J Rehabil Med 2010: 42: 60–65

ORIGINAL REPORT

EMPLOYMENT STATUS OF PATIENTS WITH NEUROMUSCULAR DISEASES IN RELATION TO PERSONAL FACTORS, FATIGUE AND HEALTH STATUS: A SECONDARY ANALYSIS

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Objective: **To determine the number of employed people in a group of patients with neuromuscular diseases and in 3 separate subgroups (facioscapulo-humeral dystrophy, hereditary motor and sensory neuropathy, and myotonic dystrophy) to investigate any differences in employment status between the patient groups, and to identify factors related to employment status.**

Design: **Cross-sectional study.**

Patients: **A total of 591 patients with neuromuscular diseases participated in the study, 138 with facioscapulo-humeral dystrophy, 135 with hereditary motor and sensory neuropathy, and 318 with myotonic dystrophy.**

Methods: **Self-report questionnaires, the Checklist Individual Strength (CIS) and the Short Form-36 (SF-36).**

Results: **Of the patients with neuromuscular diseases in the study, 56.7% were employed. Younger age, being male, and higher education contributed significantly to employment status of the neuromuscular diseases group and the hereditary motor and sensory neuropathy and myotonic dystrophy subgroups. Significant between-group differences for employed vs not employed subjects were present in the total neuromuscular diseases group on all subscales of the CIS and SF-36. Factors related to employment status differed for the 3 neuromuscular diseases subgroups.**

Conclusion: **More than half of the patients with neuromuscular diseases were employed. Patients with facioscapulo-humeral dystrophy and patients with hereditary motor and sensory neuropathy were more often employed than patients with myotonic dystrophy. Between-group analyses for differences in baseline factors revealed 11 significant factors related to employment. Multivariate logistic analyses revealed 6 factors contributing to employment for the group of patients with neuromuscular diseases.**

Key words: employment; neuromuscular disease; CIS; SF-36; rehabilitation.

J Rehabil Med 2010: 42: 60–65

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Submitted October 29; 2008; accepted October 5, 2009

INTRODUCTION

Employment is recognized worldwide as important to all people, including those with disabilities and chronic diseases. People in gainful employment, again including those with chronic diseases, enjoy greater health, wellbeing, and sense of fulfilment in their lives (1–8). Healthcare professionals, politicians, and patient organizations all recognize the value of empowering people with a disability by way of gainful employment.

Three moderately prevalent progressive neuromuscular diseases (NMD) were chosen for this study based on their onset at working age with a progressive impact on performing daily activities that is also likely to affect gainful employment (9, 10). Facioscapulo-humeral dystrophy (FSHD) is a genetic muscular dystrophy. Hereditary motor and sensory neuropathy type I (HMSN) is a genetic peripheral nerve disease. Adult-onset myotonic dystrophy (MD) is a genetic multi-organ disorder also affecting cognitive function. A systematic review revealed 10 factors associated with employment status: disorder-related factors, factors related to functions, general personal factors, and work-related personal factors (11). This study is a secondary analysis of data from the study by Kalkman et al. (10). We selected from this study those measurement instruments that were likely to impact on employment status.

This analysis seeks to answer the following research questions: (*i*) How many NMD patients of working age are gainfully employed and what are their characteristics? (*ii*) Are there differences in employment status among the 3 subgroups of

patients with FSHD, HMSN, and MD? (*iii*) Which disease-related, personal, fatigue severity, and functional health status factors, are related to employment of the NMD patient group and the 3 patient subgroups?

METHODS

Subjects

In their cross-sectional study Kalkman et al. (10) contacted patients with a definitive medical diagnosis of NMD using patient databases from the Neuromuscular Centre Nijmegen and the Dutch Neuromuscular Patient Association (Vereniging Spierziekten Nederland). With a response rate of 72%, these researchers were able to recruit 598 patients with FSHD, HMSN and MD aged 18–68 years. The study was approved by the local ethics committee and all subjects signed an informed consent. The sample was described in terms of general personal factors, participation in volunteer work, fatigue, functional health status, and employment status. For this secondary analysis examining employment status, one patient was excluded for being over the retirement age of 65 years, and 6 patients were excluded due to incomplete or missing data with regard to employment status. Thus, 591 patients were included in this secondary analysis: 138 patients with FSHD, 135 with HMSN, and 318 with MD.

Measurement instruments

For this analysis those data from measurement instruments used in the primary study (10) that were likely to be associated with employment status were selected. These included data from a patient questionnaire, the Checklist Individual Strength (CIS), and 4 subscales of the Short Form-36 (SF-36) functional health status measure.

Patient questionnaire

For the original study, employment was defined as the state of being engaged in an activity or service for salary (gainful employment). In the questionnaire used by Kalkman et al. (10) 5 categories of employment status were defined: 0–8, 9–16, 17–24, 25–32 or > 32 h/week. Although this cut-off value does not correspond to the Dutch governmental recognition of economic importance of working ≥ 12 h/week (12), for this secondary analysis the data available on employment status were dichotomized into either employed (working ≥ 9 h/week) or not employed (working 0–8 h/week).

Marital status was dichotomized as single or domestic union/married. Participation in volunteer work was dichotomized into performing volunteer work or not, because no data on the number of hours of voluntary work was included in the primary study. Data collected on highest educational level attained consisted of 3 categories: lower educated (primary school), intermediate educated (secondary school), and higher educated (post-secondary level).

Checklist Individual Strength

The CIS is a multidimensional instrument with 4 subscales (fatigue severity, concentration problems, reduced motivation, and reduced activity) to measure the level and impact of fatigue in patients with chronic diseases and in healthy people (13–15). Each subscale item can be scored on a 7-point Likert scale. A higher composite subscale score indicates higher levels of fatigue, higher levels of concentration problems, lower motivation, and lower levels of activity (13). Although in the literature the fatigue scale has been dichotomized, with a score ≥ 35 used to identify severe fatigue (10, 14), all subscale scores were analysed here as ratio-level data. The total CIS score has demonstrated good reliability and validity (16, 17).

Functional health status

The Medical Outcomes Study Short Form General Health Survey (SF-36) uses 36 questions to measure 8 aspects of functional health status (18). Item scores are added and transformed to a 100-point scale to produce subscale scores. Higher scores indicate better health status. For this secondary analysis 4 subscales were used that were thought to be relevant to employment status: physical functioning (10 items), social functioning (2 items), vitality (4 items), and bodily pain (2 items) The SF-36 has been shown to have adequate reliability and validity, both for total and subscale scores (18).

Data analysis

Descriptive statistics are presented separately for all variables of employed and not employed NMD patients. These descriptive data were analysed for between-group differences with univariate analyses (ANOVA) for numeric and continuous variables and χ^2 analyses for ordinal variables both for the total NMD group (Table I) and for the 3 subgroups (Table II). We regarded $p < 0.05$ as statistically significant.

Further statistical analyses were performed for the total NMD group and for the 3 subgroups with employment status as the dependent variable. Stepwise forward multivariate logistic regression analyses using SPSS software (Version 15.0 for Windows®) were performed to examine the contribution of the variables to employment status for the total NMD group and for the 3 patient subgroups, allowing us to present odds ratios and calculate variance (Table III). In the stepwise procedure we used $p < 0.15$ for inclusion and $p > 0.05$ for exclusion of variables in the model.

Table I. *Personal factors, level of fatigue, and health status of the total with patient group neuromuscular diseases (NMD) employed and not employed (n = 591)*

Variable	Employed†	Not employed†	*p*-value*
Total, % (*n*)	56.7 (335)	43.3 (256)	
Age mean (SD)	40.4 (9.96)	46.1 (9.52)	<0.001
Gender, % (*n*)			
Men	52.8 (177)	35.2 (90)	<0.001
Women	47.2 (158)	64.8 (166)	
Marital status, % (*n*)			
Single	31 (104)	27.1 (69)	0.291
Living together/married	69 (231)	72.9 (187)	
Education level, % (*n*)			
Lower	18.8 (63)	40.8(104)	<0.001
Intermediate	50.7 (170)	47.8 (122)	
Higher	30.4 (102)	11.4 (29)	
Volunteer, % (*n*)			
Yes	23.5 (78)	19.6 (50)	0.269
No	76.5 (254)	80.4 (205)	
CIS, mean (SD)			
CIS fatigue (8–56)	36.5 (12.17)	41.7 (11.44)	<0.001
CIS concentration (5–35)	13.4 (7.72)	17.3 (9.04)	<0.001
CIS motivation (4–28)	13.2 (6.35)	16.5 (6.76)	<0.001
CIS activity (3–21)	9.8 (5.32)	13.9 (5.57)	<0.001
SF-36 Health Status‡, mean (SD)			
Physical functioning (0–100)	52.5 (27.63)	43.8 (29.08)	<0.001
Social functioning (0–100)	72.4 (22.65)	66.8 (25.74)	0.006
Vitality (0–100)	49.0 (19.22)	45.2 (19.82)	0.017
Bodily pain (0–100)	74.0 (23.73)	69.9 (26.02)	0.046

Differences in proportions tested with χ^2; group means tested by analysis of variance (ANOVA).

*A *p*-value < 0.05 was regarded as statistically significant.

†Employed defined as working ≥ 9 h/week; not employed defined as working < 9 h/week.

‡SF-36. A higher value indicates a better health status on a scale of 0–100.

CIS: Checklist Individual Strength; SF-36: 36-item Short Form health survey; SD: standard deviation.

Table II. *Personal factors, level of fatigue and health status of patients with facioscapulo-humeral dystrophy (FSHD), hereditary motor and sensory neuropathy (HMSN) and myotonic dystropy (MD) employed and not employed*

	FSHD *n* = 138			HMSN *n* = 135			MD *n* = 318		
Variable	Employed†	Not employed†	*p*-value*	Employed†	Not employed†	*p*-value*	Employed†	Not employed†	*p*-value*
Total, % (*n*)	70.3 (97)	29.7 (41)	<0.001	63.7 (86)	36.3 (49)	0.001	47.8 (152)	52.2 (166)	0.432
Total, 95% CI	39.98–44.03	44.61–50.46		38.27–42.70	42.61–48.58		37.84–40.95	44.55–47.43	
Mean age (SD)	42 (10.05)	47.5 (9.26)	0.003	40.5 (10.33)	45.6 (10.38)	0.007	39.4 (9.61)	45.9 (9.35)	<0.000
Gender, % (*n*)									
Men	55.7 (54)	31.7 (13)	0.010	43 (37)	32.7 (16)	0.235	56.6 (86)	36.7 (61)	<0.000
Women	44.3 (43)	68.3 (28)		57 (49)	67.3 (33)		43.4 (66)	63.3 (105)	
Marital status, % (*n*)									
Single	24.7 (24)	26.8 (11)	0.797	32.6 (28)	30.6 (15)	0.815	34.2 (52)	26.1 (43)	0.114
Living together/married	75.3 (73)	73.2 (30)		67.4 (58)	69.4 (34)		65.8 (100)	73.9 (122)	
Education level, % (*n*)									
Lower	14.4 (14)	31.7 (13)	0.005	11.6 (10)	18.4 (9)	0.294	25.7 (39)	49.7 (82)	<0.000
Intermediate	48.5 (47)	56.1 (23)		50.0 (43)	55.1 (27)		52.6 (80)	43.6 (72)	
Higher	34.1 (36)	12.2 (5)		38.4 (33)	26.5 (13)		21.7 (33)	6.7 (11)	
Volunteer work, % (*n*)									
Yes	33.0 (32)	26.8 (11)	0.475	26.7 (23)	31.3 (15)	0.579	15.4 (23)	14.5 (24)	0.808
No	67.0 (65)	73.2 (30)		73.3 (63)	68.8 (33)		84.6 (126)	85.5 (142)	
CIS mean (SD)									
CIS fatigue (8–56)	34.8 (12.10)	41.4 (10.90)	0.003	37.0 (12.33)	36.8 (13.08)	0.929	37.3 (12.10)	43.2 (10.70)	<0.000
CIS concentration (5–35)	11.6 (6.99)	14.1 (10.29)	0.105	13.0 (8.28)	15.2 (9.27)	0.169	14.7 (7.65)	18.6 (8.36)	<0.000
CIS motivation (4–28)	11.8 (5.50)	13.0 (6.54)	0.257	11.9 (5.84)	12.7 (6.45)	0.459	14.9 (6.75)	18.4 (6.07)	<0.000
CIS activity (3–21)	8.9 (4.77)	13.0 (5.80)	<0.001	9.1 (5.58)	9.9 (5.35)	0.450	10.8 (5.37)	15.3 (4.96)	<0.000
SF-36 Health Status‡, mean (SD)									
Physical functioning (0–100)	52.2 (30.67)	29.0 (26.41)	<0.001	53.8 (24.67)	53.9 (28.53)	0.974	52.0 (27.33)	44.6 (28.58)	0.019
Social functioning (0–100)	74.1 (22.55)	67.9 (25.47)	0.164	68.7 (24.61)	66.2 (23.73)	0.568	73.3 (21.46)	66.7 (26.49)	0.015
Vitality (0–100)	55.5 (17.56)	48.3 (19.15)	0.033	49.6 (20.45)	50.7 (19.36)	0.752	44.6 (18.42)	42.8 (19.81)	0.393
Bodily pain (0–100)	71.3 (22.83)	57.9 (20.65)	0.002	72.7 (22.85)	61.6 (28.31)	0.015	76.4 (24.67)	75.1 (25.07)	0.646

Differences in proportions tested with χ^2; group means tested by analysis of variance (ANOVA).
*A *p*-value <0.05 was regarded as statistically significant.
†Employed defined as working ≥9 h/week; not employed defined as working <9 h/week.
‡SF-36. A higher value indicates a better health status on a scale of 0–100.
CI: confidence interval; CIS: Checklist Individual Strength; SF-36: 36-item Short Form Health Survey; SD: standard deviation.

RESULTS

Data on personal factors, level and impact of fatigue, and functional health status for the total NMD group of employed, and not employed NMD patients are presented in Table I. The results for the 3 subgroups are presented in Table II. In Table III the contribution of different factors to employment status is presented for the total NMD group and the subgroups.

Between-group analysis

Employment status. In the total NMD group, 56.7% of patients were gainfully employed. Employment status differed significantly from this percentage for the total group for both the FSHD (70.3% employed; $p < 0.001$) and the HMSN (63.7%; $p = 0.001$) subgroups, but not the MD subgroup (47.8%; $p = 0.432$) (Table I and II).

Gender and age. Between-group analysis showed significant differences with regard to gender and age: NMD patients who were employed were younger and more often male than the not employed patients (Table I). In all 3 subgroups, younger patients were employed to a significantly greater degree than older patients. For the FSHD and MD subgroups, the correlation between being male and being gainfully employed was also significant (Table II).

Participation in volunteer work. The employed NMD patients did not perform significantly more volunteer work than not employed patients (Table I and II).

Marital status. No significant differences were found for marital status for the total NMD group or for the 3 subgroups between employed and not employed patients (Table I and II).

Educational level. Significant between-group differences were noted in the level of education for the total NMD patient group. Employed NMD patients were, on average, significantly higher educated than not employed patients. Of the employed NMD patients, 30.4% had higher, 50.7% intermediate, and 18.8% lower education. For the not employed patients these percentages were 11.4%, 47.8%, and 40.8%, respectively (Table I). Of the employed patients, 81.1% had higher or intermediate educational background vs 59.2% in the non-employed group (Table I). Significant between-group differences with regard

Table III. *Logistic regression analyses to predict employment status in the total neuromuscular diseases (NMD) group and for the 3 patient groups: facioscapulo-humeral-dystrophy (FSHD), hereditary-motor- and-sensory-neuropathy (HMSN) and myotonic-dystrophy (MD)*

	Dependent variable employment							
	NMD $n=591$ (256/335)*		FSHD $n=138$ (41/97)*		HMSN $n=135$ (49/86)*		MD $n=318$ (166/152)*	
Independent variables	OR (95% CI)	*p*-value	OR (95% CI)	*p*-value	OR (95% CI)	*p*-value	OR (95% CI)	*p*-value
Age	0.94 (0.92–0.96)	<0.001			0.94 (0.89–0.98)	0.001	0.97 (0.89–0.96)	<0.001
Gender (male)	0.33 (0.22–0.49)	<0.001	0.22 (0.085–0.605)	0.003			0.28 (0.161–0.508)	<0.001
Marital status								
Education								
Lower	1	<0.001	1	0.015			1	<0.001
Intermediate	1.9 (1.21–3.01)	<0.001	1.2 (0.41–3.66)	0.008			2.2 (1.25–4.13)	<0.001
Higher	5.6 (3.12–10.37)	0.005	6.6 (1.64–26.69)	0.708			9.9 (3.93–25.19)	0.007
Volunteer								
Voluntary work								
CIS								
CIS fatigue								
CIS concentration	0.97 (0.95–0.99)	0.026			0.95 (0.91–0.99)	0.023		
CIS motivation								
CIS activity	0.89 (0.86–0.93)	<0.001	0.86 (0.79–0.94)	0.001			0.86 (0.81–0.91)	<0.001
SF-36 Health Status								
Physical functioning	1.072 (>1.000–1.149)	0.050	1.233 (1.047–1.452)	0.012				
Social functioning								
Vitality								
Bodily pain					1.26 (1.077–1.490)	0.004		
Nagelkerke R^2	0.372		0.397		0.206		0.424	

* Not employed (0–8 h)/Employed (9–40 h).
R^2 is the percentage of variance of the dependent variable score, explained by the independent variables together.
Relationship between patient factors with the dependent variable employment ($p<0.05$).
Only significant odds ratios (OR) with accompanying 95% confidence interval (95% CI).
CIS: Checklist Individual Strength; SF-36: 36-item Short Form Health Survey.

to educational level were also noted in the FSHD and MD subgroups (Table II).

Checklist Individual Strength. Significant between-group differences for the 4 subscales of the CIS were present in the total NMD group. Employed NMD patients reported significantly less fatigue, fewer concentration problems, better motivation, and higher levels of activity than the not employed NMD group (see Table I). Of note was that both employed and not employed NMD patients reported severe fatigue (cut-off ≥ 35 on the CIS fatigue subscale) (Table I). Despite this CIS fatigue score (mean 36.5, SD 12.1) a high percentage of NMD patients were still gainfully employed.

Subgroup analysis also showed significant between-group differences in the FSHD and MD subgroups with regard to fatigue severity level. Employed FSHD and MD patients reported significantly less fatigue compared with not employed patients. The fatigue score for the employed FSHD group (mean 34.8, SD 12.1) was below the cut-off for severe fatigue (Table II). The employed FSHD and MD patient group also reported significantly higher levels of activity. The employed MD patient group reported significantly fewer concentration problems and better motivation (Table II). No significant between-group differences were present for the HMSN subgroups for the 4 CIS subscales (Table II).

Functional health status. For the total NMD group between-group analysis showed significant differences in health status. The employed NMD patient group had a significantly higher score on the SF-36 subscales physical functioning, social functioning, vitality, and bodily pain compared with the not employed patient group, indicating a better health status (Table I).

Subgroup analysis showed more varied between-group differences. The employed FSHD group reported significantly better physical functioning, more vitality, and less bodily pain than the not employed FSHD group. The employed HMSN group reported significantly less bodily pain. The employed MD group reported significantly better physical and social functioning (Table II).

Multivariate analysis

Total neuromuscular diseases group. All of the factors that were found to contribute significantly to employment status from the multivariate logistic regression for the total NMD group are shown in Table III, presented as odds ratios (OR). Factors that contributed significantly to employment status for the total NMD patient group were age, gender, and educational level, CIS concentration score, CIS activity score, and SF-36 physical functioning score. Together these factors explained 37.2% of variance with regard to employment status.

For the total NMD group the odds of being employed decreased 6% for each year with increasing age, controlling for other variables in the model. The odds for a male being employed were 3 times higher than for a woman, and higher educated NMD patients had 5.6 higher odds of being employed than lower educated NMD patients (Table III). The odds of being

employed increased 3% with each higher level of CIS concentration (expressed in a lower score OR 0.97) and the odds of being employed increased 11% with each higher level of CIS activity (expressed in a lower score OR 0.89). The odds of being employed increased 0.72% with each unit increase of the score on the subscale SF-36 physical functioning (Table III).

Subgroups. Similar analyses were performed to predict employment status for all 3 subgroups. For the FSHD group, male patients with a higher education, higher CIS activity score, and better SF-36 physical functioning score were more likely to be employed: 39.7% of the variance was explained by these factors (Table III). For the HMSN group age, higher levels of concentration and less pain contributed significantly to employment status: 20.6% of the variance was explained by these factors (Table III). For the patients with MD, younger males with higher education levels and higher CIS activity score were most likely to be employed: These factors explained 42.4% of the variance in employment status (Table III). Of note was that educational level was an important explanatory variable for employment in both the FSHD and MD subgroups (OR 6.6–9.95).

DISCUSSION

In contrast to earlier published reports (9, 19), this study indicates that a high percentage of patients with NMD are gainfully employed, particularly in the FSHD and HMSN subgroups. A lower employment percentage was confirmed only for the MD subgroup in this study. In addition, it was found that employed NMD patients are younger, more often male, and higher educated than the not employed NMD patients. Four factors identified in a systematic review of the literature on factors associated with employment status in patients with NMD (11) were consistent with the findings of this study: NMD type, age, gender, and educational level. This impact of age is also in agreement with the findings by Andries (20), who reported a more rapid decrease in employment status in patients with NMD increasing age.

In our study the HMSN and patient with MD subgroups reported a significant relationship between age and employment status. Furthermore, being male was a relevant factor for the FSHD and MD subgroups. On average, the employed MD patients had attained a lower educational level than the other 2 subgroups. We hypothesize that the fact that MD is a multiorgan disorder that also affects cognitive function might explain this lower educational level and, related to the nature of this pathology, lower employment level compared with the FSHD and HMSN subgroups (21). Fowler et al. (9) also noted a correlation between the type of NMD and educational level. They stated that patients with higher education were more frequently working in clerical positions. Clerical jobs are less physically strenuous than heavy manual jobs, and higher education thereby provides a plausible explanation for employment status.

We expected to find a lower educational level in the MD subgroup, based on the nature of the pathology. Lower educational levels were expected to result in a higher percentage of these patients working in more strenuous jobs, leading to earlier disability pension and a lower employment rate (10, 19). In this study the percentage of higher educated patients with MD was found to be low. It was notable that the chance of being employed was almost 10 times better for the patients with MD higher education compared with those with lower education. The clinical implication of this finding is that special attention appears warranted to explain to patients with MD at an early age the importance of educational level and to encourage them to study, if their condition allows it, as education has been found to have a strong correlation with future opportunities in the labour market.

The variance explaining employment status for the contributing factors identified was relatively high for the FSHD (39.7%) and the MD (42.4%), but more limited for the HMSN subgroup (20.6%). Of all the factors included in the regression analyses, none were relevant for all 3 subgroups. Education was shown to be the most important variable in the FSHD and MD subgroup in explaining association with employment status. Age was an important variable for the HMSN and MD subgroups and gender for the FSHD and MD subgroups.

Severe fatigue and pain are major complaints in patients with NMD (10, 22–28) and we expected that fatigue and pain would influence employment status in the NMD patient groups. The variability with regard to fatigue severity for type of NMD was large. However, despite high levels of fatigue severity, the levels of employment were also relatively high. This seems to indicate that fatigue severity may not be the reason why the patients in this study were not participating in the workforce. There was a significant between-group difference with regard to reported pain in the total NMD group and in the FSHD and HMSN subgroups. However, less pain was a contributing factor only with regard to employment for the HMSN subgroup. In the regression analyses the CIS fatigue and motivation subscale scores did not contribute to the calculated variance in employment status in any of the 3 subgroups. This study indicates that fatigue severity and motivation do not affect participation in the workforce for patients with MD.

A significant between-group difference was found between the 4 SF-36 subscales: physical functioning, social functioning, vitality, and bodily pain. Subscale scores were higher in those patients who were employed, indicating better health status. Regression analysis detected the subscale factor SF-36 physical functioning as a variable that could partly explain the variance of employment status in the total NMD group and in the FSHD subgroup. We suggest that if factors could be found that influence employment in patients with NMD, it might be helpful in the development of treatment strategies for (allied) health professionals to assist patients with NMD to return to work and/or to stay employed.

Although 11 factors that influenced gainful employment status were found in the sample of patients with NMD studied, 6 of which were also found to be relevant using multivariate logistic analyses, a maximum of only 42.4% of the variance was explained, which leaves 57.6% unexplained with the factors in the present model. Due to the limitations with regard to data selected, additional relevant predictive factors influencing employment were probably not taken into account. Environmental factors are, for example, not encountered in this study and might influence employment status in NMD

patients, as was found in other cross-sectional studies (4, 9, 12, 29–31). Other studies also recommend that determinants such as adequate referral patterns, goal setting, motivation, expectation, job seeking, work maintenance, work demands, terms of employment (type of job, amount of hours worked, ability to regulate working hours) should be addressed (9, 12, 32, 33). Social support, facilitation, and compensation for barriers to employment when disabled and chronically ill patients such as NMD patients attempt to return to work also need to be addressed in future studies (21, 33, 34). This stresses the importance of specific qualitative research to identify further modifiable variables related to employment in order to enhance labour participation of the patient group in our study.

ACKNOWLEDGEMENTS

The study was supported by "HBO Mobiliteitsfonds" and the HAN University of Applied Sciences, Nijmegen, The Netherlands.

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