Objective: To describe multiple sclerosis and its impact on individuals’ perceived problems in functioning, particularly in the domains of self-care, mobility and domestic life.

Design: A population-based study in a prevalence cohort of multiple sclerosis subjects in Central Finland region carried out in the year 2000.

Subjects: A total of 240 subjects with multiple sclerosis.

Methods: A postal questionnaire for assessing physical functioning was developed.

Results: Ninety percent of the study population completed the study. Subjects’ average age was 48.2 years (range 20–76 years) and time since symptom onset was 15.8 years (range 0–56 years). Of the subjects, 82% were fully independent in self-care activities and 53% in domestic life, 50% were able to walk without any perceived problems and 38% had a permanent need for a walking aid. Fatigue was the most frequent complaint having an impact on subjects’ daily life. Ninety-five subjects out of 240 (40%) were engaged in working life.

Conclusion: These data give a clear indication of favourable functioning in mobility, self-care and domestic life. However, the fact remains that multiple sclerosis is a disabling and costly disease. These results provide information for use by local and national authorities in planning and co-ordinating rehabilitation interventions and social services.

Key words: Participation, activities, multiple sclerosis.

INTRODUCTION

Multiple sclerosis (MS) is a progressive disease of the central nervous system, which has a large impact not only on individuals with MS and their families but also on medical resources and the community (1). Although the epidemiology of MS is well known, relatively little information exists on the extent and nature of functional limitations in this population, despite its obvious importance for health and social service planning (2), and for counselling newly diagnosed subjects and interpreting clinical trials (3). Attempts to estimate the degree of functional limitation caused by MS have been made in some population-based studies (2, 4–7). The findings revealed that the health status of the MS subjects was more favourable than had previously been thought. So far no such studies have been performed in Finland.

Although MS is a rare disease at the population level, it is one of the most common causes of neurological disability among young and middle-aged adults. Finland is among the high-risk regions of MS, with prevalence between 100 and 200 per 100,000 population in different areas (8). The total number of MS subjects in Finland in 2000 was approximately 6000, of whom 2919 were on a disability pension (1.1% of all pensions), 2062 received a disease care allowance, 1769 used the rehabilitation services provided by the Social Insurance Institution of Finland (SII) and 3006 received special refunds for medical costs (9). In a cross-sectional study in Sweden, the total cost of MS was estimated at 586 million EUR, or 53,250 EUR annually per patient. Increased disability has a major impact on the cost of the disease (10).

Assessment of the need for rehabilitation programs is necessary. In Finland, the SII provides rehabilitation for severely disabled people younger than 65 years, but all citizens are entitled to basic healthcare rehabilitation. Municipalities provide services for all age groups and they also have a duty to provide assistive devices to reduce the effect of disability. In most cases, such equipment is provided free of charge. For severely disabled people, social services of various types, such as assistance with personal care, housing, transportation and equipment, are also necessary. Several local authorities regulate the availability of these services.

Diagnosis alone does not explain what patients can do, what they need, what their prognosis will be and what their treatment will cost (11). In order to plan and develop healthcare and resource allocation, it is essential to know the level of functioning of the population with MS. The International Classification of Functioning, Disability and Health (ICF) (12) provides a comprehensive framework for assessment and modelling of the determinants of functioning.

The present study reports a cross-sectional analysis of a prevalence MS cohort carried out in 2000. The aim was to assess physical functioning in MS subjects living in the Central Finland region, and to describe the impact of the MS on individuals’ perceived problems particularly in the ICF domains of self-care, mobility and domestic life. The study is a part of
larger project, the goal of which is to evaluate the outcome measures according to the ICF framework.

MATERIAL AND METHODS

Design and sample
The subjects were identified through an epidemiological survey in the Central Finland Health Care District, which comprises 30 local municipalities. The potential respondents to this cross-sectional study were collected from the Hospital Discharge Registry, and included all individuals with MS living in Central Finland region (population 263,886) in the year 2000. At the time the number of prevalent cases with a definite MS diagnosis was 277 (prevalence rate 105/100,000) (13). Eleven of these were excluded from this study on ethical grounds; 6 because the subject seemed unaware of the MS diagnosis, and 5 who had not contacted the Central Hospital of Jyväskylä. Among the remaining 266 subjects with MS, 240 persons returned the questionnaire, giving a response rate of 90%. Approval of the study was obtained from the Ethics Committee of the Central Finland Health Care District.

Data collection
Data were collected by a postal questionnaire, which was returned by 80% of the respondents (response rate of 90%). Approval of the study was obtained from the Ethics Committee of the Central Finland Health Care District. 266 subjects with MS, 240 persons returned the questionnaire, giving a response rate of 90%. Approval of the study was obtained from the Ethics Committee of the Central Finland Health Care District.

RESULTS

The characteristics of the respondents, non-respondents and excluded subjects are summarized in Table I. In the population-based cohort, 73 subjects with MS were resident in Jyväskylä, fewer than 10 subjects with MS came from 23 out of 30 municipalities and only one small local municipality had no subjects with MS. Answers were obtained from every municipality with MS and in 16 out of 30 municipalities the response rate was 100%. Thus the whole Finland Health Care District was represented. There were no significant differences between women and men in age or in disease duration.

Eight subjects out of 240 were in-patients in health centre wards and 9 subjects were living in sheltered accommodation. The remaining subjects were living at home either alone (20%) or with family members (72%). Almost half of the subjects (n = 111) received the SII disease care allowance and 93% of this number was on a pension. The SII provided outpatient physiotherapy for 62 subjects while a further 48 subjects were receiving it in their local healthcare centres. The average
intensity of physiotherapy was 51 (SD 36) times per year, ranging up to 120 times per year, with 87 subjects receiving 30 or more times per year.

The 3 major symptoms reported as having an impact on their daily life were fatigue (36%), balance problems (29%) and walking difficulties (28%). The frequency of symptoms along with participation restriction is presented in Fig. 1. Seventy-five subjects (31%) used symptomatic medication for their MS symptoms. Thirty-eight subjects (16%) reported that they had no symptoms or signs of MS. Their average age (38.8 years (SD 11.8)) and disease duration (8.1 years (SD 6.4)) were significantly lower ($p < 0.001$) than those who had some symptoms of MS (correspondingly, 49.8 (SD 11.0) and 17.1 (SD 10.8)). Seven subjects with disease duration $\geq$ 15 years had no symptoms of MS at that time. Forty-eight subjects (20%) were receiving disease modifying therapies, of whom 8 reported no symptoms.

**Activity limitations**

**Mobility level.** Fifty percent of the subjects reported being able to walk without any problem and 7% reported being confined to bed. Mobility level and the characteristics based on patients'...
medical records classified by a neurologist are presented in Table II. Almost half of the subjects (46%) used a walking aid outdoors and 33% indoors. Twenty-five percent were able to walk outdoors without a walking aid after disease duration ≥15 years. The most typical walking aids used outdoors were a wheelchair (n = 38) and a bilateral support (n = 26). Nine subjects had a power wheelchair. Average disease duration to the use of a permanent walking aid was 13.1 (SD 8.3) years (range 1–34 years).

**Walking capacity without assistance.** Of the subjects, 32% were able to walk distances over 1 km without any difficulty, 25% had slight difficulties walking without walking aids, 20% had considerable difficulties walking without walking aids, and 23% of the subjects were unable to walk even 5 metres indoors without a walking aid. The mean WIQ distance score was 50.3 (SD 43.6). It ranged from 0 to 100 in all the disease duration groups. The WIQ distance score in the different disease duration groups is presented in Fig. 2. Overall 66% of those with disease duration less than 15 years had no or only minor difficulties in walking distances up to 1000 metres without a walking aid.

**Self-care.** The majority (82%) classified themselves as independent with no or some difficulties regarding self-care activities in daily living. The FSQ score is illustrated graphically in Fig. 3. The mean FSQ P-ADL score was 80.2 (SD 33.2). In those with disease duration under 5 years and 10–14 years the FSQ P-ADL score ranged from 33 to 100; in all the other disease duration groups the range was 0–100. In self-care activities 94% of those with less than 15 years of disease duration were independent with no or some difficulties.

**Participation restriction**

**Domestic life and vigorous activities.** Forty-seven percent of subjects (n = 111) reported participation restriction in domestic life, i.e. needed some aid or assistance, or could not perform the FSQ I-ADL items at all because of MS. The FSQ scores are illustrated graphically in Fig. 3. The mean FSQ I-ADL score was 55.6 (SD 38.6). It ranged from 0 to 100 in all the disease duration groups decreasing gradually with disease duration (Fig. 4). Seventy percent of those whose disease duration was less than 15 years reported no restrictions in domestic life.

Of the subjects 61 (25%) were fully independent without any subjective difficulties in all 3 I-ADL items, 66 subjects (28%) were independent, but with subjective difficulties such as fatigue in one or more of the items, and 47 subjects (20%) required at least some aid or assistance in all the I-ADL items. Twenty percent of the subjects reported ability to participate in vigorous activities, such as sports, without difficulty, while almost 40% were not able to take part in sports at all (Fig. 3).

**Employment status.** Ninety-five subjects out of 240 (40%) were engaged in working life: 61 subjects were employed either full- or part-time, 11 were students, 10 were unemployed, 7 were a housewife/husband and 6 were on sick leave. Thus, over half of the subjects (60%) were retired either on a full disability pension (n = 118), a part-time disability pension (n = 9) or an old age pension (n = 18).

Separate analysis was conducted for 217 subjects who were under age 65 years and not on an old age pension. Seven of them were students, 80 had completed secondary education with practical courses, 111 had completed vocational education

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Table II. Demographics based on medical records from subjects with multiple sclerosis by mobility level

<table>
<thead>
<tr>
<th>Description of mobility level</th>
<th>n ( %)</th>
<th>Gender, % female</th>
<th>Age (years), mean (SD; range)</th>
<th>Years since diagnosis, mean (SD; range)</th>
<th>Years since onset, mean (SD; range)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Can walk without any problems</td>
<td>122 (50.8%)</td>
<td>78.7</td>
<td>42.9 (11.7; 20–71)*</td>
<td>6.3 (6.4; 0–26)*</td>
<td>11.1 (8.9; 0–34)*</td>
</tr>
<tr>
<td>2. Have some difficulties in walking but can walk unaided 100–500 metres</td>
<td>27 (11.3%)</td>
<td>66.7</td>
<td>47.6 (9.6; 34–73)*</td>
<td>9.6 (7.7; 0–30)*</td>
<td>14.5 (9.1; 1–34)*</td>
</tr>
<tr>
<td>3. Can walk about 100 metres using a walking aid (e.g. cane, crutch, walker)</td>
<td>37 (15.4%)</td>
<td>70.3</td>
<td>54.0 (7.1; 41–67)*</td>
<td>13.5 (8.5; 3–42)*</td>
<td>20.0 (8.8; 5–42)*</td>
</tr>
<tr>
<td>4. Use wheelchair regularly</td>
<td>38 (15.8%)</td>
<td>73.7</td>
<td>55.9 (9.6; 36–76)*</td>
<td>16.5 (8.9; 1–39)*</td>
<td>23.2 (11.8; 4–56)*</td>
</tr>
<tr>
<td>5. Are confined to bed</td>
<td>16 (6.7%)</td>
<td>68.8</td>
<td>58.4 (9.0; 39–74)*</td>
<td>20.9 (6.5; 5–35)*</td>
<td>26.1 (7.1; 6–38)*</td>
</tr>
</tbody>
</table>

*p < 0.001 for comparison between groups (ANOVA).
or polytechnics, and 19 had completed university education. Fifty-six percent of them (n = 122) were on a disability pension. No association was found between level of education and employment status. Mean duration from symptom onset to disability pension was 9.1 (SD 7.1) years (range 0–31 years). The proportions of subjects who were engaged in working life decreased sharply in the age groups over 35 years and at the same time participation restriction in domestic life increased (Fig. 5). Among 35–44-year-olds 15% reported participation restriction in domestic life but were still working. By contrast, in the older age group about 30% of those on a disability pension did not report participation restriction. An association was found between employment status and other diseases (p < 0.001), but not between other diseases and self-care activities, walking capacity or participation in domestic life.

DISCUSSION

In this study postal questionnaires focusing on the ICF domains of self-care, mobility and domestic life were used to identify the level of physical functioning of subjects with MS in the Central Finland region. The data provides a mix of encouraging and disappointing messages. Forty percent of the subjects were engaged in working life after an average duration of 15.8 years from symptom onset. Nonetheless, the proportion of working subjects is relatively small considering their high level of activities and participation, i.e. 82% reporting independence in self-care, 50% ability to walk without any problems, and 53% ability to carry out domestic life independently.

The sex ratios, age, disease duration and clinical presentation resemble those of previous larger population-based studies in Northern Ireland (n = 248) (2) and in the USA (n = 162) (4). In our study 69% were fully independent without difficulties in self-care, which compares with the results obtained in the USA. In contrast, in Northern Ireland only 29% were fully independent in self-care. The proportion of subjects we found in full- or part-time employment (25%) is similar to that reported in Northern Ireland, but rather lower than in the USA (53%). In line with the previous population-based studies (2, 4–7) only a minority of our subjects (6%) were institutionalized or in sheltered accommodation. Thus, according to our results almost one-third of the subjects with MS in Finland need special services at home provided by local authorities for people with disabilities, such as a personal assistant, caregiver’s allowance, transportation services or home conversion.

We found an association between self-reported other diseases and employment status. The data on other diseases were not confirmed by reviewing medical records; therefore only the presence of other diseases was used in the analysis. Higher education was not associated with a lower probability of a disability pension. Premature retirement cannot be explained solely by the impact of MS or of physical disability factors. There is known to be an interaction between physical/psychosocial disability and social program factors that contributes to employment status (19).
The self-reported symptoms of our cohort resembled those of the earlier studies by Kraft et al. (20). Fatigue was the most frequent complaint having an impact on subjects’ daily life. In previous studies fatigue has been found to be related to lack of working ability (5) and might separately increase the limitations on functioning of subjects with MS, as reported elsewhere (21). Fatigue and balance problems were the most prevalent in subjects with no participation restriction. Thus, interventions regarding them should be carried out from the onset of the disease. Instead, those who reported participation restriction had greater variation in symptoms; thus effective physiotherapy interventions must address the full range of impairments in body functions and activity limitations.

Assessment of mobility in a disabled population must take into account people who use methods other than walking as their primary means of mobility. In our study 54 subjects (23%) were essentially restricted to a wheelchair or a bed. Nevertheless, more detailed information on the subjective experience of those who are ambulatory is needed. Hence another assessment of mobility, the WIQ distance score, was included in our study. Thirty-eight percent of those who, according to the question of mobility level, were able to walk without any problems reported slight or considerable difficulties in walking without a walking aid over the different WIQ distances. This group of subjects might be at high risk for further deterioration and thus should be a target of preventive healthcare and rehabilitation services aimed at maintaining an independent level of mobility for as long as possible among them.

Limitations in ADL performance also have a great impact on the social roles of subjects with MS and on the well-being of their families (22), and are among the aspects of quality of life that are most affected by the disease (18). Assessments of both P-ADL and I-ADL are advocated to evaluate performance in everyday life in order to implement appropriate management strategies for individuals with MS (23). The majority (82%) classified themselves as independent with no or some difficulties in P-ADL and correspondingly 53% in I-ADL. The ratings of perceived difficulty gave a more complete picture of the situation, since a considerable number of the subjects who were independent in I-ADL reported difficulties in various items (35–62%). The corresponding figure for P-ADL among the independent subjects was lower (16%). Rating of perceived restriction in everyday life indicates a need for interventions to prevent overload and increased ADL dependence.

The number of subjects makes this study one of the largest population-based assessments of MS-related physical functioning in the literature. By studying a population-based sample, we have sought to gain as representative a picture as possible, free from the biases inherent in clinical or hospital-based studies. Given that the study covered 87% of the prevalent population in Central Finland region, we are confident that this has been achieved. We found differences only in the gender distribution between the respondents, non-respondents and excluded subjects with MS, and thus our study showed good internal validity. The representativeness of our study sample is also good, as it formed 4% of the estimated Finnish MS population, and thus can be deemed quite sufficient to estimate national needs for rehabilitation and social services. This study is limited by its cross-sectional design. Many of the questions the study raises relate to temporality, and a cross-sectional design cannot address this issue.

Self-report measures are appealing because they are relatively inexpensive to obtain, data collection is rapid, and they take into account the influence of both environmental and personal factors. It has to be remembered that the perception of difficulty is a personal experience influenced by each individual’s frame of reference. The need of some subjects for help in filling out the questionnaire may have influenced the answers in the present study. There is always a risk that questions in surveys are misunderstood or interpreted differently by different persons. Cognitive impairments (24) and depression (25) can also adversely affect MS subjects’ perception of their disability. However, Gold et al. (26) did not find cognitive impairment in MS to affect the reliability of self-report health measures. The FSQ scale has been found to be internally consistent and valid for MS (18). The WIQ was a reliable measure in patients with peripheral arterial disease (15). Its psychometric properties in MS have not been studied, and may therefore constitute a possible cause of bias. It was originally designed to measure community-walking ability and thus seemed to be practical tool for use among MS population.

The data were collected at the end of the year 2000 and beginning of 2001, and remain up to date, despite the substantial advance in the management of MS with the availability of new disease modifying therapies. Recent studies suggest that MS may be a rather more benign disease than has previously recognised (27, 28), even according to a 50-year prospective study in untreated MS subjects (29). Subjects can fare relatively well without these new disease-modifying therapies and available medications have, at best, moderate short-term efficacy (28). In addition, in Finland a high-quality healthcare services, access to services and a client-orientation make for a more favourable prognosis. For example, 48% of our cohort received physiotherapy compared with 23% in the study by Freeman & Thompson (30).

In this study the concept of functioning refers to the ICF limitations and restrictions related to a health problem. The questionnaire items were linked to the most precise ICF category, as recommended by Cieza et al. (31), and the categories used to measure physical functioning resemble those by Jette et al. (32). The aim of the study was to describe what subjects with MS do in their current environment, i.e. to describe their performance (12). It is distinct from the capacity, which indicate the highest probable level of functioning that a person may reach in a standardized environment. This distinction might be one reason for the poor associations between subjective and objective, performance-based measures of ADL found by Goverover et al. (33), rather than just inaccurate measurement. The ICF enables us to capture more detailed information on ADL performance in subjects with MS and to
identify the impairments or contextual factors contributing to decreased ADL performance.

In conclusion, this study assessed and classified the physical functioning of subjects with MS in the Central Finland region. This study has significant implications for subjects with MS, their family members and rehabilitation professionals. First and foremost, this population-based survey shows mobility and self-care limitations and participation restriction of subjects with MS to be lower than expected. However, MS remains a disabling disease with a large proportion of subjects receiving disability pensions, medication, physiotherapy and special services at home. In Finland MS is thus also a costly disease. Our results provide information for use by local and national authorities in planning and co-ordinating rehabilitation interventions and social services. Because legislation varies from country to country, the results of this study should be viewed accordingly.

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