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Vocational perspectives and neuromuscular disorders

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The present study analyses the actual occupational situation, vocational handicaps and past labour career of a group of about 1000 Dutch patients suffering from a neuromuscular disorder (NMD). On the basis of the likelihood of a substantial employment history and sufficient numbers of patients, four types of NMD were selected: dystrophia myotonica (DM), hereditary motor and sensory neuropathy (HMSN), spinal muscular atrophy (SMA) and myasthenia gravis (MG). Results show that a labour career is in reach of most NMD patients, even for those with severe limitations. It is concluded that physical limitations seem not to be decisive in that respect. The loss of the quality of communication, the loss of mental abilities and the effect of the diseases on the facial expression, as with some DM patients, are also important for chances on the labour market. Though the labour participation of NMD patients tends to decrease after the age of 34, the availability of work adaptations makes it possible to prolong the labour career. Analysis of the actual work situation of NMD patients shows that both disorder-related limitations and work characteristics play an important role in the amount of physical work problems encountered. It is argued that physical labour has to be regarded as generally unsuitable for NMD patients. This has implications for the sort and level of education to be attained by NMD patients. Career counselling as a focus point for the choice of an educational programme may improve labour market opportunities as well as quality of employment of NMD patients. Allowing for and accepting the possible effects of the disorder in the work situation are considered to be important in respect to labour participation and work satisfaction of workers with NMD. Reducing time pressure demands and increasing the freedom to organize one's work, are measures to be given especial consideration.

Berufliche Perspektiven bei neuromuskulären Störungen

Die vorliegende Studie untersucht die konkrete berufliche Situation, berufliche Handicaps und bisherige Arbeitsbiographie einer Gruppe von rund 1 000 niederländischen Patienten mit einer neuromuskulären Störung („neuromuscular disorder" – NMD). Mit Blick auf die Wahrscheinlichkeit einer substantiellen Berufstätigkeit und ausreichende Patientenzahlen wurden vier NMD-Krankheitsbilder ausgewählt: myotonische Dystrophie, hereditäre motorische und sensible Neuropathie,

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spinale Muskelatrophie und Myasthenia gravis. Die Ergebnisse zeigen, daß Berufstätigkeit für die meisten NMD-Patienten erreichbar ist, selbst für diejenigen mit schwerwiegenderen Einschränkungen. Demnach scheinen körperliche Krankheitsauswirkungen in dieser Hinsicht nicht entscheidend sind qualitative Einbußen in der Kommunikationsfähigkeit, nachlassende intellektuelle Fähigkeiten und die Auswirkungen der Krankheit auf den Gesichtsausdruck wie bei manchen Patienten mit myotonischer Dystrophie. Obwohl die Erwerbsbeteiligung von NMD-Patienten nach dem 34. Lebensjahr tendenziell sinkt, kann durch angepaßte Arbeitsgestaltung eine längere Berufstätigkeit ermöglicht werden. Die Analyse der konkreten Arbeitssituation von NMD-Patienten zeigt, daß sowohl krankheitsbezogene Einschränkungen als auch Tätigkeitsmerkmale eine große Rolle für das Ausmaß physischer Probleme am Arbeitsplatz spielen. Es wird dargelegt, daß körperliche Arbeit für NMD-Patienten generell als ungeeignet anzusehen ist. Hieraus ergeben sich Folgerungen für Art und Niveau der Ausbildung, die NMD-Patienten anstreben sollten. Durch gezielte Berufs-und Arbeitsberatung als Angelpunkt der Wahl eines geeigneten Ausbildungsangebots können die Arbeitsmarktchancen wie auch die Qualität der Beschäftigung von NMD-Patienten verbessert werden. Als wichtige Faktoren für Erwerbsbeteiligung und Arbeitszufriedenheit von Beschäftigten mit NMD werden Rücksichtnahme auf die Möglichkeit einschränkender Krankheitsauswirkungen und deren Akzeptanz gesehen. Insbesondere soliten mit Zeitdruck verbundene Anforderungen reduziert und größere Spielräume in der Arbeitsorganisation eingeräumt werden.

Perspectives professionnelles et troubles neuromusculaires

La présente étude, analyse la situation professionnelle actuelle, le désavantage d'occupation et la carrière professionnelle antérieure d'un groupe d'environ 1000 patients néerlandais souffrant de « difficultés neuromusculaires » désignées sous le sigle «NMD ». Partant de la probabilité d'un passé professionnel riche et d'un nombre suffisant de patients on a sélectionné quatre types de patients souffrant de troubles neuromusculaires:dystrophie myotonique, pathologies neurologiques motrices et sensorielles héréditaires, atrophie musculaire d'origine spinale, myasthénie gravis. Les résultats montrent qu'une carrière professionnelle est à portée de la plupart des patients NMD, même de ceux qui ont des limitations sévères. On en déduit que les limitations physiques ne semblent pas représenter un facteur décisif par rapport à cette question. La perte de la qualité de communication, la perte des habiletés cognitives et les conséquences de la maladie sur l'expression faciale comme cela se produit chez certains patients DM, ont également leur importance pour ce qui concerne les chances sur la marché du travail. La participation au travail des patients NMD tend cependant à décroître après 34 ans, mais les possibilités d'adaptation des postes de travail permettent une prolongation de la carrière professionnelle. L'analyse de la situation du travail actuel des patients NMD montre que les troubles à l'origine des incapacités tout comme les caractéristiques du travail jouent un rôle important dans l'ensemble des problèmes rencontrés dans le travail physique. Il est démontré que le travail physique devrait en général être considéré comme peu approprié pour les patients NMD. Ceci a des conséquences sur le genre et le niveau d' éducation à rechercher pour les patients. L'orientation professionnelle considérée comme vitale lors du choix d'un programme de formation doit tenir compte aussi bien des caractéristiques du marché du travail que de la qualité de l'emploi des patients NMD. Tenir compte et accepter les possibles gênes dans le travail suite aux troubles est important en ce qui concerne la participation au travail et la satisfaction professionnelle des patients NMD. Il faut rechercher la réduction du temps des contraintes et la liberté d' organiser soi-même son travail tout particulièrement.

Perspectivas vocacionales y trastornos neuronmusculares

El presente estudio analiza la situación ocupacional, las minusvalías vocacionales y la trayectoria laboral pasada de un grupo de cerca de 1.000 pacientes holandeses afectados por un trastorno neuomuscular (TNM). En función de la disponibilidad de un número suficiente de pacientes con una historia laboral substancial se seleccionaron cuatro tipos de TNM: Distrofia Miotónica, Neuropatía

Sensoriomotriz Hereditaria, Atrofia Muscular Espinal y Myasthenia Gravis. Los resultados indican que una carrera laboral está al alcance de la mayoria de los pacientes de TNM, incluso de aquellos con graves limitaciones. La conclusión es que las limitaciones fisicas no parecen ser decisivas al respecto. La pérdida de la calidad de la comunicación, la pérdida de las capacidades mentales y el efecto de la enfermedad en la expresión facial, que se produce en algunos pacientes de Distrofia Miotónica, también modifican las oportunidades en el mercado de trabajo. Aunque la participación laboral de los pacientes de TNM tiende a decrecer después de los 34 años, la disponibilidad de adaptaciones del puesto de trabajo posibilita una prolongación de la carrera laboral. El análisis de la situación laboral actual de los pacientes de TNM muestra que tanto las limitaciones relacionadas con el trastorno como las características del trabajo desempeñan un papel importante en el aumento de los problemas de trabaio fisico que han de afrontar. Se argumenta que, generalmente, el trabajo fisico se ha de considerar inadecuado para los pacientes de TNM. Esto tiene implicaciones para el tipo y el nivel de educación que han de alcanzar estos pacientes. La orientación vocaciopnal, punto focal de la elección de un programa educativo, puede mejorar las oportunidades en el mercado de trabajo asi como la calidad del empleo de los pacientes de TNM. El tener en cuenta y el aceptar los posibles efectos limitadores que el trastorno produce en la situación laboral se considera importante en relación con la participación laboral y con la satisfacción en el empleo de los trabajadores con TNM. Reducir la tensión apremiante del tiempo e incrementar la libertad de organizar el propio trabajo, son medidas que deben considerarse especialmente.

Keywords: neuromuscular disorders, labour participation, work adaptation, physical problems, work satisfaction

Introduction

In the Netherlands, poverty and social insecurity are kept within limits by a well-organized social security system. Social security benefits for people with an illness or disability are higher than those for the unemployed in general. In recent years, however, access to these higher benefits for the disabled has become substantially more limited. Due to this, chronically ill and handicapped people have to rely more often on unemployment benefits only. At the same time unemployment rates remain high despite recent favourable economic developments. Therefore, the vocational perspectives of the chronically ill or handicapped and the enhancement of their remaining vocational abilities are increasingly important. However, the position on the labour market of the chronically ill or handicapped is unfavourable, as shown in a recent review of literature in the Netherlands (Wevers *et al.*, 1993b). From the few studies on the labour market position of people with specific illnesses it has become clear that their participation in the labour force is low compared to that of the general adult population. In fact, many patients report problems, such as limited access to insurance schemes, discrimination when applying for jobs, physical problems in the workplace, difficulties in contacts with colleagues and superiors and little chance for promotion. Amongst others this has been demonstrated for employees with CARA, epilepsy, Crohn's disease, cancer and multiple sclerosis (Wevers *et al.*, 1993b). Also, employees tend to select applicants more strongly on health than in the past (Ministry of Social Affairs and Employment, 1994; National Committee on Chronically Ill, 1995).

Several studies show that employment is an important determinant in well-being (Warr, 1987). This holds for healthy people as well as for the chronically ill (van Elderen, 1995). Work gives meaning to life, places a person in a social context, is accompanied by higher

self-esteem and, not least, a higher income. The latter is especially important because chronic illness increases living costs (van Agt, 1994). For some diseases it has been found that work or returning to work after unemployment can have a favourable effect on the well-being of the patient as well as in coping with the disease. This was demonstrated for multiple sclerosis and cancer (Barofsky, 1989; Ketelaer, 1993). For the unemployed in general, re-employment can reduce physical, depressive and phobic complaints. Social support, the self-concept and coping strategies appear to improve as well (Kessler *et al.*, 1988). In the Netherlands it has been demonstrated that specific diseases and unemployment are associated with poor health and use of health care facilities. Re-employment has an ameliorating effect (Verkleij, 1991).

Findings on working conditions for employees with a chronic disease are inconclusive. In a large Dutch company (Akzo Coatings) chronically ill workers did not report more complaints about working conditions than their healthy colleagues (Nijboer and Wevers, 1991). However in one other study in the general population (including people with a chronic illness) Timmermans found that in comparison to their healthy colleagues, workers with disabilities were less pleased with their job and found their job to be more physically strenuous or monotonous (Timmermans, 1994). They were altogether less satisfied with their job and with their chances for promotion and income.

In a study on job perspectives of patients with facioscapulohumeral muscular dystrophy (Wevers *et al.*, 1993a), physical problems due to the work environment were reported in almost half of the cases. Only a few work places had been adjusted. In general, the work demanded great effort. Still, 85% of these patients were satisfied with their job (a much higher percentage than was the case in a reference population of healthy individuals); 15% reported a higher performance compared to colleagues, 11% reported a lower performance. Similarly to studies on the employment status of patients with chronic disorders, this study demonstrated that characteristics of the disease are not a decisive factor in remaining at work.

In a study on patients with rheumatoid arthritis, Yelin *et al.* (1980) reported that social and work factors, such as the ability to control one's own work place and activities – the so-called 'job decision latitude' (Karasek, 1979) – have a greater impact on employment status than specific disease characteristics. The crucial role of this kind of job modification was also demonstrated for employees with multiple sclerosis (Kornblith *et al.*, 1986; Gulick *et al.*, 1989; Ketelaer, 1993) as well as for the chronically ill in general (ter Huurne *et al.*, 1990; Andries *et al.*, 1993; Nijboer *et al.*, 1993).

Aim of the study

The present study analyses the actual occupational situation, vocational handicaps and past labour career of a large group of Dutch patients suffering from a neuromuscular disorder (NMD) (Andries and Wevers, 1996). The study details:

1. the health status, physical and mental disabilities of patients with NMD;
2. the main determinants of the labour force participation of patients;
3. the way in which those who are presently employed experience their working situation, particularly with regard to physical and mental disabilities.

The study aims to contribute to the improvement of vocational guidance and employment prospects of patients with a NMD. It strives to promote a more positive image of patients with a NMD among employers.

Methods

Patients suffering from four types of NMD were selected. The four disorders are:

1. Dystrophia myotonica (DM) (only if onset after the age of 10)
2. Hereditary motor and sensory neuropathy (HMSN) type I and II
3. Spinal muscular atrophy (SMA) type II and III
4. Myasthenia gravis (MG)

These disorders have been chosen for two reasons: (1) subjects were more likely to have a substantial employment history, because of the chronic nature of these disorders and (2) it was assumed that sufficient numbers of patients with these four diseases could be reached by the seven university neuromuscular clinics in the Netherlands and by the Dutch patient organization for people with NMD (VSN).

These NMD are rare. Little is known about their prevalence, but it is estimated to be lower than 10 in 100 000. In comparison, multiple sclerosis in Northern Europe has an occurrence of 75 to 110 in 100 000 population (Ketelaer, 1993; Hassinck *et al.*, 1993). Due to the rarity of the disorders and the variability of the symptoms, the diagnosis is difficult. The university neuromuscular clinics act as important centres for referral. Therefore the files of these seven clinics were used for this study.

The first three disorders (DM, HMSN and SMA) are characterized by a progressive muscle weakness and are genetically determined. MG is neither hereditary nor progressive. These four disorders have one characteristics in common: impairment of movement. They differ with respect to the clinical course and the involvement of specific muscle groups, with possible impairment of ocular movements, facial expressions, articulation, power of the arms or locomotion. In addition, psychological problems like lack of incentive may occur in DM. Table 1 summarizes symptoms and disabilities.

Persons with the aforementioned disorders registered at the seven university clinics in the age range of 16 to 65 – 1299 patients in total – were approached. Affected members of the VSN – 1080 persons – were addressed as well. In this first phase of the project the patients received a form from the clinics and the VSN with which they could give their permission to participate in the project. Duplicate reactions were eliminated. For reasons of privacy the files of the clinics and VSN could not be used (and compared) to calculate the response in phase 1. In phase 2 a questionnaire specific for the kind of work experience indicated on the form was sent to each patient: for these presently working (type 1), for those with previous work experience (type 2) and for those with no work experience at all (type 3). The differences between these three types of questionnaires consist of the amount of (possible) questions on labour experience. Table 2 shows numbers and response figures in phase 2 (completing and sending in the questionnaire). Information from patients with no working experience will not be reported in this article.

The questionnaire used was validated in other research projects within the TNO Vocational Handicap Research Programme (Nijboer and Wevers, 1989, and 1991; Wevers *et al.*, 1993a). For the measurement of health status (psychological, physical, social and

overall well-being) a general health questionnaire was used (RAND-36). It measures health perception on eight multi-item dimensions (Stewart *et al.*, 1988).

Vocational handicaps were assessed by comparing job demands and patient/worker (dis)abilities as well as opinions on working conditions and the social atmosphere at work (only in type 1). Topics referring to job latitude and decision and demands are based on the

Table 1. Descriptive data on the four neuromuscular disorders

Dystrophia Myotonica (DM)
Multi-system disorder, mainly affecting skeletal muscle
Onset at any age, most commonly in second decade
More severe clinical course with early onset
Muscle weakness and stiffness mainly affecting facial expression, articulation, hands and feet
Often excessive daytime sleepiness
Tendency to delay activities
Dominant inheritance, variable severity, tendency to affect next generation earlier and more severely
Hereditary Motor and Sensory Neuropathy (HMSN)
Impairment restricted to the limbs, mainly motor hands and feet
Onset first or second decade, sometimes later
Main symptom deformity of feet, ill-fitting shoes, weakness of feet with ankle sprains, falls and inability to run
More widespread weakness in severe cases
Dominant or recessive inheritance
Spinal muscular atrophy (SMA)
Generalized weakness, mainly shoulder and pelvic girdles, legs more than arms
Onset before 1½ years (type II) or later (type III), steady progression
Many patients wheelchair bound before age 10–20
Inheritance usually recessive
Myasthenia Gravis (MG)
Weakness and excessive fatiguability of movements of eyes and/or face, articulation, deglutition and/or other skeletal muscles
Typically increasing weakness with prolonged use of corresponding muscles
Acquired auto-immune disease, may occur at any age, but preferential affliction of young women
Disease often progressive in weeks or months with little tendency to spontaneous recovery
Treatment including removal of thymus and medication, often induces recovery within months or years, complete recovery rare, residual minor symptoms common
Sporadic disease, familial occurrence exceptional

Table 2. Response figures for three types of patients relative to their work experience

	phase 1: permission granted	*phase 2: completed questionnaire*
type 1 (presently working)	442	414 (94%)
type 2 (previously working)	537	499 (93%)
type 3 (no working experience)	93	83 (89%)
Total	1072	996 (93%)

Job Control/Job Demands Model (Karasek, 1979) and the Job Characteristics Model (Hachkman and Oldham, 1975). Tables 3 and 4 show operationalizations variables. Reliability coefficients (Cronbachs α) show a satisfying amount of internal consistency for all scales. Table 5 presents frequencies of the variables used in multivariate analyses for those retired and for those presently working.

Table 6 gives correlations of all independent variables. It thereby gives information on their possible use as separate variables in multivariate analysis.*

It is concluded that all independent variables presented in Table 6 can be used as separate determinants. The disorder-related characteristics loss of mobility, loss of power and loss of self-care are more closely interrelated.

Data analysis

The following types of analyses are used:

1. Differences in the scores on health status (RAND-36) are analysed by the use of means (test of significance by T-distribution; alpha <0.005); differences in the scores on disabilities by a two-dimensional cross-tabulation (Chi square; $P<0.005$)
2. The assessment of effects on labour participation and the evaluation of the present labour experiences are based on logistic regression analysis. The logistic regression model requires fewer assumptions than other forms of multivariate analysis (Pedhazur, 1982); it allows for categorical data and curve-linear relations. Logistic regression produces odds ratios, which represent the chance that the predicted phenomenon occurs under the unique influence (i.e. not reducible to other possible predictors) of a specific variable. The method used is Stepwise (LR). The probability for the entrance and the removal of a variable in the model is 0.05. The 95% confidence interval shows the precision with which this chance can be ascertained; when the interval incudes 1.0, the odds ratio is considered non-significant.

Results

Health status and disabilities among patients with four types of NMDs

Table 7 presents means of the nine indicators of the RAND-36 and percentages of patients having specific disabilities. Results are given for each type of disorder. Reference data are available for the scores on the RAND-36 (van der Zee and Sanderman, 1993).

Among patients with NMD, the means of all indictors of the RAND-36 – except 'pain' – are significantly below (i.e. more favourable than) those in a reference population of predominantly healthy people. There are more pronounced differences with regard to 'physical functioning', 'role limitations due to physical functioning' and 'general health perception'.

When means of each of the four types of disorders are compared to the means in the total population of patients, it is shown that:

*Due to high intercorrelations (approximately >0.80) between independent variables estimates of regression weights can become unstable (multicollinearity) (Pedhazur, 1982).

Table 3. Operationalization of variables: categories, recodes and Cronbach's α

Item	*Categories*	*Recode*	α
Gender	1, male; 2, female	–	–
Age	–	1, > 35 2, 35–50 3, > 50	–
Education	8 levels (highest completed form)	1, low (1–3) 2, middle (4) 3, high (5–9)	–
NMD	DM MG SMA HMSN	Dummies	–
Loss of mobility	Trouble: climbing ladder, running, walking, sitting, chair/getting up, bending/coming up, keeping balance, accurate movements leg/feet, accurate movements arms/fingers, squatting/kneeling, taking step up	1, no trouble walking/trouble 1 other activity 2, trouble walking/trouble > 1 other activity	0.88
Loss of use hands/arms	Trouble: accurate movements, fingers/hands, gross movement arms; no = 0 yes = 1; sumscore 0–2	1, score 0 2, score 1–2	0.63
Loss of communication	Trouble: speaking audibly, hearing, seeing, expressing oneself in spoken language; no = 0 yes = 1; sumscore 0–4	1, score 0 2, score 1–4	0.65
Loss of mental abilities	Trouble: concentrating, remembering things longer than 5 minutes, planning/organizing; no = 0; sumscore 0–3	1, score 0 2, score 1–3	0.60
Loss of physical power	Loss: hands/fingers, lower part arms, upper parts arms/shoulders, cervical muscles, lower part legs/feet, upper part legs/feet; 0 = none 1 = bit 3 = lot; sumscore 1–12	1, score 1–5 2, score 6–12	0.80
Dependent on help	Dependent on help: personal care (×6), light work in household (score ×5), heavy work in household (×4), cooking (×3), shopping (×2), transport (×1); 0 = not 1 = partly 3 = fully; weighted sumscore 0–42	1, score 1–7 2, score 8–42	0.83
Work adaptation realized	Work adapted in relation to your sickness or disorder: no = 1 yes = 2		
Work adaptation needed	Need for (further) adaptations: 12 aspects regarding working hours, pace, tasks, material aspects, training etc.: sumscore 0–12	1, score 0–2 2, score 3–12	0.98
No acceptance of disorder in work	Negative remarks superior, negative remarks colleagues, not taken seriously by colleagues due to appearance, no consideration by colleagues, no consideration by superiors, less chances promotion, illness become worse due to disorder: no = 0 yes = 1; sumscore 0–7	1, score 0–2 2, score 3–7	0.70

Period: physical demanding work	1, no period, 2, period with physical demanding work	–	–
Period: mentally demanding work	1, no period, 2, period with psychological demanding work		
Period: unemployment	1, no period, 2, period with unemployment	–	–
Period: shift work	1, no period, 2, period with shift work	–	–
Effect disorder finding a job	Due to disorder problems: finding work, finding a new job; disorder plays role in choice of last job; no = 0 yes = 1; sumscore 0–3	1, score 0 2, score 1–3	0.67
Physical strain	Work demands: gross movements with arms, pushing or pulling something, working in bended/twisted position, bending/twisting upper body; no = 0 yes = 1; sumscore 0–4	1, score 0–2 2, score 3–4	0.76
High strain job	Work demands: time pressure, working to deadlines, working under time pressure and autonomy: in pace of work, order of work, manner of work, amount of work, taking a break	1, max. 1 time pressure/> 2 autonomy 2, 2 time pressure/< 3 autonomy	0.60 0.84
Job content	Work demands: learning new skills, thinking out/performing complicated things, taking decisions yourself, being active with different things, dealing with unexpected events, planning/organizing, taking courses; no = 0 yes = 1; sumscore 0–7	1, score 1–5 2, score 6–7	0.82
Social contacts in job	Work demands: cooperating, working together with others, being able to have a chat, regular discussion on progress, helping each other finish a job; no = 0 yes = 1; sumscore 0–4	1, score 0–3 2, score 4–5	0.60
Adverse physical labour conditions	In work: safety insufficient, fumes, stench, dirt, noise, vibrations, insufficient lighting, bad lighting, heat, coldness, change of temperature, humid air, dry air, lack of fresh air, influence of the weather, dust; no = 0 yes = 1; sumscore 0–18	1, score 0–3 2, score 4–18	0.85
Irregular working hours	Working: long hours, irregular hours, extra hours, in weekend, outside office hours, skipping breakfast; no = 0 yes = 1; sumscore 0–6	1, score 1 2, score 2–6	0.76
Physical work problems	Trouble in daily life *and* work: standing, sitting, climbing ladder, running, walking, sitting in chair/getting up, bending/coming up again, keeping balance, accurate movements legs/feet, accurate movements arms/fingers, squatting/kneeling, talking step up, reaching out arms, gross movements arms, lifting/carrying things more than 5 kg, pushing/pulling no = 0 yes = 1; sumscore 0–16	1, score 0–1 2, score 2–16	0.90
Job dissatisfaction	All in all, your work suits you well (1), reasonably (2), moderately (3) not well (4)	1, score 1 2, score 2–4	–

Table 4. Operationalization of RAND-36 health indicators and Cronbach's α

Item	*Operationalization*	α
Physical functioning	How much limitation during a typical day (1, yes, limited a lot; 2, yes limited a little; 3, no, not limited at all): walking (one block, several blocks, more than a mile); climbing a stair (one flight, several flights); lifting/carrying groceries; bending, kneeling/stooping, bathing/dressing yourself, vigorous activities (like running, lifting heavy objects, strenuous sports); moderate activities (like moving a table, pushing a vacuum cleaner). Sumscore range 0–100; higher = more favourable	0.93
Social functioning	To what extent, in past 4 weeks, has your physical health/have emotional problems interfered with normal social activities with family, friends, neighbours or others? (1, not at all; 2, slightly; 3, moderately; 4, quite a bit; 5, extremely). How much of the time has your physical health or have emotional problems interfered with your social activities (like visiting with friends, relatives) (1, all of the time; 2, most of the time; 3, some of the time; 4, none of the time). Sumscore range 0–100; higher = more favourable	0.71
Role limitations physical	Any of the following problems during past 4 weeks, with your work or other regular daily activities as a result of your physical health? (1, no; 2, yes): cut down the amount of time you spent on work or other activities; accomplished less than you would like; were limited in the kind of work or other activities; had difficulty performing the work or other activities. Sumscore range 0–100: higher = more favourable	0.87
Role limitations emotional	Any of the following problems during past 4 weeks with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)? (1, no; 2, yes): cut down on the amount of time you spent on work or other activities; accomplished less than you would like; didn't do work or other activities as carefully as usual: higher = more favourable	0.82
Mental health	How much of the time during the last 4 weeks (1, all of the time; 2, most of the time; 3, a good bit of the time; 4, some of the time; 5, a little of the time; 6, none of the time): have you been a very nervous person; have you felt so down in the dumps that nothing could cheer you up; have you felt calm or peaceful; have you felt downhearted and blue; have you been a happy person? Sumscore range 0–100; higher = more favourable	0.89
Vitality	How much of the time during the last 4 weeks (1, all of the time; 2, most of the time; 3, a good bit of the time; 4, some of the time; 5, a little of the time; 6, none of the time): did you feel full of pep; have you felt calm and peaceful; did you have a lot of energy; did you feel worn out; did you feel tired? Sumscore range 0–100; higher = more favourable	0.81
Pain	Bodily pain during past 4 weeks (1, none; 2, very mild; 3, mild; 4, moderate; 5, severe; 6, very severe). Interference pain during past 4 weeks with normal work (1, not at all; 2, a little bit; 3, moderately; 4, quite a bit; 5, extremely). Sumscore range 0–100; higher = more favourable	0.78
General health perception	How true or false is each of the following statements for you? (1, definitely true; 2, mostly true; 3, don't know; 4, mostly false; 5, definitely false): I seem to get sick a little easier than other people; I am as healthy as anybody I know; I expect my health to get worse; my health is excellent. In general would you say your health is (1, excellent; 2, very good; 3, good; 4, fair; 5, poor). Sumscore range 0–100; higher = more favourable	0.79
Health change	Compared to one year ago, how would you rate your health in general now? (1, much better than one year ago; 2, somewhat better now than one year ago; 3, about the same as one year ago; 4, somewhat worse than one year ago; 5, much worse now than one year ago). Score ranging from 0–100; higher = more favourable	

Table 5. Frequencies of variables in total population, those retired and those presently working

	Total (n = 987)	*Retired (n = 498)*	*Presently working (n = 410)*
I Independent variables			
1. Personal data			
Women	53%	56%	46%
Men	47%	44%	54%
Age > 35	30%	14%	43%
Age 36–50	42%	42%	47%
Age > 50	28%	44%	11%
Education level low	36%	26%	23%
Education level middle	21%	40%	21%
Education level high	43%	34%	56%
2. Disorder-related characteristics			
SMA	8%	5%	9%
HMSN	24%	19%	32%
DM	27%	31%	23%
MG	35%	39%	30%
Loss of mobility	61%	71%	50%
Loss of use hands/arms	60%	68%	51%
Loss of communication	51%	62%	38%
Loss of mental abilities	29%	35%	22%
Loss of physical power	47%	57%	34%
Dependent on help	32%	44%	17%
3. (Former) work/labour market related characteristics			
Work adaptation realized		22%	42%
Work adaptation needed		30%	27%
No acceptance of disorder in work		32%	30%
Periods with:			
– mentally demanding work		49%	49%
– physical demanding work		50%	41%
– shift work		38%	25%
– unemployment		21%	22%
Effect disorder finding a job		36%	41%
4. Present work characteristics			
Physical strain			27%
High strain job			22%
Job content			41%
Social contacts			68%
Adverse physical labour conditions			18%
Irregular working hours			23%
II Dependent variables			
Retired	50%		
Physical work problems			21%
Job dissatisfaction			39%

1. Patients with SMA indicate more limitations in their physical functioning, though their scores on role limitations due to either physical or emotional problems do not differ significantly.
2. Patients with MG indicate fewer limitations in their physical functioning but they experience, on average, more role limitations due to their physical functioning. Their score on change of health (compared to one year ago) is more favourable.
3. Patients with DM indicate less interference in their social functioning and less role limitations due to physical problems, though their general health perception is relatively unfavourable.

When specific disabilities are taken into consideration, the four types of disorder can be broadly divided into two groups: one mainly characterized by loss of mobility (SMA and

Table 6. Correlation matrices of disorder-related characteristics (n = 986); (former) work and career-related characteristics (n = 908) and present job characteristics (n = 410)

Disorder-related characteristics

Disabilities	1	2	3	4	5	6	7	8	9	10
1. Loss of mobility	–	0.31	0.43	0.42	–0.02	–0.02	–0.04	–0.30	0.16	0.28
2. Loss of use hands/arms		–	0.35	0.35	0.16	0.14	–0.02	–0.07	0.14	0.03
3. Loss of physical power			–	0.39	0.07	0.08	0.08	–0.17	0.19	–0.02
4. Dependent of help				–	0.16	0.10	0.03	–0.02	0.17	–0.10
5. Loss of communication					–	0.34	0.29	0.12	–0.21	–0.26
6. Loss of mental abilities						–	0.26	–0.06	–0.12	–0.11
7. DM							–	–0.45	–0.18	–0.34
8. MG								–	–0.22	–0.34
9. SMA									–	–0.16
10. HMSN										–

(Former) job and career-related characteristics

	1	2	3	4	5	6	7	8
Periods with:								
1. Physically demanding work	–	0.13	0.35	0.08	0.06	0.02	0.17	0.09
2. Psychologically demanding work		–	0.13	0.05	0.06	–0.03	0.15	0.09
3. Shift work			–	0.08	0.03	0.04	0.09	0.02
4. Unemployment				–	0.30	–0.03	0.17	0.09
5. Effect of disorder finding job					–	–0.24	0.17	0.22
6. Work adaptation realized						–	–0.14	–0.26
7. Work adaptation needed							–	0.28
8. No acceptance of disorder								–

Present job characteristics

	1	2	3	4	5	6	7	8	9
1. Work adaptation	–	0.18	0.25	–0.13	–0.11	0.00	0.02	–0.16	0.01
2. Work adaptation needed		–	0.18	0.15	–0.07	–0.01	0.18	0.06	0.30
3. No acceptance disorder			–	–0.02	–0.07	0.05	0.09	–0.13	0.17
4. High strain job				–	0.03	–0.04	0.18	0.14	0.10
5. Job content					–	0.40	–0.02	0.38	–0.04
6. Physical strain						–	0.01	0.15	0.02
7. Social contacts							–	0.19	0.18
8. Irregular working hours								–	0.06
9. Adverse physical labour conditions									–

HMSN) and one mainly characterized by loss of quality of communication (DM and MG). For SMA patients loss of power, mobility and the use of hands and fingers is an almost general feature. This is underlined by the fact that 72% of them are partly or complete dependent on the use of a wheelchair.

The data on specific physical and mental disabilities will again figure in the analysis of labour participation and in the analysis of the way in which the actual working situation is perceived. The data on the quality of health (RAND-36) provide a background to the results on labour participation of patients with these NMD but will not be used in further analyses regarding the working situation. After all, on the basis of the available cross-sectional data it cannot be decided whether the perceived health status is the cause or the result of having a job or not having a job.

Estimating determinants of retirement

As in the overall Dutch population, three personal characteristics are found to be related to labour participation of patients with a NMD: gender, age and level of education. When compared to male labour participation in the overall Dutch population, male NMD patients show a notable drop in their labour participation from the age of approximately 34 years onwards. Between 20 and 30 years, the labour participation of NMD patients increases from 45% to 75% as compared to 66% to 95% in the overall population. While in the

Table 7. Quality of health indicators (means: RAND-36) and types of disabilities (as percentages) in neuromuscular disorder

	DM (%) (*n* = 254)	*MG* (%) (*n* = 326)	*SMA* (%) (*n* = 77)	*HMSN* (%) (*n* = 227)	*Total* (%) (*n* = 884)	*Reference*[a] (*n* = 1063)
RAND-36 indicators[b]						
Physical functioning	53	62*	21*	48	52*	82
Social functioning	80*	71	77	73	74*	87
Role limitation (physical)	71*	55*	67	62	62*	79
Role limitation (emotional)	84	76	83	78	79*	84
Mental health	75	74	77	72	74*	77
Vitality	49	54	60	54	54*	67
Pain	78	83*	77	72*	78	79
General health perception	44*	52	56	57*	52*	73
Health change	35	52*	39	40	43*	52
Disabilities: loss in[c]						
Physical power	54	36*	80*	45	47	
Mobility	58	41	90*	84*	61	
Use of hands/arms	54	59	84*	63	60	
Communication	76*	60*	15*	28*	48	
Mental abilities	49*	25	10*	20*	29	
Dependent on help	37	27	66*	26	32	

[a] The reference group consists of a random sample ($n = 1063$) drawn from the population register of a medium sized town in the Netherlands (Van der Zee and Sanderman 1993).

[b] Asterisk (*) indicates significancy (t-distribution; alpha < 0.005); means per disorder related to overall mean and overall mean related to mean in reference group.

[c] Asterisk (*) indicates significancy (Chi-square distribution; alpha < 0.005); means per disorder related to overall mean and overall mean related to mean reference group.

Table 8. Level of education among working and retired patients with a neuromuscular disease compared to the overall Dutch population, working and unemployed

	Patients		*Overall Dutch population*	
Level of education[a]	*Working (%) (n = 409)*	*Retired (%) (n = 498)*	*Working (%) (n ± 5.7 million)*	*Unemployed (%) (n ± 481 000)*
Low	23	47	25	38
Middle	51	39	51	44
High	26	14	24	17

[a] For reasons of comparability levels of education are defined differently from those in Table 3; low: elementary level or lower vocational training; middle: general education at a middle or higher level and vocational training at a middle level; high: vocational training at a higher level or university.

overall population this rate remains at approximately 90% until the age of 54, in the group of male patients this percentage drops to a level of about 60%.

In the overall female population labour participation is generally lower than among men except in the age category between 25 and 29. It shows a more rapid decrease of labour participation after the age of 29. With female NMD patients, labour participation follows this overall trend with 53% of the women working until age 34 against 58% in the overall female population. After age 34, labour participation of female NMD patients drops steeply to 34% as compared to 54% in the overall population. Between the age of 40 to 44 this percentage rises again to 47% as compared to 55% in the overall population. After age 44 the percentage drops to 20%, while in the overall population the decrease is more gradual.

A third important factor influencing labour participation – next to age and gender – is educational level. Table 8 shows that the educational levels of the working NMD patients resemble those of the overall Dutch labour force; the educational level of unemployed NMD patients is at a somewhat lower level than among Dutch unemployed in general (Statistics Netherlands, 1994).

On the basis of the data regarding the actual retirement age of male and female NMD patients, the probable length of the labour career of the patients still working in 1994 can be estimated. This estimation results in a probable total labour career of 31 years for men and 26 years for women, whereby the considerably higher educational level of those presently working is not taken into account.

To estimate the effects of disorder and work-related characteristics on retirement from the job, unique effects – not reducible to other effects – were calculated. In this analysis gender, age and level of education were also taken into account. Table 9 shows the results of this calculation.

Next to the considerable effects of age, gender and education as already shown before, all disorder-related characteristics except loss of physical power play a role determining retirement. The effect of loss of physical power is already accounted for through the effects of loss of mobility and loss of the use of hands and arms. Apart from these disorder-related characteristics, patients with SMA and those with HMSN have better chances for a prolonged working career.

None of the characteristics related to the labour career have a separate effect on retirement except the presence (for those working) or absence (for those retired) of work adaptations. Work adaptations consist mainly of possibilities to reduce time pressure

demands: working at a slower pace, for less hours and being able to organize work more freely.

The risk of early retirement is four times greater with an unadapted workplace. Asked whether they could have continued if their work had been adapted, of those who retired from work in the last 10 years, 40% replied in the affirmative.

Physical work problems and an overall evaluation of the job

Two aspects in the evaluation of the job of patients presently working are analysed:

1. Disorder-related physical work problems
2. An overall evaluation of the job

Table 9. Personal data and disorder-related and (former) work/labour characteristics predicting retirement from the job among persons with neuromuscular disorders in the age up to 55 years (n = 712): odds ratio with confidence intervals between brackets

	Odds ratio
1. Personal data	
Gender: women	3.3 (2.2–5.1)
Age: >35 (reference category)	–
30–50	2.6 (1.6–4.1)
>50	4.8 (2.1–11.7)
Level of education:	
low	2.5 (1.6–4.1)
middle	NS
high (reference category)	–
2. Disorder-related characteristics	
SMA	0.3 (0.1–8.1)
HMSN	0.3 (0.2–0.6)
DM	NS
MG	NS
Dependent on help	2.2 (1.3–3.8)
Loss of mobility	2.7 (1.7–4.4)
Loss of physical power	NS
Loss of communication	1.7 (1.1–2.7)
Loss of mental abilities	1.8 (1.1–2.9)
Loss of use hands/arms	1.7 (1.1–2.6)
3. (Former) work/labour market related characteristics	
Work adaptations realized	0.2 (0.1–0.4)
Work adaptation needed	
No acceptance disorder	NS
Effect disorder finding job	NS
Periods with:	
mentally demanding work	NS
physically demanding work	NS
shift work	NS
unemployment	NS

Loss of mobility and loss of the use of hands and fingers are determinants of physical work problems (Table 10). Of the job-related characteristics, physical strain and work adaption, wanted as well as realized, are related to physical work problems. The overall evaluation of the job is not related to characteristics of the disorder. Of the job-related characteristics, mental and – especially – physical strain, lack of social contacts, being in want of a work adaption and a poor acceptance of the disorder in the work situation, are determinants of a less favourable evaluation of the job.

Discussion

The results from this study among NMD patients show that a labour career is in reach of NMD patients, even for those with severe limitations. From data gathered in this study it is estimated that for NMD patients presently working, a labour career of 31 years duration (male patients) and 26 years duration (female patients), is quite probable.

Labour participation of NMD patients decreases more rapidly than in the overall population after the age of about 30 to 35. A temporarily drop in labour participation among women between 30 and 35 can possibly be attributed to a period of childbirth and the extra burden caused by the disorder.

Table 10. Personal data and disorder-related and work-related characteristics predicting disorder-related physical work problems and a negative job evaluation among employees with neuromuscular disorders (n = 336): odds ratios with confidence intervals between brackets

	Physical work problems *Odds ratio*	*Negative job evaluation* *Odds ratio*
1. Personal data		
Gender	NS	NS
Age	NS	NS
2. Disorder-related characteristics		
SMA	NS	NS
HMSN	NS	NS
DM	NS	NS
MG	NS	NS
Dependent on help	NS	
Loss of mobility	9.5 (4.8–16.9)	NS
Loss of physical power	NS	NS
Loss of communication	S	NS
Loss of mental abilities	NS	NS
Loss of use hands/arms	4.0 (1.8–9.6)	
3. Work-related characteristics		
Work adaptations realized	2.1 (1.2–3.6)	NS
Work adaptation needed	2.6 (1.4–4.6)	2.9 (1.8–5.1)
Physical strain	4.7 (2.3–8.6)	2.1 (1.2–3.9)
High strain job	NS	2.0 (1.2–3.5)
(Lack of) social contacts	NS	2.0 (1.2–3.2)
(Lack of) job content	NS	NS
Irregular working hours	NS	NS
Adverse physical labour conditions	NS	NS
No acceptance disorder	NS	2.4 (1.4–4.9)

Between the four types of NMDs the amount and the type of limitations as well the perceived health status differ considerably. Though most types of limitations due to NMD diminish chances to continue a labour career, it is concluded that physical limitations seem not to be decisive in that respect. This fits in with conclusions drawn by Yelin *et al.* (1980) regarding patients with rheumatoid arthritis. In this study SMA patients, who are almost all confronted with severe physical limitations, have even better than average chances to continue working. Their early experience with limitations caused by the disease could well be an advantage in the process of adaptation to the special demands imposed by the symptoms of the disease. Those who acquire a NMD at an older age probably have more difficulty in adapting, being forced to deviate from already formed patterns of behaviour. It can be argued that the loss of the quality of communication, the loss of mental abilities and the effect of the diseases on the facial expression, as with some DM patients, are also important for chances on the labour market.

Though the labour participation of NMD patients tends to decrease after the age of 34, the availability of work adaptations makes it possible to prolong the labour career. Many of those who stopped working in recent years indicate that they could have continued working if their job had been adapted to their handicaps.

Analysis of the actual work situation of NMD patients shows that both disorder-related limitations as well as work characteristics play an important role in the amount of physical work problems encountered. It can be argued that physical labour has to be regarded as generally unsuitable for NMD patients. This has implications for the sort and level of education to be attained by NMD patients. Career counselling as a focus point for the choice of an educational programme may improve labour market opportunities as well as quality of employment of NMD patients. Work adaptations may prolong the working career of NMD patients, but the implementation of work adaptations seems not to be without problems. Results suggest that adapting the workplace for persons with a NMD requires more effort and should consist of measures that fit personal requirements. Adaptations aimed at the reduction of time pressure are in great demand: working at a slower pace, for less hours and being able to organize the work more freely.

The overall appreciation of the job is not directly linked to disorder-related characteristics. This suggests that work, even for those with serious physical and other disabilities, can be as rewarding as for persons without (serious) disabilities. There is however an indirect effect of disorder-related characteristics: employees who feel a need for (further) adaptations in the workplace and those experiencing negative (social) effects on the workplace due to their disorder, are less satisfied with their job. Allowing for and accepting the possible limiting effects of the disorder in the work situation are considered to be important in respect to labour participation and work satisfaction of workers with NMD. Reducing time pressure demands and increasing the freedom to organize one's work, are measures to be considered especially.

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