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Patient satisfaction in rehabilitation of patients with multiple sclerosis

ORIGINAL ARTICLE

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Background.

The motor and non-motor symptoms of multiple sclerosis often result in a substantially reduced health-related quality of life. We surveyed patient satisfaction and own evaluation of the benefit of a period spent at a specialised rehabilitation centre.

Material and method.

All patients who spent a period at the Multiple Sclerosis Center Hakadal in 2010 were asked to complete a validated questionnaire designed to determine patient satisfaction with rehabilitation institutions.

Results.

Of a total of 339 patients, 277 (82 %) returned the questionnaire. The great majority of respondents were satisfied with the knowledge, cooperation, care and engagement of those providing treatment, as well as with the advance information provided and the premises. They also found that they were consulted concerning their rehabilitation programme and that they were prepared for the period following their stay. More than 85 % of the respondents stated that the stay would have major or very great importance for their general quality of life and physical health. A similar score for mental health was given by 83 %, mastery of day-to-day tasks by 77 % and participation in social activities by 71 %.

Interpretation.

Patients who have had stays at the Multiple Sclerosis Center Hakadal are satisfied and feel that the stay will be of great importance to their level of functioning and mastery.

More than 7000 people in Norway suffer from multiple sclerosis (MS) (1), which is the most frequently occurring disease causing neurological disability in young adults. The disease strikes women approximately twice as frequntly as men, and often has its onset in the age group 20 – 40 years. In spite of therapeutic progress, most patients develop symptoms that reduce their health-related quality of life considerably (2). In addition to motor symptoms leading to reduced mobility, spasticity and coordination, problems such as urinary disorders (urge incontinence and urinary retention), problems with bowel motility (constipation and faecal incontinence), sexual dysfunction, neuralgic pains, depression and fatigue occur frequently (3). Approximately 70 per cent of patients develop cognitive symptoms, most frequently in the form of problems related to memory, complex attention, processing speed and executive functions (4, 5).

The Multiple Sclerosis Center Hakadal is a national rehabilitation centre dedicated to people suffering from MS. The centre provides rehabilitation programmes lasting three to four weeks, as well as shorter information courses for patients who have recently been diagnosed, and communication courses for couples. To promote group dynamics and opportunities for peer interaction, all patients staying for the same period arrive and depart at the same time. The patients are followed up by an interdisciplinary team comprising a neurologist, a physiotherapist, nursing staff, an occupational therapist and a social worker. During their stay, all patients will have at least two individual consultations with the neurologist, and will be followed up by the physiotherapist with an individually adapted training programme. There are daily options for group sessions and lectures about various MS-related topics, and opportunities for a neuropsychological examination, consultations with the psychologist, individual nutritional advice, acupuncture and group discussions. The patients vary in their need to consult the psychologist, the neuropsychologist and the nutritionist, and the opportunity to contact these professions is more restricted. The centre aims to establish an open, solution-oriented dialogue between the patient and the interdisciplinary team, in which results from the interdisciplinary examination are discussed with the patient in light of his or her life situation, needs and wishes. Individual goals and measures are defined at the start of the rehabilitation programme, and the achievement of these goals is evaluated before departure from the centre. Examples of individually adapted rehabilitation programmes include rehabilitation with a work-oriented focus and rehabilitation with a cognitive focus.

We have limited knowledge of the effect of various rehabilitation measures. A relatively recent literature review nevertheless concluded that there was «strong evidence» to suggest that a stay in an interdisciplinary rehabilitation centre had a positive effect on level of activity and coping (6). It has previously been shown that physical treatment at the Multiple Sclerosis Center Hakadal improves motor functions (7). The purpose of this study was to identify patient satisfaction with and perceived benefits of a specialised rehabilitation programme at the Multiple Sclerosis Center Hakadal.

Material and method

All patients who were admitted to a rehabilitation programme in 2010 were asked to complete an anonymous evaluation questionnaire at the end of their stay (appendix). The questionnaire was elaborated by the Norwegian Knowledge Centre for the Health Services after a request from the specialised health institutions, and is intended to measure the patients' satisfaction with training institutions, health and sports centres and rehabilitation institutions (8). The questionnaire has pre-set response alternatives for each question, and most of the questions also include opportunities for supplementary comments.

The reliability and validity of the questionnaire were assessed as satisfactory by a pilot study comprising 371 patients in a total of eight rehabilitation institutions (8). Since the Multiple Sclerosis Center Hakadal also has an affiliated psychologist and a neuropsychologist, additional questions pertained directly to contact with these professions. The patients were informed that participation in the study was voluntary, and that the resulting data would be used for purposes of quality assurance at the Multiple Sclerosis Center Hakadal. Pursuant to the Health Research Act, the study was perceived as part of the centre's quality assurance and not as a research project, and was therefore not submitted to the Regional Committee on Medical Research Ethics for approval. Missing responses to individual items were not followed up.

Results

During the period of study a total of 339 patients (217 women and 122 men) with an average age of 45 years completed a four-week rehabilitation programme. Of these, a total of 277 patients (171 women, 91 men, 17 with gender not stated) filled in the questionnaire. The total response rate was thus 82 per cent.

The reported distribution of contacts with the various professions is shown in figure 1.

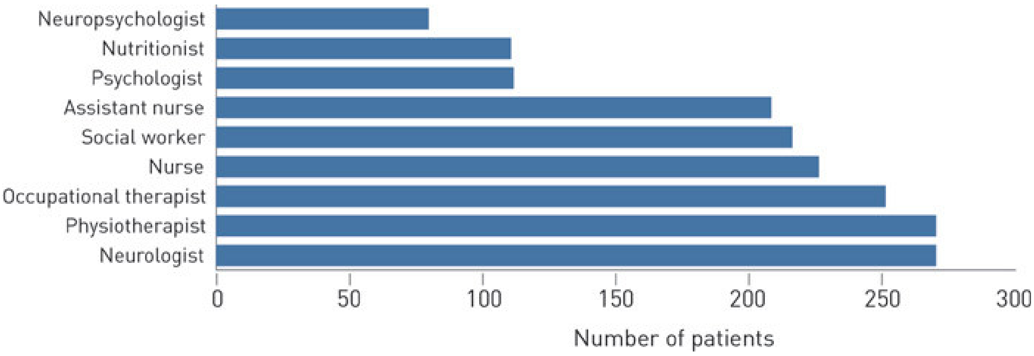

Figure 1: The patients' reporting of contact with groups of professionals at the Multiple Sclerosis Center Hakadal

The patients' assessments of advance information, organisation, opportunity to influence their stay and the follow-up provided by therapists are shown in table 1. The proportion of respondents who expressed satisfaction ranged from 77 to 97 per cent for the various aspects. Supplementary comments provided by patients who were dissatisfied with the therapists tended to focus on a perception of insufficient competence and involvement by the doctor. A total of five patients expressed dissatisfaction with the centre's doctor. Dissatisfaction regarding a lack of continuity among the physiotherapists was voiced by three patients who had attended a stay during which there had been an unusual amount of absence by this profession. This apart, there were no recurring elements in the critical comments. Some claimed that the stay was too long, others that it was too short; some found the programme too intensive, some claimed that it was not intensive enough. Some patients pointed to a lack of advance information regarding the opportunity for training in the swimming pool, the limited capacity for rehabilitation with a cognitive focus and insufficient communication of the centre's provision of separate courses for couples.

Table 1:

Satisfaction with various aspects of the rehabilitation programme. The number of missing responses among all respondents totalled from 7 to 35 for the various questions.

	Yes	No
	Number (%)	Number (%)
Did you receive sufficient advance information on your stay?	224 (81)	27 (10)
Are you satisfied with the length of your stay?	213 (77)	32 (12)
Did you perceive the therapists whom you encountered as professionally competent?	255 (92)	14 (5)
Did you feel that you were included in the process of setting goals and determining the programme for your rehabilitation?	268 (97)	2 (1)
Did you feel that the therapists were interested in your description of your own situation?	266 (96)	4 (1)
Did the therapists provide sufficient guidance on how you can cope with challenges arising from your condition?	262 (95)	5 (2)
Did you feel that the therapists cooperated appropriately with regard to your rehabilitation?	238 (86)	8 (3)
Were you prepared for the time after the rehabilitation programme?	229 (83)	13 (5)
Did you perceive the centre's work as well organised?	242 (87)	4 (1)
Were you satisfied with the schedule for your activities during your stay?	224 (81)	24 (9)
Was the schedule followed up as planned?	248 (90)	21 (8)
Were the premises of the centre adapted to your needs?	260 (94)	9 (3)
Were the outdoor areas adapted to your needs?	256 (92)	10 (4)
Did you have the impression that the equipment used for rehabilitation was kept in good repair?	249 (90)	5 (2)

The patients' assessment of the benefits of the rehabilitation programme with regard to quality of life, mental and physical health, coping and participation in daily life is shown in table 2. More than 85 per cent of the respondents gave the highest or the second highest score regarding the benefits of the stay for their general quality of life and physical health. Corresponding scores for mental health were entered by 83 per cent, for coping with daily activities by 74 per cent and for participation in social activities by 71 per cent.

Table 2:

Patients' assessments of the benefits of the rehabilitation programme (1 = to a small extent, 4 = to a great extent). The number of missing responses totalled from 11 to 24 for the various questions.

To what extent do you think that the programme will benefit your:	**1**	**2**	**3**	**4**
Quality of life in general?	1	18	115	123
Physical health?	2	23	124	116
Mental health?	15	22	124	105
Coping with daily activities?	8	40	117	88
Participation in social activities?	22	40	91	107

Discussion

This study shows that most of those who have attended a four-week specialised rehabilitation programme at the Multiple Sclerosis Center Hakadal are satisfied with their stay and believe that it will have a positive effect on their general quality of life, their physical and mental health, their ability to cope with daily tasks and their participation in social activities.

Increasing importance is ascribed to so-called patient-centred outcomes as a quality indicator in the health services (9), including in treatment of MS (10). Patient satisfaction depends on the patient's expectations, processes in the encounter between the patient and the therapist, structural and organisational aspects of the health institution, as well as the patient's perception of treatment outcome. It has been claimed that patients most often have no qualifications for assessing the professional standard of diagnostics and treatment, and will therefore tend to emphasise their perception of care, participation, premises and food (11). It has also been pointed out that high patient satisfaction not necessarily reflects high professional standards, for example because patients may have unreasonable demands, the compliance with which could be more or less wrong or even harmful (12). Unfortunately, we have no knowledge as to whether patient satisfaction is correlated with other measures of treatment effectiveness, such as physical function, need for assistance or employment after discharge. Neither can we tell how long the level of satisfaction upon discharge tends to endure. An exclusive focus on patient satisfaction after the end of the stay may thus be a poor guideline for setting priorities in the health services (13).

On the other hand, it is far from obvious that outcomes defined by the therapist will provide a more truthful or relevant impression of the quality of rehabilitation programmes for chronic and serious diseases such as multiple sclerosis, for which more objective measures such as employment and independence from the health and care services tend to be utopian. It is also worth noting that an improvement in the ability to function physically, which can be quantified fairly easily with the aid of objective tests, is not necessarily correlated with health-related quality of life (7). Patient satisfaction therefore represents a value in itself, independent of outcomes defined by the therapist.

The majority of the patients at the Multiple Sclerosis Center Hakadal are relatively familiar with the centre before arrival, for example through previous admissions. This may give rise to a selection of patients who are satisfied with the forms of treatment provided, so that a high level of patient satisfaction may appear to be a self-fulfilling prophecy. It is therefore important to identify the needs and expectations of rehabilitation also among patients who do not apply for existing rehabilitation programmes.

Even though cognitive symptoms occur frequently in patients suffering from multiple sclerosis, we have little knowledge of what interventions are the most appropriate (14, 15). The Multiple Sclerosis Center Hakadal has developed a model for cognitive rehabilitation, and some of the participants presented in this article also participated in a prospective evaluation of this model. The model comprises a neuropsychological examination and weekly individual consultations with the neuropsychologist and the occupational therapist, as well as group-based training, practical exercises and sharing of experiences. The participants receive advice on how to establish goals for coping with cognitive challenges in daily situations, and after discharge they are followed up with telephone conversations focusing on goal achievement. Only one-third of the patients in our study reported having had contact with a psychologist or a neuropsychologist. This is partly a reflection of the fact that there is limited availability of these professions, which is backed up by feedback from some patients who were dissatisfied with not having been granted cognitive rehabilitation as desired. Neither did all the patients report having been in contact with a doctor or a physiotherapist, even though all patients have individual consultations with these professionals. It is possible that this reflects dissatisfaction with the contact with these professionals on the part of some patients. However, this assumption is not supported by corresponding free-text comments provided by those who reported not having seen a doctor or a physiotherapist.

The strengths of this study rest in its high participation rate and a high response rate for each question, as well as its use of a validated questionnaire. We may therefore assume that the results are representative of the patients who were admitted to the Multiple Sclerosis Center Hakadal during the period of study. On the other hand, the study also has some limitations. Many of the questions were of such a general nature that they are not very suitable for identifying aspects of the rehabilitation programme that possibly ought to be amended. Since all but a few of the patients were satisfied with their stay, we have too little variance in the material to conduct a statistical analysis in order to detect correlations between the responses to the various questions. Moreover, we have no longitudinal data that could allow for investigation of whether changes to procedures have had an effect on patient satisfaction. A further limitation is that factors such as age, gender and degree of disability in individual respondents were not identified, and we can therefore draw no conclusions as to whether the programme should be adjusted with regard to certain groups of patients (16). However, this is likely to be less important, since the vast majority of the patients were satisfied. Neither have we investigated other outcomes, and can therefore not conclude whether patient satisfaction is correlated to better ability to function, health-related quality of life or other relevant measures for the effect of the rehabilitation programme.

Appendix

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Tabell

Main message

- The patients admitted for rehabilitation at the Multiple Sclerosis Center Hakadal were on the whole very satisfied with the organisation of the programme and the follow-up by the therapists.
- Most of them believed that the stay would be of great importance to their quality of life, their mental and physical health and their ability to cope with daily activities.

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