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SELF-PERCEIVED PERFORMANCE AND SATISFACTION WITH PERFORMANCE OF DAILY ACTIVITIES IN PERSONS WITH MULTIPLE SCLEROSIS FOLLOWING INTERDISCIPLINARY REHABILITATION

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ABSTRACT

Purpose: To assess self-perceived performance and satisfaction with performance of daily activities in persons with multiple sclerosis (MS) on admission to and at discharge from interdisciplinary rehabilitation.

Method: A retrospective study with a pre-post design. Twenty-seven women and 16 men with MS (mean age 51 years; median EDSS 6.5) participated in an individualised, goal-oriented, interdisciplinary, rehabilitation programme (average length 4 weeks). The Canadian Occupational Performance Measure (COPM) was used on admission to rehabilitation and at discharge.

Results: On admission, the persons prioritised 216 activities that they perceived difficult to perform (mean number 3, range 2-8). Of these, 136 (63%) were in the COPM area of self-care, 52 (24%) in productivity and 28 (13%) in leisure. The lowest mean ratings of performance were found in the subgroups active recreation, community management and socialisation, and for satisfaction in the subgroup socialisation. For about 60% of the 216 prioritised activities, ratings of COPM performance as well as satisfaction were higher at discharge than on admission. For 18 (42%) and 24 (56%) persons, respectively, the mean change scores of performance and of satisfaction were equal to or greater than 2.0 at discharge, indicating a clinically significant change.

Conclusions: Persons with MS can experience problems with all types of daily activities upon admission to rehabilitation, but also perceive improvements in their performance and satisfaction with performance in these activities at discharge from rehabilitation. Using patient-reported outcome measures, such as the COPM, may contribute to a broader understanding of the benefits of interdisciplinary rehabilitation in persons with MS.

247 words

KEYWORDS

Multiple sclerosis; Activities of daily living; Rehabilitation; Canadian Occupational Performance Measure (COPM)

INTRODUCTION

Multiple Sclerosis (MS) is a chronic progressive neurological disorder that can lead to a complex disability pattern and many persons with MS can experience limitations in their daily activities [1, 2]. Despite the development of disease modifying treatment for the early phases of MS, rehabilitation still remains the main intervention for a majority of people with a more advanced disease course. Several studies have described the effects of in-patient rehabilitation in persons with MS [3-5]. In a recent Cochrane review [6], the outcome of these studies was summarised and it was concluded that there is strong evidence that in-patient rehabilitation has an effect on activity and participation, but not on body functions. Even though it is well-known that rehabilitation can positively influence the disability of persons with MS, there are many aspects of the rehabilitation process that have not been studied in detail [7].

One aspect is that the assessment tools previously used only cover some areas of disability, as defined by the WHO International Classification of Functioning, Disability and Health (ICF) [8]. For example, the Functional Independence Measure (FIM), which assesses self-care, was the only assessment tool used representing the ICF domain 'activity' [3-5]. It is well known that persons with MS can experience a complex disability pattern, particularly related to activity and participation. Studies that have evaluated the persons' own perception of their disability found that they experienced problems related to all areas of daily life activities, i.e., self-care and household management, as well as work and leisure [9, 10]. Also, persons with MS described a complexity of their activity limitations, from very specific parts of task performance to more overarching problems comprising a sequence of task performances in many different activities [10]. Consequently, there is a need to undertake studies that also reveal if and how the performance in other activities changes following rehabilitation.

All of the studies included in the Cochrane review [6] used a multidisciplinary approach to rehabilitation, i.e., different professions work in parallel with each other, but not necessarily towards a mutual goal. This is different from an interdisciplinary approach, where professionals work together on the same hierarchical level and with the patient's goals in focus, an approach that is now advocated [11]. Another aspect is the use of a client-centred approach in modern goal-oriented rehabilitation, which also influences the choice of outcome measures. Today, patients take an active part in the planning of their interventions, which enable the setting of individual goals that focus on issues related to activity and participation. Consequently, patient-reported outcome

measures (PROMs), such as the Goal Attainment Scale (GAS), are commonly used [12, 13].

A commonly used PROM in rehabilitation is the Canadian Occupational Performance Measure (COPM) [14]. It is designed to capture problems in relation to activity and participation, by assessing a person's self-perception of their performance and satisfaction with performance of daily activities. The COPM can both support a person with a disability to define goals that should be targeted during rehabilitation and can be used to evaluate different interventions [15-22]. In persons with MS, one study used the COPM and evaluated the effects of a single intervention, namely how a drop-foot stimulator could enhance performance in activities of daily living [22]. However, our knowledge of how persons with MS perceive their performance and satisfaction with performance of daily activities following interdisciplinary rehabilitation is non-existing. Such knowledge would enable rehabilitation professionals, in collaboration with persons with MS, to design and implement appropriate rehabilitation interventions.

The overall aim of this study was to assess self-perceived performance and satisfaction with performance of daily activities in persons with MS on admission to and at discharge from interdisciplinary rehabilitation.

MATERIAL AND METHODS

Sample

This is a retrospective study and all data were retrieved from a database in the clinic. A total of 27 women and 16 men who had been admitted to a period of comprehensive goal-oriented interdisciplinary rehabilitation in a university hospital rehabilitation medicine clinic were included. The inclusion criteria were: i) clinically definite MS; ii) a stable disease course with no recent relapses; iii) no other disease that would significantly impact on their disability; and iv) a COPM assessment made on admission to and at discharge from rehabilitation. Participants were included over a three year period. A total of 121 persons were admitted and 43 met the inclusion criteria. The characteristics of the 43 persons are presented in Table 1. All persons were community-dwelling, seven were classified as relapsing-remitting MS (RRMS), 32 had secondary progressive MS (SPMS) and four had a primary progressive MS (PPMS).

[Insert Table 1 about here]

Ethics

At the time of admission, each person gave their written informed consent to be included in a database at the clinic and that data could be used in clinical studies. The principles of the Helsinki Declaration were followed.

The MS rehabilitation programme

The overarching goal of the MS rehabilitation programme was to reduce self-perceived disability. Prior to admission, each person that was referred to the programme was assessed by the treating rehabilitation team. The team comprised a rehabilitation medicine physician, a physiotherapist, an occupational therapist and a social worker, all with experience of interdisciplinary rehabilitation for persons with MS. During a one-day visit to the clinic, the persons' needs were evaluated in order to plan the upcoming comprehensive goal-oriented interdisciplinary rehabilitation period. Upon admission, each person was then assessed in-depth by each team member. The assessment focused on the nature and extent of the persons' disability and their motivation to actively participate in the goal-setting process. Based on this assessment, the content during the rehabilitation period was customised according to the needs of the person. Goals, related to participation in different types of daily activities, were set and a rehabilitation plan, based on the International Classification of Functioning, Disability and Health (ICF) [8], was written together with each person. In this plan, the person's problems, resources, goals and interventions, according to his/her needs, were listed. During the rehabilitation period, different interventions, such as symptomatic management and medication, patient education, person and group exercises on land and in water, social and psychological counselling, prescription of assistive devices and adaptations, and learning of compensatory techniques during performance in self-care, household management, work, and leisure, were given. At discharge, the rehabilitation plan was evaluated and a plan for further interventions in the community as well as follow-ups at the clinic was made. As a result of this individualised, yet standardised procedure with individually set goals that took variable amount of time to achieve, the length of the rehabilitation for the participants in the present study period varied from 2 to 12 weeks (mean 4 weeks).

Canadian Occupational Performance Measure (COPM)

The COPM enables a client-centred approach when rehabilitation goals are planned, set and evaluated [14]. It is valid and reliable for different populations including persons

with MS [22-27]. The COPM is administered through a semi-structured interview where the person reports those daily activities that he/she perceives difficult to perform. The COPM includes activities in three areas, each comprising three subgroups: i) self-care (personal care; functional mobility; community management); ii) productivity (paid/unpaid work; household management; play/school); and iii) leisure (quiet recreation; active recreation; socialisation). Activities that are difficult to perform are noted in the interview guide and within the appropriate COPM area. After that, the person rates the importance of each activity on a 10-point Visual Analogue Scale (VAS), ranging from 1 (not important) to 10 (most important). According to the COPM manual [14], the person selects the five most important activities and ranks them according to degree of priority. In this study, the participants were allowed to prioritise as many activities as they wanted, as part of the rehabilitation programme. The person's self-perceived performance and satisfaction with their performance are then rated on the VAS, ranging from 1 ("not able to do" or "not satisfied") to 10 ("able to do extremely well" or "extremely satisfied"). After an intervention or a rehabilitation period, the performance and satisfaction with performance in the selected activities are again rated on the VAS. When the COPM is used as an outcome measure, each person's ratings of performance and satisfaction with performance are summarized and mean values, representing an overall score, are calculated. Previous research, with a mixture of participants, has described that a change score of at least 2.0 is a clinically important change [19, 28].

Procedure

Within the first three days of admission, assessments of disease severity using the Expanded Disability Status Scale (EDSS) [29]) was performed by the responsible physician and the COPM was administered by the treating occupational therapist. All prioritised activities within each COPM occupational area and subgroup were noted, and ratings of performance and satisfaction with performance together with the overall scores were registered. All data and information on each participant collected by the other team members were entered into the database as part of the clinic's international accreditation (Commission on Accreditation of Rehabilitation Facilities, CARF), and subsequently retrieved for analysis. At the end of the rehabilitation period, one to three days prior to discharge, the COPM was again administered by the treating occupational therapist. The performance and satisfaction with performance in the selected activities were rated on the

VAS, and the ratings and calculated overall scores were registered and entered into the database.

Data and statistical analyses

For each person, the prioritised activities within each COPM occupational area and subgroup were summarised. The COPM ratings are ordinal data, but according to the manual and in general practice, they are treated as continuous variables [14]. Thus, mean values for each person's score of performance and satisfaction, respectively, were calculated. Since the sample was small and may not represent a normal distribution, non-parametric statistics were applied: a Kruskal-Wallis test was used to evaluate differences in the ratings of importance of prioritised activities in the three COPM occupational areas and relationships were analysed using the Spearman's rank correlation coefficient. Throughout, significance levels smaller than 5% are considered significant. All statistical analyses were performed with the SPSS version 18.0

RESULTS

COPM on admission to rehabilitation

A total of 347 activities (mean 8 per person, 3 to 15) were identified as difficult to perform, and of these 216 activities were prioritised (mean 3 per person, 2 to 8). The number of prioritised activities in each occupational subgroup is presented in Table 2. The highest number was found in the COPM area self-care (63%), followed by productivity (24%) and leisure (13%). Among the nine COPM subgroups, personal care (29%), functional mobility (26%), and household management (22%), accounted for more than two thirds of all the prioritised activities.

The ratings of importance for the prioritised activities were generally high, and there were no significant differences between the three different COPM areas. The highest ratings were in work (mean 9.4; range 9 to 10) and socialisation (mean 9.4; range 6 to 10), and the lowest in quiet recreation (mean 8.0; range 5 to 10) and community management (mean 8.2; range 4 to 10). Since none of the persons perceived any activity problems in the subgroup play/school, this was not included in the ratings.

The mean ratings of performance varied from 1.7 to 4.4, with the highest in personal care (4.4), followed by paid/unpaid work (4.2) and household management (4.2). The lowest mean ratings were found in the subgroups active recreation (1.7),

community management (3.2) and socialisation (3.2) (Table 2). For satisfaction, the mean ratings varied from 1.5 to 4.4, with work as the highest and socialisation the lowest.

[Insert table 2 about here]

COPM at discharge from rehabilitation

For 131 (61%) of the 216 prioritised activities, ratings of COPM performance were higher at discharge, for 71 (33%) activities ratings were unchanged and for 14 (6%) ratings were lower than on admission. For satisfaction, 130 (60%) of the 216 activities were rated higher at discharge, for 78 (36%) activities ratings were unchanged and for 8 (4%) ratings were lower than on admission.

In Table 2, the number of activities in each COPM area and subgroup where the ratings at discharge were equal to or greater than 2.0, indicating a clinically important change, is presented. For performance and satisfaction, respectively, the number of activities that were rated higher at discharge in the three COPM areas varied from 41% to 53% (46% of the 216 activities) and from 38% to 52 % (49% of the 216 activities).

In Figure 1, the mean scores on admission and discharge for performance and satisfaction for each person are presented; the dotted line indicates a change score of 2.0, the cut-off limit for a clinically important change. For 18 (42%) of the 43 persons, the mean change scores for performance were equal to or greater than 2.0 at discharge, and for 24 (56%) of the 43 persons, the mean change scores for satisfaction were equal or greater than 2.0 at discharge. There was a significant correlation between changes in performance and in satisfaction from admission to discharge ($rho=0.85$; $p<0.001$), and for 16 of the 43 persons (37%) the mean change scores for both performance and satisfaction were equal to or greater than 2.0 at discharge. There were no significant correlations between performance on admission and the difference at discharge or between satisfaction on admission and the difference at discharge, and no significant correlation between the changes from admission to discharge and the length of the rehabilitation period.

[Insert the figure about here]

DISCUSSION

The overall aim of the present study was to assess self-perceived performance and satisfaction with performance of daily activities in persons with MS on admission to and

at discharge from interdisciplinary rehabilitation. The main findings were that the participants on admission to rehabilitation reported a variety of problems with daily activities. At discharge, 42% and 56%, respectively, of the participants rated that their performance and satisfaction with performance had increased 2.0 or more scores, indicating a clinically significant change. There is a lack of knowledge regarding how rehabilitation can contribute to an enhanced performance in domestic life activities [30]. As our study focussed on all daily activities, it can contribute to an enhanced understanding of how persons with MS experience activity limitations in relation to domestic life, and how self-perceived performance and satisfaction in these types of activities change after interdisciplinary rehabilitation.

About three quarters of all activities that the participants reported to have problems with were related to personal care, functional mobility and household management. This is in agreement with two studies of persons with MS that also used the COPM and reported problems with these types of activities [9, 10]. Similarly, a study using the COPM to validate the ICF Core Sets for MS, found that personal care, domestic life and mobility together accounted for more than 60% of all reported activity and participation problems [31]. In the study by Esnouf et al. [22], only activity problems related to each COPM area but not each subgroup were reported. This makes it difficult to compare our results on a subgroup level with the results in the study by Esnouf et al. [22]. However, it was found that self-care (personal care, functional mobility and community management) was the major area of concern (76%) [22]. Similar results have also been reported in studies with other neurological disorders [15-21]. Taken together, it is not surprising that self-care are reported as most problematic as these activities are among the most relevant for independent living, and people with disabilities naturally require support to improve their performance in this area [6].

The ratings of importance were generally high which indicates that the participants wanted to engage in activities that they find meaningful and purposeful. Furthermore, ratings of performance and satisfaction were generally low throughout the different COPM subgroups. This is also in agreement with previous studies using the COPM in persons with MS [9, 10], and compared to the median scores presented by Esnouf et al [22]. This emphasizes the importance to acknowledge problems related to the broad spectrum of activities of daily living, from personal care to leisure, during rehabilitation of persons with MS.

Following rehabilitation, about a third of the participants rated both their performance and satisfaction equal to or greater than 2.0 at discharge. This cut-off limit was developed in a pilot study by Law et al. [28], where the clinical utility as well as the responsiveness of the COPM was investigated. The authors concluded that since the mean change scores for both performance and satisfaction were approximately 1.5 times the standard deviation in scores – which equals a change of approximately 2.0 – the COPM is sensitive to change. Thus, our findings of an improvement of 2.0 or more in as much as a third of all the participants, indicates a clinically important change for both performance and satisfaction in these persons. As previous studies with the COPM have presented their results differently, results are difficult to compare. Overall, though, our results are either higher or lower than previous studies.

Only one study has used the COPM to evaluate the outcome after an intervention in persons with MS [22]. This study found that 17% of the reported activity problems in the control group (exercise only) and 35% in the intervention group (drop-foot stimulator) increased of 2.0 or more in both performance and satisfaction. This is lower than in the present study where more than 40% of the activities had increased 2.0 or more scores.

There are a number of limitations to this study. No control group was included. However, to understand the relationship between an intervention, the person and the outcome, an RCT may not always be the most appropriate design [32]. Our main aim was not to assess if interdisciplinary outpatient rehabilitation had any effect on the daily lives for MS-persons, but instead to assess their self-perceived performance and satisfaction with performance in daily activities on admission to and at discharge from interdisciplinary rehabilitation. This study had a retrospective design and a set of specific inclusion criteria were defined. Therefore, some data were not available, such as what goals that were set during rehabilitation, and not all persons treated by the team were included in the study. The assessments were performed by the same staff that performed the intervention. Moreover, the present study did not include any follow-up assessments, and therefore we do not know if the participants' performance and satisfaction scores were maintained or had changed after discharge. Many rehabilitation interventions are made in the person's own environment, e.g., housing adaptations or prescriptions of assistive devices. This requires that the person has the possibility to try these adaptations in their own home. Thus, an enhanced performance due to a housing adaption or an assistive device may only be captured at follow-up, several weeks after discharge.

In conclusion, this study confirms that persons with MS can experience difficulties in all their daily activities, but also that they can perceive improvements in their performance and satisfaction with performance in these activities at discharge from rehabilitation. Our results also indicate that the use of PROMS, such as the COPM, may contribute to a broader understanding of the benefits of interdisciplinary rehabilitation in persons with MS.

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DECLARATION OF INTEREST

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Table 1. Characteristics of the 43 persons with multiple sclerosis (MS).

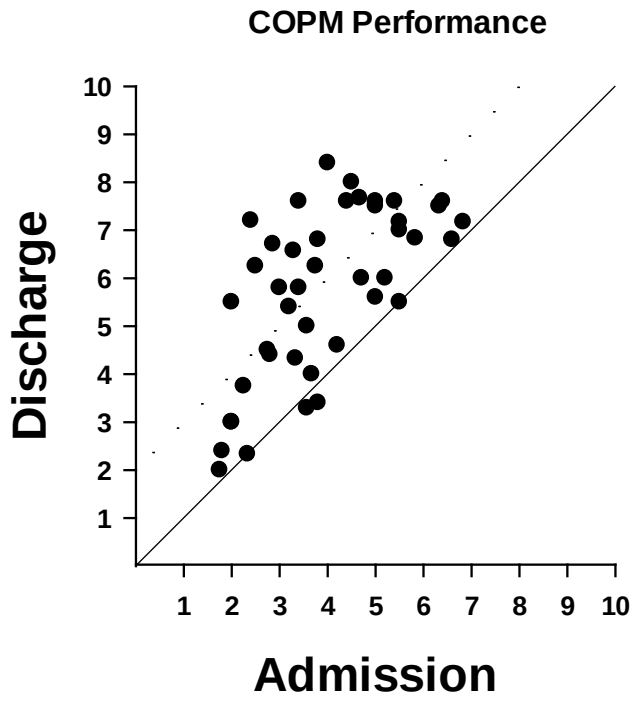
	Men	Women
Sex	16	27
Age (years)		
Mean (±SD), range	48 (10), 22-60	53 (11), 30-69
Years since MS onset		
Mean (±SD), range	15 (9), 1-33	18 (12), 0-50
Type of MS (N)		
Relapsing remitting (RRMS)	1	6
Secondary progressive (SPMS)	14	18
Primary progressive (PPMS)	1	3
EDSS score[a]		
Median, range	6.5, 5.5-7.5	6.5, 3.0-8.0
Marital status (N)		
Married or co-habiting	9	23
Single	7	4
Marital status (N)		
Living alone	5	5
Living with another person (partner, spouse, parent)	11	22
Living condition (N)		
Living in a flat	8	12
Living in a house	8	15
Vocational situation (N)		
Working part time or full time, with no disability pension	2	1
Working part time, with part time temporary or permanent disability pension	3	5
Full temporary or permanent disability pension	10	16
Not working (old-age pension, un-employed, housewife)	1	5
Social support and/or home help (N)		
No assistance or help from relative	7	14
Assistance less than 1 time/week	4	5
Assistance 1-3 times/week	2	3
Assistance more than 3 times/week	3	5

[a] The EDSS rates the disease severity of MS, where 0-5.5 represents early stages of the disease with no assistance during walking, 6.0-6.5 uni- or bilateral assistance, walking ability approximately 100 meter, 7.0-7.5 severely restricted walking ability, 8.0-8.5 cannot walk at all, are restricted to chair/wheelchair (25).

Table 2. The number of prioritised activities (N=216) that the 43 persons with multiple sclerosis (MS) perceived as difficult to perform according to the Canadian Occupational Performance Measure (COPM), their ratings on admission and discharge, and the number of ratings that had improved 2 scores or more.

	Performance				Satisfaction		
	N (%)	On admission	At discharge	Number of ratings ≥2 (%)	On admission	At discharge	Number of ratings ≥2 (%)
Self-care							
Personal care	63 (29)	4.4 (1-10)	6.4 (1-10)	30 (48)	3.9 (1-10)	6.4 (1-10)	38 (60)
Functional mobility	55 (26)	4.0 (1-9)	5.3 (1-10)	22 (40)	2.5 (1-7)	4.1 (1-10)	23 (42)
Community management	16 (7)	3.2 (1-6)	4.9 (1-9)	7 (48)	2.7 (1-5)	5.0 (1-10)	8 (50)
Total	134 (63)			59 (44)			69 (52)
Productivity							
Paid/unpaid work	5 (2)	4.2 (1-9)	5.0 (2-9)	1 (20)	4.4 (1-10)	4.6 (1-8)	1 (20)
Household management	48 (22)	4.2 (1-10)	6.6 (2-10)	27 (56)	3.9 (1-10)	6.4 (1-10)	25 (52)
Play/school	0	0		0	0	0	0
Total	53 (24)			28 (53)			26 (49)
Leisure							
Quiet recreation	11 (5)	3.8 (1-7)	6.4 (1-10)	7 (64)	4.0 (1-6)	6.4 (2-10)	5 (55)
Active recreation	10 (5)	1.7 (1-8)	3.1 (1-9)	3 (30)	1.7 (1-8)	3.4 (1-9)	2 (20)
Socialisation	8 (4)	3.2 (1-7)	4.6 (1-8)	2 (25)	1.5 (1-5)	3.2 (1-5)	4 (50)
Total	29 (13)			12 (41)			11 (38)

Values are presented as mean and range.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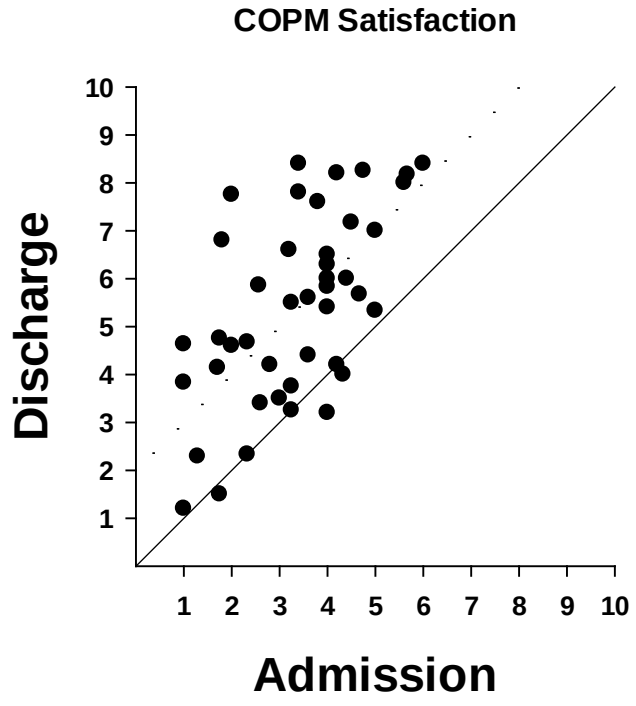
COPM Satisfaction
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8
9
10

Figure 1

Legend to Figure 1

Figure 1. Graphical presentation of performance and satisfaction scores before and after rehabilitation, evaluated with the Canadian Occupational Performance Measure (COPM).