

A primary care-based needs assessment of people with multiple sclerosis

K MacLurg, P Reilly, S Hawkins, O Gray, E Evason and D Whittington

ABSTRACT

Background

Multiple sclerosis (MS) is a common cause of chronic progressive neurological disability where reduction in quality of life is an important feature. Many GPs have MS patients with a range of disabilities. Little is known about the supply of medical and community services and how this compares with demand.

Aim

We aim to describe a community based sample of MS patients and investigate how disease characteristics, benefits, services accessed and perceived needs relate to sense of wellbeing.

Design

Cross-sectional survey.

Setting

Participants were recruited from a representative network of 30 GP practices across Northern Ireland.

Method

MS patients answered a professionally administered questionnaire and agreed to their medical records being examined. Information was collected about their medical condition, sociodemographic characteristics, receipt of benefits and services, perceived needs and sense of wellbeing.

Results

Of the 149 participants, 23% were mildly affected (Kurtzke's Expanded Disability Status Scale [EDSS] 0–4.5), 41% were moderately disabled (EDSS 5.0–6.5) and 36% were severely disabled (EDSS 7.0–9.5). Disability was related to employment, receipt of benefits and services. Physiotherapy was a commonly perceived need. Other perceived needs differed between the moderately and severely disabled groups. Scores relating to wellbeing were related to disability and perceived needs.

Conclusions

The relationship between use of medical and community services and disability is important for planning service provision. We have shown that perceived needs are related to wellbeing. In a progressive illness these developing needs could be anticipated.

Keywords

disability; multiple sclerosis; needs assessment.

INTRODUCTION

Multiple sclerosis (MS) is the most common cause of chronic neurological disability in young adults. Although it often causes progressively worsening disability, life expectancy is not substantially shortened. The costs of MS are significant in clinical, social and economic terms, and reduction in quality of life is an important feature.¹

Northern Ireland has one of the highest prevalences of MS in the world.^{2–4} Since this prevalence is almost 1 in 600,² we would expect an average practice of 5000 patients to have about eight patients with MS. As individuals progress through various stages of the disease, serial cross-sectional studies report a wide spread of disabilities.⁵ Uncertainty (initially about the diagnosis, then about the prognosis), is a feature of MS — thus, it may be difficult for GPs to identify needs promptly or target resources appropriately.

Within the NHS we can access GPs who coordinate the medical care for almost all of the population, and particularly those with chronic conditions. This research opportunity does not exist within European or US healthcare systems. Studies that recruit participants via outpatient clinics or

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Box 1. Wellbeing score.

Fulfilment questions

Please indicate how true each statement has been for you during the past 7 days (not at all/a little bit/somewhat/quite a bit/very much).

1. Your role has been fulfilling.
2. You have enjoyed the things you usually do for fun.
3. You have been content with the quality of your life.
4. You have felt a sense of purpose in your life.
5. You have felt motivated or keen to do things.

Quality of life questions

1. Overall, how would you rate your own quality of life (11 point scale using appropriate face symbols: 0 [worst possible quality of life] to 10 [best possible quality of life])?



2. Which word best describes how you feel about your life as a whole (terrible/unhappy/mostly dissatisfied/mixed/mostly satisfied/pleased/delighted)?

Box 2. Disability group.

Kurtzke's Expanded Disability Status Scale equates to at least the following mobility:

- Mild (0–4.5). Able to walk 300m without aid or rest.
- Moderate (5.0–6.5). Can walk at least 5m with aids.
- Severe (7.0–9.5). Wheelchair or bed bound.

voluntary groups will disregard people who do not attend these, often the most or least disabled.

In Northern Ireland access is available to a network of primary care practices that have been selected to provide a patient profile broadly representative of the population profile. These practices provide medical services to approximately 180 000 patients (about 10% of the population).

With increasing emphasis on multidisciplinary teams managing chronic disease in primary care, there is a need for coordination between medical and community services⁶ to address the multiple and complex needs of patients. No studies have examined how the supply of community services at home compares with demand.⁶ It might be anticipated that use of services would be related to demographic or

disease characteristics, and that these variables may also influence patients' wellbeing.

Our aim was to describe a representative sample of clinically definite MS patients in terms of demographic and disease characteristics, services accessed and perceived needs, and to explore how these results relate to sense of wellbeing.

METHODS

GPs in the representative network of practices were asked to identify all patients with MS registered with them in 2001 and invite them to participate in the study. Participation involved answering a questionnaire administered by a professional interviewer (in the patient's own home) and giving consent to their medical records being examined.

Questions covered sex, age, employment, marital and residential status, receipt of benefits or pensions and house alterations. Participants were shown a comprehensive list of community services and asked which services they had and also which services they felt they needed but were not receiving. They answered five questions about their sense of fulfilment and completed two Likert scales about their quality of life (Box 1).

Participants also completed a self-assessment sheet based on Kurtzke's Expanded Disability Status Scale (EDSS).⁷ Kurtzke's EDSS is widely used in MS research, and the self-assessment approach has previously been validated.⁸ The EDSS scores were used to divide the participants into three groups determined by their level of disability (Box 2). Data was analysed using these three disability groups, which also facilitated comparison with other studies.⁶

Subsequently, one of two experienced GPs visited the practices and examined participants' primary care medical records. We used a protocol based on Poser's criteria⁹ and piloted with the consultant neurologist to verify the diagnosis of MS from the content of hospital letters. The disease pattern was noted as benign, relapsing remitting, secondary progressive or primary progressive. Timing of symptoms and diagnosis, GP attendances, medications and hospital outpatient appointments were noted in each case.

Data analysis

Information collected was entered on a database (SPSS Version 11.0) for analysis. χ^2 tests were used to explore the relationship between disability group and: employment; medical retirement; receiving disability related income; receiving pension income; housing alterations; over six GP consultations per year; taking less than five, 6–10, or more than 11 regular medications; attending neurology clinics

How this fits in

Many people with multiple sclerosis receive no community services, and little is known about how the supply of these services compares with demand. Quality of life is known to decrease with increasing disability. The patients' sense of wellbeing is related to their perception of having unmet needs, and perceived needs differ between the moderately and the severely disabled.

Table 1. Demographic data.

	Total sample (n = 149) n (%)	Mild EDSS 0–4.5 (n = 35) n (%)	Moderate EDSS 5.0–6.5 (n = 61) n (%)	Severe EDSS 7.0–9.5 (n = 53) n (%)
Male/female (% male)	50/99 (34)	9/26 (26)	22/39 (36)	19/34 (36)
Mean age in years (SD) (range)	51.0 (13.1) (24–82)	47.9 (12.9) (26–82)	50.7 (12.4) (26–78)	53.4 (13.9) (24–76)
Disease pattern (%)				
Secondary progressive	61 (41)	3 (9)	22 (36)	36 (68)
Primary progressive	22 (15)	1 (3)	10 (16)	11 (21)
Relapsing remitting	57 (38)	22 (63)	29 (48)	6 (11)
Benign	9 (6)	9 (26)	-	-
Mean years since first symptoms (SD) (range)				
	19.0 (9.0) (0–41)	13.7 (8.1) (3–33)	15.5 (9.2) (2–37)	18.1 (9.1) (0–41)
Mean years since diagnosis (SD) (range)				
	11.8 (8.4) (0–39)	8.0 (6.2) (0–22)	11.0 (8.5) (0–36)	15.2 (8.3) (0–39)
Marital status (%)				
Married/cohabiting	98 (66)	28 (80)	38 (62)	32 (60)
Separated/divorced	14 (9)	4 (11)	9 (15)	1 (2)
Widowed	14 (9)	2 (6)	5 (8)	7 (13)
Single, never married	23 (15)	1 (3)	9 (15)	13 (25)
Household (%)				
Lives alone	26 (17)	4 (11)	16 (26)	6 (11)
Lives with children only (<18 years)	4 (3)	1 (3)	3 (5)	0
Lives with spouse only	38 (26)	11 (31)	16 (26)	11 (21)
Lives with family or friend	77 (52)	19 (54)	26 (43)	32 (60)
Lives in a care home	4 (3)	0	0	4 (8)
House alterations (%)				
No	79 (53)	30 (86)	29 (48)	20 (38)
Yes	70 (47)	5 (14)	32 (52)	33 (62)
Waiting for house alterations	7 (5)	1 (3)	5 (8)	1 (2)
Employment (%)				
Employed	32 (21)	15 (43)	13 (21)	4 (8)
Medically retired	83 (56)	12 (34)	31 (51)	40 (75)
Retired due to age	16 (11)	4 (11)	8 (13)	4 (8)
Homemaker/student/unemployed	18 (12)	4 (11)	9 (15)	5 (9)
Pensions and benefits (%)				
Pension	47 (32)	8 (23)	14 (23)	25 (47)
Disability related income	116 (78)	14 (40)	54 (89)	48 (91)
Other benefit	24 (16)	2 (6)	14 (23)	8 (15)
No benefits	23 (15)	15 (43)	6 (10)	2 (4)

EDSS = Expanded Disability Status Score. SD = standard deviation.

within the previous year; and having accessed various community services.

The questions on sense of fulfilment in life and perceived quality of life were combined to produce a wellbeing score that had good internal reliability (Cronbach's $\alpha = 0.89$).

ANOVA was used to explore the variance in wellbeing score with disability group, receiving care, receiving therapy, wanting care, wanting therapy or perceiving any unmet needs. The interaction between these measures was examined using linear regression.

RESULTS

Characteristics of participants

178 people with MS were identified, of whom 168 (94%) agreed to participate in the study. Notes were unavailable for 11 and eight did not have a definite diagnosis of MS, leaving 149 participants.

Demographic, disease and socioeconomic details are shown in Table 1. Two-thirds were female. The age of the participants ranged from 24 to 82 years, with a mean age of 51 years. On average, patients were diagnosed with MS 12 years previously, and had experienced symptoms of MS for almost 20 years. Of these, 23% were mildly disabled, 41% were moderately disabled and 36% were severely disabled. Two-fifths had relapsing remitting MS and another two-fifths had secondary progressive MS.

Although most participants were married, this decreased with increasing disability. A quarter of the severely disabled had never married. One-fifth of the participants were the only adult in their household, including four females with children under 18 years.

Twenty-one per cent were employed and 56% were medically retired. Employment decreased with increasing disability ($P < 0.0005$) and medical

Table 2. Medical services.

	Total sample (<i>n</i> = 149) <i>n</i> (%)	Mild EDSS 0.0–4.5 (<i>n</i> = 35) <i>n</i> (%)	Moderate EDSS 5.0–6.5 (<i>n</i> = 61) <i>n</i> (%)	Severe EDSS 7.0–9.5 (<i>n</i> = 53) <i>n</i> (%)
GP consultations per year				
≤3	66 (44)	23 (66)	25 (41)	18 (34)
4–6	51 (34)	11 (31)	20 (33)	20 (38)
7–12	24 (16)	0	13 (21)	11 (21)
≥13	8 (5)	1 (3)	3 (5)	4 (8)
Regular medications				
0–5	82 (55)	33 (94)	32 (52)	17 (32)
6–10	55 (37)	2 (6)	22 (36)	31 (58)
≥11	12 (8)	0	7 (11)	5 (9)
Neurology outpatients				
In past 6 months	27 (18)	6 (17)	14 (23)	7 (13)
In past year	48 (32)	4 (11)	26 (43)	18 (34)
> a year ago	11 (7)	1 (3)	4 (7)	6 (11)
Discharged	63 (42)	24 (69)	17 (28)	22 (42)

EDSS = Expanded Disability Status Scale.

Table 3. Community services.

	Total sample (<i>n</i> = 149) <i>n</i> (%)	EDSS Range (mean, SD)	Mild EDSS 0.0–4.5 (<i>n</i> = 35) <i>n</i> (%)	Moderate EDSS 5.0–6.5 (<i>n</i> = 61) <i>n</i> (%)	Severe EDSS 7.0–9.5 (<i>n</i> = 53) <i>n</i> (%)
Community nursing	28 (19)	6.0–8.5 (7.30, 0.67)	0	6 (10)	22 (42)
Care attendant	17 (11)	6.5–9.5 (7.6, 0.66)	0	1 (2)	16 (30)
Home help	18 (12)	4.5–8.0 (6.8, 1.02)	1 (3)	8 (13)	9 (17)
Physiotherapy	19 (13)	6.0–9.5 (7.0, 0.92)	0	8 (13)	11 (21)
Occupational therapy	14 (9)	2.0–8.0 (6.7, 1.49)	1 (3)	4 (7)	9 (17)
Social work	20 (13)	4.0–8.0 (7.1, 1.08)	1 (3)	4 (7)	15 (28)
Incontinence service	10 (7)	6.0–8.0 (6.9, 0.88)	0	5 (8)	5 (9)
Chiroprapist	6 (4)	6.0–8.0 (6.9, 0.74)	0	3 (5)	3 (6)
Day centre	6 (4)	6.0–9.5 (7.5, 1.30)	0	2 (3)	4 (8)
Respite care	12 (8)	6.0–8.5 (7.5, 1.30)	0	1 (2)	11 (21)

EDSS = Expanded Disability Status Scale. SD = standard deviation.

retirement increased ($P < 0.0005$). However, 12 of the mildly affected were medically retired, while four of the severely disabled were employed.

Forty per cent of those mildly affected received disability-related income. This increased to 91% of those severely disabled ($P < 0.0005$). Receipt of pensions followed a similar trend ($P = 0.010$). Having had house alterations was also related to disability ($P < 0.0005$). Those waiting for house alterations were mostly moderately disabled.

Medical services accessed

The frequency of GP consultations, medication use and neurology outpatient attendances are shown in Table 2. There is weak evidence that the more disabled patients saw their GP more frequently ($P = 0.012$). Taking more medications regularly was very significantly related to increasing disability ($P < 0.0005$). Twelve participants took no regular medications. Only two (6%) of the mildly disabled participants took more than five regular medications, whereas 36 (68%) of the severely disabled participants did so.

Half of the participants were attending neurology clinics. The moderately disabled were most likely to have seen a neurologist in the past year (66%), compared with 47% of the severely disabled and 29% of the mildly affected ($P = 0.002$).

Community services accessed

Table 3 shows which community services were accessed by our respondents. Community nursing is the most commonly accessed service. Receipt of community nursing, care attendant and social work services were significantly related to increasing disability ($P < 0.0005$). Receipt of physiotherapy was weakly related to disability ($P = 0.017$). Similar trends in home help and occupational therapy services failed to reach significance. Respite care is mostly accessed by the severely disabled.

Perceived needs

Table 4 shows the number of people in each group expressing a need for a particular community service.

Physiotherapy is the most frequently perceived need, irrespective of disability. Overall, 13% of the

Table 4. Perceived needs.^a

	Total sample (n, %)	Mild EDSS 0–4.5 (n, %)	Moderate EDSS 5.0–6.5 (n, %)	Severe EDSS 7.0–9.5 (n, %)
Community nursing	4 (128, 3)	0	4 (55, 7)	0
Care attendant	2 (132, 2)	0	1 (60, 2)	1 (37, 3)
Home help	10 (131, 8)	1 (34, 3)	4 (53, 7)	5 (44, 11)
Physiotherapy	21 (130, 16)	1 (34, 3)	11 (53, 21)	9 (42, 21)
Occupational therapy	7 (135, 5)	0	6 (57, 11)	1 (44, 2)
Social work	6 (129, 5)	1 (34, 3)	4 (57, 7)	1 (38, 3)
Incontinence service	7 (139, 5)	2 (35, 3)	1 (56, 2)	4 (48, 8)
Chiropodist	11 (143, 8)	1 (35, 3)	4 (58, 7)	6 (50, 12)
Day centre	1 (143, 1)	0	1 (59, 2)	0
Respite care	16 (137, 12)	1 (35, 3)	5 (60, 8)	10 (42, 24)

^aAlso shows data as a percentage of the number in that group not already receiving the service, as when someone is already receiving it they could not express an unmet need for it.

study group already receive physiotherapy but 16% of the remainder would like to. Although 13% of moderately disabled participants and 17% of severely disabled participants already receive physiotherapy, 21% of the remainder in each group perceived a need for it.

The next most frequently perceived needs were for respite care (12%), chiropody (8%) and home help services (8%). Community nursing was the service already received by the largest number of participants (19%): those who felt they needed but were not receiving community nursing were all moderately disabled. The moderately disabled also perceived needs for occupational therapy and social work. In addition to the list of community services shown, participants also perceived needs for advice ($n = 21$), social support ($n = 10$), specialist nurses ($n = 4$) or a night sitting service ($n = 4$).

Wellbeing

The wellbeing score was related to the disability group ($P < 0.0005$). The lowest possible score was 6 and the highest possible score was 44; the average score for the mildly disabled was 27, for the moderately disabled was 21 and for the severely disabled was 19. This wellbeing score was not related to the services received, but it was related to perceived needs ($P = 0.010$). Wanting care services such as community nursing, care attendants or home help was particularly important ($P < 0.0005$). Stepwise linear regression showed that disability accounted for 18.9% of the variation in wellbeing score (standardised β coefficient -0.435 , $P < 0.001$) and wanting care services accounted for a further 5.2% of this variation (standardised β coefficient -0.231 , $P = 0.002$).

DISCUSSION

Summary of main findings

This is a population-based survey of use of medical and community services, financial support, home

modifications, perceptions of unmet needs and quality of life for people with MS. Overall, receipt of benefits and use of GP and community services increases with increasing disability. Although this finding was anticipated it is useful to quantify for planning service provision.

The association between increasing disability and increasing GP consultation rates is not as marked as might be anticipated, possibly because the biggest difference is between the mildly affected and the other two groups. Moderately and severely disabled patients may be consulting about different issues as evidenced by a significant difference in their medication use. Neurology outpatient attendances are highest in the moderately disabled group.

Evidence for increased receipt of physiotherapy with increasing disability is weak, possibly because of the generally low rate of physiotherapy provision or because limited resources are accessed by the moderately disabled. Overall, physiotherapy is the most commonly perceived need. The nature of other perceived needs differs between the moderately disabled and severely disabled groups. Perceived needs of the moderately disabled such as community nursing, occupational therapy and respite care are already received by severely disabled participants, suggesting a lag time between a need developing and a service being accessed.

A patient's sense of wellbeing is not related to the services they already receive, as might be anticipated, but is related to them having a perception of unmet needs. A perceived need for care, such as community nursing, a care attendant or a home help is particularly significant. We suggest that addressing these unmet needs may improve patients' sense of wellbeing. However, it is possible that a poor sense of wellbeing could be expressed as a desire for more services; this study design does not explore causality.

Comparison with other studies

The range of disability, demographic and diagnostic characteristics are broadly similar to those reported from other studies,^{4,6,10,11} so we suggest that our findings may be applicable in other settings. A smaller proportion of our participants were employed compared to the study by Freeman.⁶ This study has been performed in a region known to have high unemployment in the general population (which may make work harder to find or the concept of giving up work more acceptable).

The increased receipt of benefits and use of GP and community services with increasing disability in this study agrees with previous findings.^{6,11} Our results also concur with reports that only half the population with MS are regularly seeing consultant neurologists.¹⁰

In this study, community nurses visited a similar proportion (19%) of participants to that reported elsewhere.^{6,10} However, our participants received less input from home helps, physiotherapists and occupational therapists than these studies report. Here, 13% of participants were attending physiotherapy compared to 23% in Freeman's study⁶ and 38% in Somerset's.¹⁰ The disability range for those receiving community nursing, physiotherapy and home help is narrower in our study than reported elsewhere.⁶ This is relevant when perceived needs are examined.

Disability measured by Kurtzke's EDSS⁷ has been shown to follow a bimodal distribution with peaks between 1 and 3.5 and between 6 and 6.5.^{12,13} This suggests there are at least three different groups of patients with different needs and expectations: those with minimal disability who are 'getting on with their lives'; those who are working hard to 'stay on their feet' but are starting to fall out of employment; and those who have become dependent on their family and social services. Our findings agree with this model.

Strengths and limitations of this study

GPs asked to identify cases for this study may have omitted or overlooked less severe cases (particularly in males). In this study, 23% of participants were mildly disabled compared to 32% in Freeman study.⁶ Within our mildly disabled group 26% were male compared to 40% in Freeman's. The theory that GPs selected cases likely to respond to our request is supported by the high participation rate from those identified. They may not have wished to disturb those with minimal disability, however, if participants had been recruited from the neurology clinic, more of the severely disabled would also have been excluded. We would have anticipated identification of up to 300 cases from this population. Those without disability may be under-represented among our participants but this may not be a disadvantage in the context of this study.

Participants' judgement of their own EDSS⁷ has previously been validated^{8,14} and minor variations are unlikely to have affected their disability group. However, assessing disability on a scale dominated by mobility may not reflect patients' priorities, and a questionnaire study focuses on areas of interest to the researchers. Since this study aims to explore how a patient's perception of unmet needs is related to their sense of wellbeing, we do not attempt to explore how justified that perception is the viewpoint of a health professional. We used a few simple questions on fulfilment and quality of life to produce a wellbeing score with good internal reliability. As the score reflects the perception of each participant it also has face validity.

Implications for future research and practice

We have shown that the use of medical and community services increases with increasing disability, but it is the perception of unmet needs that influences a patient's sense of wellbeing. The moderately disabled perceive different unmet needs from those perceived by the severely disabled. In a progressive illness this could be anticipated and mechanisms put in place to address these needs as they develop.

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Ethics committee

Approval was obtained from Queens University research ethics committee, 179/00.

Competing interests

None

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