ORIGINAL ARTICLE

Exploring Employment in Consultation Reports of Patients With Neuromuscular Diseases

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ABSTRACT. Minis MA, Cup EH, Heerkens YF, Engels JA, van Engelen BG, Oostendorp RA. Exploring employment in consultation reports of patients with neuromuscular diseases. Arch Phys Med Rehabil 2012;93:2276-80.

Objectives: To explore consultation reports for patient and employment characteristics and recommendations on employment regarding patients with neuromuscular diseases (NMDs).

Design: Retrospective study of multidisciplinary reports.

Setting: An outpatient neuromuscular clinic at a university hospital.

Participants: Reports (N=102) of patients with NMDs.

Interventions: Based on one-off consultations by occupational therapists, physical therapists, and speech therapists and a multidisciplinary meeting, recommendations were developed regarding therapy content and volume in primary care or rehabilitation settings.

Main Outcome Measures: A checklist has been developed to examine employment characteristics. A general questionnaire has been used including demographic variables and data on employment.

Results: Of the 102 reports available, 86 were included for analysis. Sixty-nine reports contained information on employment. Thirty-seven patients (43%) with NMD were employed, most in white-collar or moderately strenuous jobs. Of the 37 employed patients, 28 (76%) worked using adaptations. Thirty-two (87%) had employment problems; of these, 15 (40%) needed improvement in 1 or more environmental factors. Twenty patients (54%) needed advice regarding participation in employment, of whom 19 were referred to primary care or rehabilitation settings for treatment to enhance employment participation.

Conclusions: Eighty percent of the included consultation reports contained information on employment. Less than half the patients with NMD were employed, most in office-related jobs, using some kind of adaptations. Nineteen of 20 patients who agreed to recommendations regarding therapy were adequately referred by occupational therapists and physical therapists for treatment of employment problems.

Key Words: Employment; Muscular diseases; Occupations; Referral and consultation; Rehabilitation; Rehabilitation, vocational; Work.

EMPLOYMENT PLAYS A MAJOR role in the lives of people. This is not only the case for healthy people but also for people with a chronic progressive disease, such as a neuromuscular disease (NMD).[1,2] In a systematic review[3] of factors influencing employment of patients with NMD, few studies were found in which patients with a slowly progressive NMD were the subject of investigation. In addition to factors affecting employment of healthy people, such as age, sex, and education, the type of NMD also influenced possibilities for employment.[4] In a study[4] of 591 patients with NMD, employment status varied from 47.8% for patients with myotonic dystrophy, to 63.7% for patients with hereditary motor and sensory neuropathy type I, to 70.3% for patients with facioscapulohumeral muscular dystrophy. Early identification of the aforementioned factors is important in facilitating continued engagement in employment activities for patients with a progressive disease such as NMD. Because of the slow progressive deterioration, patients with NMD need regular support (eg, by a job coach or case manager) to maintain employment participation.[4] Employment was defined as "the state of being engaged in an activity or service in exchange for wages or salary."[5] Based on their professional domain, occupational therapists, physical therapists, and speech therapists who support chronically ill patients in their daily performance may play a role in preventing job loss.[6] Occupational therapists, physical therapists, and speech therapists are in a position to identify participation problems related to employment.[6] If needed, these therapists can also refer patients to occupational health or vocational rehabilitation services.[6]

Generally, patients with NMDs visit neurologists for medical diagnoses and treatment, not primarily for participation problems regarding employment. After a visit to the neurologist, a group of patients with NMD were consecutively referred to a specialized team of occupational therapists, physical therapists, and speech therapists for a one-off consultation.[7] Based on the results of these consultations and a multidisciplinary meeting in which a neurologist, a rehabilitation physician, and the therapists participated, treatment recommendations were formulated specifying content (including frequency) by occupational therapy (OT), physical therapy (PT), and speech therapy (ST) in primary care or rehabilitation settings.[7] There is a lack of knowledge regarding the

List of Abbreviations

NMD	neuromuscular disease
OT	occupational therapy
PT	physical therapy
ST	speech therapy

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contribution of occupational therapists, physical therapists, and speech therapists in optimizing employment participation of patients with NMDs. The aim of this study was to explore the consultation reports for patient characteristics and employment characteristics, as well as frequency and content of recommendations on employment, of patients with NMDs.

METHODS

Design and Setting

A retrospective analysis was performed using multidisciplinary reports of 102 consecutive patients with NMD visiting the Neuromuscular Centre Nijmegen from December 2002 until June 2003. Inclusion criteria were (1) probable or definite NMD according to the medical records; (2) age 18 years or older; and (3) sufficient command of the Dutch language.[7] Reports of patients with a fast progressive type of NMD, such as amyotrophic lateral sclerosis,[8] and of patients older than 64 years were excluded from analyses.

The multidisciplinary reports consisted of 5 sections: a semi-structured general section containing diagnosis, demographic data, marital status, data on education, leisure activities, work status, and presence of personal equipment or adaptations; 3 specific sections with findings of OT, PT, and ST consultations; and a fifth section with general conclusions and recommendations for treatment (including volume) based on the one-off consultations and multidisciplinary meetings.

General Questionnaire

A general questionnaire including demographic variables (age, sex, marital status, education) and information related to the disease, such as medical diagnosis and duration of complaints, was used. Specific items of the general questionnaire related to paid employment were as follows: employment status (yes/no), source of income (job income, allowance, both job income and allowance, or no personal income), weekly job hours (8–12h, 13–20h, 21–40h), monthly income (<€1000, €1000–€1500, €1500–€2000, >€2000, does not know or wants to keep it private), weekly hours of sick leave (4–12h, 13–20h, 21–40h), percentage working disability (8%–50%, 51%–80%, 81%–100%), and patient status currently under review for disability percentage assessment.[7,9]

Procedure

For analysis of employment problems, the multidisciplinary reports were made anonymous and numbered. For analysis of the reports, a checklist was developed. The first researcher (M.A.M.) analyzed all reports, and 2 other raters (Y.F.H. and R.A.O.) each rated half of the reports. Meetings were used to reach consensus for detailed exploration of employment problems. The procedure consisted of 6 steps:

- Step 1: Selection of reports eligible for analysis.
- Step 2: Exploration of the presence of information on employment in the different sections of the reports.
- Step 3: Division of the reports into 2 groups: "not employed" patients and "employed" patients. Regarding patients who were not employed, reasons for unemployment were recorded. The reports on employed patients were checked in more detail; that is, they were examined to identify employment problems and type of job (office-related white-collar jobs, moderately strenuous jobs for patients with NMD such as nursing and teaching, and labor-intensive blue-collar jobs).[10] If patients worked under preconditions of the presence of adaptations, this was also registered.
- Step 4: Examination of the reports pertaining to work-related environmental factors that needed improvement; that is, terms of employment, task content, working conditions, and social relationships at work.[11]
- Step 5: Examination of whether therapists made recommendations regarding the employment for patients with NMD. Patients' indications that recommendations were not yet necessary or their decisions to postpone them were also registered.
- Step 6: Examination of the reports regarding recommendations for further treatment, patients' consent regarding these recommendations, and how many patients were referred accordingly.

The Medical Ethics Committee of the Radboud University Nijmegen Medical Centre in the Netherlands approved the research project in accordance with the Helsinki Declaration.[12]

Statistical Analysis

Percentage agreement regarding the presence of information on employment in the reports between M.A.M., Y.F.H., and R.A.O. was calculated. For the general questionnaire of the employed and not employed groups, descriptive data were presented. These descriptive data were tested for between-group differences regarding age, sex, marital status, education level, medical diagnosis, or duration of complaints with an unpaired *t* test for the continuous variable "age" and chi-square analyses for the nominal variables.

A *P* value of ≤.05 was considered statistically significant. If data were missing, patients were excluded from analyses. The variables with empty cells or only applicable for the employed were excluded from the table and described in the text. All statistical analyses were performed with the statistical package SPSS for Windows (Version 17.0).[a]

RESULTS

Of the 102 multidisciplinary reports of consecutively referred patients with NMDs, 86 were eligible for analysis. Sixteen reports were not eligible for analysis because of age (≥64y) or the progressive type of NMD such as amyotrophic lateral sclerosis (fig 1, step 1). Two consensus meetings between M.A.M., Y.F.H., and R.A.O. were necessary to reach 100% consensus about the presence of information on employment in 1 or more sections of the multidisciplinary reports.

The presence of work-related information was found in the general section of 69 multidisciplinary reports (80%), in 1 or more specific sections (OT section, 41%; PT section, 23%; ST section, 7%), or in the conclusion (8%) (fig 1, step 2). The reports eligible for analyses (n=86) showed that 37 patients (43%) were employed and wished to stay employed, and 49 (57%) were unemployed (fig 1, step 3).

The demographic data of the 86 patients included showed that the employed patients with NMD (n=37) were significantly younger, predominantly men, and more highly educated. No significant differences between the employed group and the unemployed group were found for marital status, medical diagnosis, and duration of complaints (table 1). Working hours and level of income and percentage disability for work differed significantly between the 2 groups. More than half of the employed patients worked 21 to 40 hours a week. Eight employed patients with NMD reported weekly hours of sick leave, and 3 patients were under review for disability percentage assessment.

The unemployed group (n=49) comprised 29 patients (59%) on disability pension, 3 patients (6%) who wished to return to work, and 17 (35%) for whom no information was present in the reports for obvious reasons. They either were unable to work