. (1999). Correlates of stress in long-term spinal cord injury. *Spinal Cord*, 37, 183-190.
- Judd, F.K. & Burrows, G.D. (1986). Liaison psychiatry in a spinal injuries unit. *Paraplegia*, 24, 6-19.
- North, N.T. (1999). The psychological effects of spinal cord injury: a review. *Spinal Cord*, 37, 671-679
- OECD. (1997). *Benchmarking, evaluation, and strategic management in the public sector*. Paris: OECD.
- Pachalska, M., Baranowski, P., MacQueen, B.D., Knapik, H., Pachalski, A. & Franczuk, B. (2001). A program of comprehensive care for cervical SCI patients. In: G. Brunelli (ed.) *Proceedings of the Third International Conference on Spinal Cord Regeneration*; Brescia, Italy: Fondazione per la Ricerca sulle Lesioni del Midollo Spinale.
- Pachalska, M., Haftek, I., Haftek, K.N., MacQueen, B.D., Bielecki, D. (2000). Modyfikacja strategii rozwiązywania sytuacji trudnych u chorych z urazami rdzenia. *Kwartalnik Ortopedyczny*, 3, 182-186
- Pachalska, M., MacQueen, B.D. (2000). *Standardowa Skala Oceny Samodzielności (Functional Independence Measure, FIM)*. Authorized Polish version. Cracow: Foundation for Persons with Brain Dysfunctions.
- Pachalska, M. (1985). *Teoria i praktyka rehabilitacji w chorobach psychicznych*. Kraków: AWF Monograph Series.
- Pachalski, A. & Pachalska, M. (1984). Programme of active education in the psychosocial integration of paraplegics. *Paraplegia*, 22, 238.
- Tłokiński, W. & Krawczyński M. (1997). *Wypełnianie starości. Trening ku życiu*. Manchester & Gdańsk: AEL Publishing House.
- Vilki, J. (1995). The neuropsychology of mental programming: an approach for the evaluation of frontal lobe dysfunction. *Applied Neuropsychology*, 2, 93

Address for correspondence:

Prof. dr hab. Maria Pąchalska

Institute of Psychology, University of Gdansk

ul. Pomorska 68, Gdansk, POLAND

e-mail: m.pachalska@medscimonit.com

Received: 15 December 2007

Annex 1. SWOT Questionnaire (Strengths – Weaknesses – Opportunities – Threats)

Clinical status of the patient	
Primary symptoms	
Main limitations in daily life	
Barriers to return to work	
Realistic prospects of improvement in clinical status	
Possibilities to compensate for lost or disturbed functions	
Patient's attitude	
Premorbid personality (active/passive; optimistic/pessimistic; dreamer/realist; cooperative/loner; dependent/independent; joyful/depressive; calm/anxious; adjusted/neurotic;etc.)	
Changes in personality evoked by injury/illness	
Level of motivation to exercise	
Readiness to work on self-improvement	
Attitude of the environment	
Material situation (financial, residential) enabling patient to survive and develop his/her possibilities	
Need for special care (if there is such a need, does the patient have a caregiver who is physically and psychologically ready to help?)	
Support and understanding at home.	

Accepted: 12 February 2008