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The impact of rehabilitation on the functioning of patients with amyotrophic lateral sclerosis: a pilot study

Abstract

Background. Amyotrophic lateral sclerosis (ALS) is a rapidly progressive neurologic disorder during which results in a progressive deterioration of motor function. Rehabilitation is one of the elements of symptomatic treatment in patients with ALS. The aim of the study was to evaluate the impact of rehabilitation on the functioning of ALS patients in terms of daily living activities.

Material and methods. Ten ALS patients participated in this pilot study. The study involved completing a questionnaire by the patient. The questionnaire consisted of 5 parts: general information of the patient, the Amyotrophic Lateral Sclerosis Functional Rating Scale (ALSFRS), the Edmonton Symptom Assessment Scale (ESAS), the Hospital Anxiety and Depression Scale — Modified Version (HADS-M) and the part assessing the impact of rehabilitation on the patient's functioning.

Results. Most patients reported that rehabilitation was helping them breathe, reduced pain and improved sleep quality. An improvement in mental state was also observed in most patients. According to the responses provided by the patients, the treatment often led to hardly any or no improvement at all in terms of such activities as: walking, walking up and down the stairs, writing or preparing meals.

Conclusions. Rehabilitation should be an element of symptomatic treatment provided to patients with ALS, at least because it has been shown to improve their mental state, although in many cases therapy has very little effect overall. The information provided in this paper may be of value for carers and physiotherapists working with the patients, as it may enable them to increase the effectiveness of their decisions to improve the patients' comfort and quality of life.

Key words: ALS, rehabilitation, physiotherapy

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Introduction

Amyotrophic lateral sclerosis (ALS) is a rapidly progressive neurologic disorder in which upper and lower motor neurons are damaged [1]. The disease is characterised by a gradual deterioration of motor function, leading to a considerably decreased activity in everyday life. As ALS is an incurable condition, the most important element of care provided to patients with this condition is multidirectional symptomatic treatment focused on severe manifestations that interfere with normal functioning of the

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patient [2]. Rehabilitation is one of the elements of symptomatic treatment [3]. The goals of rehabilitation usually are to preserve optimal functional capacity and to relieve negative consequences of limited motor activity. Rehabilitation needs to be planned individually, taking into account the severity of the disease and the related neurologic deficits [4, 5].

The aim of the study was to perform a clinical evaluation of patients suffering from ALS and to define the patient-reported impact of rehabilitation on their functioning in terms of the activities of daily living.

Material and methods

Patients

The study was conducted in patients under the care of two facilities: the Care and Treatment Facility in Chełm and the Home Ventilation Centre in Bydgoszcz, Poland. The study had been approved by the Bioethics Committee of Nicolaus Copernicus University Medical College in Bydgoszcz. Each patient provided written informed consent before entering the study. A total of 10 patients were included in this pilot study, 8 from the Home Ventilation Centre in Bydgoszcz and 2 from the Care and Treatment Facility in Chełm.

Methods

Each patient was asked to complete, along with the investigator, a special questionnaire (Box 1), which included:

— general information of the patient;
— the Amyotrophic Lateral Sclerosis Functional Rating Scale (ALSFRS) [6];
— the Edmonton Symptom Assessment Scale (ESAS) [7];
— the Hospital Anxiety and Depression Scale — Modified Version (HADS-M) [7];
— assessment of the impact of rehabilitation on the patient's functioning;
— assessment of the patient's satisfaction with the rehabilitation programme.

Results

Ten patients, including 3 men and 7 women, were enrolled in the study. The mean age was 54.2 ± 12.26 years. The diagnosis had been established more than 3 years before the study in 6 patients, less than a year before the study in 2 patients, between 1 and 2 years before the study in 1 patient and between 2 and 3 years in one patient. Only 1 patient was working part-time, while all the others were not professionally active.

The second part of the questionnaire consisted of an assessment of the patient's functioning on the ALSFRS scale (Table 1). A total of 5 patients managed to perform many activities (speaking, swallowing, handwriting, walking), although it required much effort on their part. Half of the patients were unable to change the position in bed without the help of others. Two patients were completely bedridden, were ventilated invasively through a tracheostomy tube connected to a ventilator and were struggling with excess saliva. Six patients received non-invasive ventilation.

The third part of the questionnaire evaluated the severity of symptoms on the ESAS scale (Table 2). Eight patients suffered from at least one severe symptom (≥ 7/10) with 4 patients complaining of at least 3 severe symptoms. The analysis of the symptoms reported by the patients showed that the most

Table 1. Functional status of the patients according to the ALSFRS scale

Patient number	Speech	Salivation	Swallowing	Handwriting	Food preparation[1]	Food preparation[2]	Dressing and hygiene	Turning in bed	Walking	Climbing stairs	Breathing
1	0	0	0	0	-	0	0	0	0	0	0
2	3	2	3	2	2	–	1	2	3	3	4
3	4	4	4	3	0	–	0	0	1	0	1
4	1	2	3	3	1	–	0	0	1	0	2
5	0	0	3	3	4	–	4	4	4	4	3
6	3	1	2	1	0	–	1	0	1	0	4
7	4	3	3	4	4	–	3	3	3	3	3
8	3	4	4	3	3	–	3	3	3	4	3
9	1	4	1	0	–	0	0	0	1	0	0
10	1	0	1	3	–	1	2	4	3	1	1

For each parameter, "4" means normal performance of a given activity and "0" means a complete inability to perform a given activity; [1]patients on natural nutrition; [2]PEG, parenteral nutrition

Table 2. Symptom severity scales: ESAS and HADS-M*

Patient	ESAS										HADS-M	
number	Pain	Tiredness	Nausea	Depression	Anxiety	Drowsiness	Appetite	Well-being	Shortness of breath	Other	Depression	Anxiety
1	8	6	0	10	10	8	1	10	10	0	16	19
2	0	3	3	5	5	5	6	4	4	3	12	11
3	5	3	0	8	9	2	4	3	4	0	10	9
4	3	5	0	4	7	1	0	4	2	0	3	8
5	1	3	0	0	3	0	3	5	0	0	0	2
6	8	7	5	8	8	4	7	6	5	0	10	9
7	4	4	2	5	5	3	2	7	5	0	11	14
8	6	8	3	9	8	8	5	6	9	0	9	10
9	0	0	0	5	3	1	8	2	0	0	10	6
10	0	8	0	0	5	0	8	7	0	0	5	5
Mean	**3,5**	**4,7**	**1,3**	**5,4**	**6,3**	**3,2**	**4,4**	**5,4**	**3,9**	**0,3**	**8,6**	**9,3**
SD	**3,2**	**2,58**	**1,83**	**3,47**	**2,45**	**3,01**	**2,87**	**2,32**	**3,57**	**0,95**	**4,7**	**4,8**

*HADS-M scores: 0–7 — normal; 8–10 — borderline; 11–21 — abnormal

severe ones included: anxiety (6.3 ± 2.4), depressed mood (5.4 ± 3.4), malaise (5.4 ± 2.3). The following symptoms were also relatively severe: fatigue (4.7 ± 2.5) and loss of appetite (4.4 ± 2.87). Shortness of breath and pain were symptoms at a similar level of severity with the mean score of 3.9 and 3.5, respectively (severe dyspnoea was present in 2 patients and severe pain also in 2 patients).

The fourth part of the questionnaire assessed the severity of anxiety and depression on the HADS-M scale. Three patients had high anxiety and depression scores, which indicated potential anxiety and depressive disorders. Four patients had borderline anxiety and depression scores, while the remaining three had low scores, indicating the absence of anxiety and depressive disorders (Table 2).

The fifth part of the questionnaire assessed the impact of rehabilitation of the functioning of the patients included in the study. Half of the patients received rehabilitation treatments at home as part of visits paid by home ventilation centre physiotherapists and four patients received rehabilitation treatments at hospital. Three patients received therapy as part of outpatient rehabilitation and two patients used paid rehabilitation services. One patient underwent therapy at another facility, namely at a sanatorium. As part of rehabilitation treatment an overwhelming majority of patients received kinesitherapy (9 patients) and traditional massage (8 patients). Half of the patients received physiotherapy (electrotherapy, phototherapy, hydrotherapy, magnetotherapy). As part of their rehabilitation programme four patients were treated with special methods: PNF (proprioceptive neuromuscular facilitation) and NDT (neurodevelopment treatment)/Bobath. The same number of patients received consultations regarding orthopaedic and rehabilitation aids (selection of ortheses, walking aids, wheelchairs and rehabilitation equipment).

Most patients (nine) declared performing rehabilitation exercises at home in accordance with the instructions provided by the physiotherapist, nurse or doctor. The details of rehabilitation treatment provided to the study patients are given in Table 3.

The impact of rehabilitation on everyday functioning of the patients was assessed on the basis of partial assessments of the impact of rehabilitation on: selected activities of daily living (such as getting dressed/undressed, hygiene, preparing of meals, writing, walking, speaking), general mood and the severity of selected symptoms. According to the responses provided, therapy led to no or hardly any functional improvement in terms of such activities as: walking, walking up and down the stairs, writing or preparing meals. A considerable or partially beneficial effect was observed in the following areas: breathing, sleep quality and pain severity. Mood also improved in 7 patients. The details of the impact of rehabilitation on individual activities are given in Table 4.

Median patient satisfaction with rehabilitation in the study group was 0.5 (range: –3 to 3). Four patients were dissatisfied with the treatment, one patient declared a neutral level of satisfaction, while 5 patients were satisfied with the treatment (with a score between 1 to 3).

Table 3. Rehabilitation treatments received by the patients enrolled in the study

Patient number	Facility providing rehabilitation treatments					Types of rehabilitation treatments					Exercises performed by the patient	
	Hospital	Out-patient clinic	Home ventilation centre	Sana-torium	Private facility	Kinesi-therapy	Mas-sage	Physio-therapy	Special methods[1]	Orthopaedic aids	Yes	No
1	X	–	–	–	–	X	X	X	–	–	–	X
2	–	–	–	X	–	–	X	X	–	–	X	–
3	–	–	X	–	–	X	X	–	–	X	X	–
4	–	X	X	–	–	X	X	X	X	X	X	–
5	–	–	X	–	–	X	X	–	X	–	X	–
6	–	X	–	–	–	X	X	X	–	X	X	–
7	–	–	X	–	–	X	X	–	X	–	X	–
8	X	–	X	–	–	X	X	X	–	–	X	–
9	X	–	–	–	X	X	–	–	–	X	X	–
10	–	–	–	–	X	X	–	–	X	–	X	-

[1]NDT Bobath, PNF

Discussion

The aim of this pilot study was to perform a preliminary assessment of the impact of rehabilitation of the functioning of patients with ALS. The study sample was small (n = 10), which may be a certain limitation as far as drawing reliable conclusions is concerned. The ALSFRS, ESAS and HADS-M scales used in the study proved to be useful research tools, as they allowed us to observe certain correlations between functional status, the severity of symptoms and the effectiveness of rehabilitation treatments. Patients with a relatively good functional status without severe symptoms gave the effectiveness of rehabilitation a much higher rating.

According to the majority of patients, rehabilitation helped them to breathe, relieved pain and improved the quality of sleep. An improvement in mental state was also observed in most patients. According to the responses provided, therapy led to no or hardly any functional improvement in terms of such activities as: walking, walking up and down the stairs, writing or preparing meals. Rehabilitation of patients suffering from ALS is mainly based on optimising their functional status so that they could face the challenges associated with the progression of their disease with as much comfort as possible [8]. Hence any dramatic improvement in the ability to perform such activities as walking, for instance, is rarely seen as a result of therapy. Of note is the fact that slightly fewer than half of the patients included in the study were receiving rehabilitation with such specialist neurorehabilitation methods as PNF or NDT/Bobath. This may be associated with the fact that rehabilitation treatments were provided by non-specialist facilities. We were also surprised by the low number (n = 4) of patients receiving consultations regarding orthopaedic and rehabilitation aids, which is one of the most important elements and tasks of rehabilitation provided to patients suffering from ALS. Selection of appropriate ortheses, equipment facilitating locomotion and equipment facilitating care provided to the completely immobilised patient is of great importance in this patient group. In addition, education on the possibilities of using appropriate accessories aiding in eating, dressing and other activities of daily living often help to quickly develop certain strategies of coping with many discomforts associated with the progressive neurologic deficit.

The assessment of satisfaction with treatment also merits discussion. Most patients (n = 6) were dissatisfied with the outcomes of rehabilitation. It might have been associated with the fact that no-one had prepared the patients for what to expect during their illness. Their expectations of the effectiveness of therapy were most likely unrealistic. This topic should be further explored in order to find the reasons for the lack of satisfaction with rehabilitation in some of the patients at a further stage of the study. While extending the study, it would be a good idea to broaden the scope of the questionnaire to include an assessment of patient expectations associated with rehabilitation.

Table 4. A summary of the impact of rehabilitation on the functioning of patients based on their own assessment

Patient number	Degree of limitation	Symptoms ESAS ≥ 7/10	Anxiety, depression HADS-M ≥ 11	Physical improvement	Improvement in the mental state	SS*
1	Invasive ventilation; PEG; patient stays in bed	Pain, depression, anxiety, shortness of breath	Anxiety Depression	None	None	-3
2	No ventilatory support; slowed functions	None	Anxiety Depression	None	None	-3
3	Non-invasive ventilation; considerable problems with locomotion; patient stays in bed	Depression, anxiety	No	Considerable or partial improvement in speech, swallowing and breathing	Partial improvement in mood	1
4	Non-invasive ventilation; considerable problems with locomotion; patient stays in bed	Anxiety	No	Slight improvement in dressing, walking, turning in bed; partial and considerable improvement in speech, swallowing, breathing and pain	Considerable improvement in mood	2
5	Non-invasive ventilation; normal functionality	None	No	Partial improvement in dressing/undressing, meal preparation, turning in bed; slight improvement in hygiene and handwriting	Partial improvement	2
6	Considerable problems with locomotion and the basic activities of daily living; patient stays in bed	Pain, tiredness, depression, anxiety	No	Minimal improvement in dressing and hygiene; partial improvement in turning in bed and breathing	None	-1
7	Non-invasive ventilation; independent functioning	None	Anxiety Depression	Slight improvement in meal preparation, handwriting, walking on even surfaces, walking up and down the stairs	None	-2
8	Non-invasive ventilation; independent functioning	Tiredness, depression, anxiety, drowsiness, shortness of breath	Anxiety	Partial improvement in breathing	None	1
9 pain	Invasive ventilation; patient stays in bed None	1	None	No	Slight improvement in	
1.	Non-invasive ventilation; PEG	Tiredness, malaise	No	Minimal improvement in dressing and hygiene	Partial improvement in mood	3

*SS — *Satisfaction Scores* (–3 ± +3)

Identification of the reasons for the low level of patient satisfaction could be helpful in communicating with the patient in general and in making the patient's expectations of rehabilitation more realistic as well as in planning an individual treatment programme.

Conclusions

Our pilot study demonstrated the main problems that ALS patients have to contend with at various stages of their illness. The results of the preliminary analysis of the impact of rehabilitation treatment on physical activity and functioning demonstrate a limited effectiveness of this treatment in this patient group. Rehabilitation should still, however, be an element of symptomatic treatment, at least because it improves mental wellbeing and offers the possibility of effective relief of such symptoms as pain or shortness of breath. It requires, however, collaboration between the doctor, physiotherapist and other persons involved in care of the patient. Effective communication, rapid identification of troublesome symptoms and effective medical intervention all offer a chance to improve the effectiveness of physiotherapy provided to ALS patients. It should be emphasised that rehabilitation treatment should be initiated

at the moment of diagnosis, in anticipation of progressive neurologic deficits, as only then are we able to better communicate with the patients and motivate them, setting realistic goals of therapy. This will allow patients to avoid disappointment associated with unrealistic expectations. In this aspect, communication between the patient and the doctor concerning the prognosis and potential complications associated with the progression of the disease is of utmost importance.

The information provided in this paper may be of value for carers and physiotherapists working with the patients, as it may enable them to increase the effectiveness of their decisions to improve the patients' comfort and quality of life.

A considerable limitation of the study was the low sample size. Continuation of the study, in accordance with the assumptions of the protocol and modifications, upon the completion of the pilot phase, of the project will make it possible to draw unequivocal conclusions.

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Box 1. PATIENT ASSESSMENT QUESTIONNAIRE

PATIENT DETAILS

1. NAME AND SURNAME: .....
2. CODE NUMBER FOR THE DETAILS OF THE STUDY SUBJECT: .....
3. AGE: ..... SEX: .....
4. DIAGNOSIS (ICD-10): .....
5. ADDRESS: .....
6. STUDY SITE*:

   [A] ..... [B] .....
7. How long have you been suffering from ALS?

   < 1 year ..... > 1 to <2 years ..... > 2 years to < 3 years ..... > 3 years .....
8. Employment status

Full-time employment ..... Part-time employment .....

Disability / old age pension ..... Unemployed ..... Other .....

* A — Home Ventilation Centre in Bydgoszcz, B — Care and Treatment Facility in Chełm

I. PATIENT FUNCTIONAL ASSESSMENT (ALSFRS*)

The Amyotrophic Lateral Sclerosis Functional Rating Scale

An assessment conducted in comparison to the patient's condition from before the diagnosis.

The degree of functional abilities corresponds with the response to the question: "How are you coping with…?"

SPEECH	
4	Normal
3	Detectable speech disturbance
2	Intelligible with repeating
1	Speech combines with non-vocal communications
0	Loss of useful speech

SALIVATION	
4	Normal
3	Slight but definite excess of saliva in mouth; may have nighttime drooling
2	Moderately excessive saliva; may have minimal drooling
1	Marked excess of saliva with some drooling
0	Marked drooling; requires constant tissue or handkerchief

SWALLOWING	
4	Normal
3	Early eating problems; occasional choking
2	Dietary consistency changes
1	Needs supplemental tube feedings
0	Nothing by mouth (NPO); exclusively parenteral or enteral feeding

HANDWRITING	
4	Normal
3	Slow or sloppy; all words are legible
2	Not all words are legible
1	Able to grasp pen but unable to write
0	Unable to grip pen

ALSFRS (continued)

CUTTING FOOD AND HANDLING UTENSILS (patients without gastrostomy)	
4	Normal
3	Somewhat slow and clumsy but no help required
2	Can cut most foods but although clumsy and slow; some help needed
1	Food must be cut by someone but can still feed slowly
0	Needs to be fed

CUTTING FOOD AND HANDLING UTENSILS (patients with gastrostomy)	
4	Normal
3	Clumsy but able to perform all manipulations independently
2	Some help needed with closures and fasteners
1	Provided minimal assistance by caregiver
0	Unable to perform any aspect of task

DRESSING AND HYGIENE	
4	Normal
3	Independent and complete self-care with effort or decreased efficiency
2	Intermittent assistance or substitute method
1	Needs attendant for self-care
0	Total dependence

TURNING IN BED AND ADJUSTING BED CLOTHES	
4	Normal
3	Somewhat slow and clumsy but no help needed
2	Can turn alone or adjust sheets but with general difficulty
1	Can initiate but not turn or adjust sheets alone
0	Helpless

ALSFRS (continued)

WALKING	
4	Normal
3	Early ambulation difficulties
2	Walks with assistance
1	Non-ambulatory functional movement only
0	No purposeful leg movement

CLIMBING STAIRS	
4	Normal
3	Slow
4	Mild unsteadiness or fatigue
1	Needs assistance
0	Cannot do

BREATHING

4	Normal
3	Shortness of breath with minimal exertion (e.g. walking, talking)
2	Shortness of breath at rest
1	Intermittent (e.g. nocturnal) ventilatory assistance required
0	Ventilator dependent*

*Please indicate if the ventilatory support is invasive or non-invasive.

II. SYMPTOM SEVERITY ASSESSMENT – ESAS

(*) The Edmonton Symptom Assessment Scale (ESAS)

Please circle the number which best describes your:

	0	1	2	3	4	5	6	7	8	9	10
Pain:	0	1	2	3	4	5	6	7	8	9	10
Tiredness:	0	1	2	3	4	5	6	7	8	9	10
Nausea:	0	1	2	3	4	5	6	7	8	9	10
Depression:	0	1	2	3	4	5	6	7	8	9	10
Anxiety:	0	1	2	3	4	5	6	7	8	9	10
Drowsiness:	0	1	2	3	4	5	6	7	8	9	10
Appetite:	0	1	2	3	4	5	6	7	8	9	10
Well-being:	0	1	2	3	4	5	6	7	8	9	10
Shortness of breath:	0	1	2	3	4	5	6	7	8	9	10
Other problems:	0	1	2	3	4	5	6	7	8	9	10

III. ANXIETY AND DEPRESSION SEVERITY ASSESSMENT – HADS-M*

HADS-M – The Hospital Anxiety and Depression Scale, Modified

Tick the box with the reply which comes closest to how you have been feeling in the past week. Don't take too long over your replies. Your immediate reaction to each item will probably be more accurate than a long thought-out response.

I. I feel tense or wound-up

Most of the time .....
A lot of the time.....
From time to time .....
Not at all .....

II. I still enjoy the things I used to enjoy

Definitely as much.....
Not quite so much .....
Only a little.....
Hardly at all.....

III. I get a sort of frightened feeling as if something awful is about to happen

Very definitely and quite badly
Yes, but not too badly
A little, but it doesn't worry me
Not at all

IV. I can laugh and see the funny side of things

Not at all
Not often
Sometimes
Most of the time

V. Worrying thoughts go through my mind

A great deal of the time
A lot of the time
From time to time but not too often
Only occasionally
Not at all

VI. I feel cheerful

As much as I always could
Not quite so much now
Definitely not so much now
Not at all

VII. I can sit at ease and feel relaxed

Nearly all the time
Very often
Sometimes
Not at all

VIII. I feel as if I'm slowed down

Definitely
Usually
Not often
Not at all

IX. I get a sort of frightened feeling

Definitely
Usually
Not often
Not at all

X. I have lost interest in my appearance like "butterflies" in my stomach

Not at all
From time to time
Quite often
Very often
Definitely
I don't take so much care as I should
I may not take quite as much care
I take just as much care as ever

XI. I feel restless as if I have to be on the move

Very much indeed
Quite a lot
Not very much
Not at all

XII. I look forward with enjoyment to things

As much as every I did
Rather less than I used to
Definitely less than I used to
Hardly at all

XIII. I get sudden feelings of panic

Very often indeed
Quite often
Not very often
Not at all

XIV. I can enjoy a good book or radio or TV programme

Often
Sometimes
Not often
Very seldom

XV. I have had outbursts of anger in the past week

Often
Sometimes
Rarely
Not at all

XVI. I have become irritated and angry in the past week

Often
Sometimes
Rarely
Not at all

IV. THE IMPACT OF REHABILITATION ON THE PATIENT'S FUNCTIONING

The questions the patient is asked apply to the period following the diagnosis.

1. Have you received rehabilitation treatments as part of the treatment plan for your illness?

YES ..... NO .....

2. Where were these rehabilitation treatments given?

At a hospital (neurology, rehabilitation ward) .....

Outpatient rehabilitation .....

Home Ventilation Centre .....

Private rehabilitation services (home visits, visits to a rehabilitation facility) .....

Other (please specify):.....

3. Which rehabilitation treatments have you received?

Kinesitherapy .....

Kinesitherapy using special methods (e.g. PNF, NDT Bobath for adults, S-E-T) .....

Massage Physiotherapy .....

Orthopaedic/rehabilitation aids (locomotion aids, self-fare aids etc.).....

Other (please specify):.....

4. Do you exercise at home?

YES ..... NO .....

4.a. How often do you exercise independently at home?

1-2 times a week..... 3-4 times a week..... Every day .....

5. Have you been instructed regarding exercises you can independently perform at home?

YES ..... NO .....

5.a. Who has given you the instructions?

A physiotherapist .....

A nurse .....

A doctor.....

Another person.....

Other .....

6. How would you rate the impact of your rehabilitation treatments on your everyday functioning?

Activities of daily living:	SIGNIFICANT IMPROVEMENT	PARTIAL	SLIGHT IMPROVEMENT	NO FFECT IMPROVEMENT	WORSENING	DON'T KNOW
Dressing/undressing						
Hygiene (washing, using the toilet)						
Preparing meals on your own						
Writing						
Walking on an even surface						
Walking up/down the stairs						
Speech						
Swallowing						
Turning in bed						
Breathing						
Sleep						
Mood						
Pain						
Social contacts						
Other activities not mentioned in the table:						
Please specify:						

7. Assessment of treatment satisfaction

How would you rate the treatment? (–3 → +3)