

**The nature of care giving in a community sample of people with
multiple sclerosis.**

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The nature of care giving in a community sample of people with multiple sclerosis.

Abstract

Purpose The provision of informal care plays a crucial role in supporting those with long term illness such as MS to stay in the community, but there is no recent United Kingdom (UK) research into the nature of this care provision and how it interacts with professional community care. The aim of this study was to investigate the nature of informal and professional care in a community population of people with MS living in the UK from the perspectives of people with MS.

Method Data on the Standard Day Dependency Record (SDDR), Barthel Index, a measure of disability, and SF-36 were collected from a community sample of volunteers with MS from a postal questionnaire and visits from researchers

Results The response rate was 61%, (n=169). Respondents in this study were most likely to be assisted by family rather than health or social service professionals and the help was considered essential for approximately 70% of individuals. Only 15% of respondents in this survey received visits from a professional in the preceding 24 hours. There was a subgroup who considered help to be significantly more essential and who required assistance on more occasions by the SDDR ($t=13.01$, $df=622$, $p<0.001$, $t=10.38$, $df=36.4$, $p<0.001$). Other subgroups were also identified who may be in need of support from professionals but who were not receiving it.

Conclusions There are reports of considerable amounts of care being provided by families to people with MS who may not be receiving the support required from professional caregivers. Further work needs to establish which groups need assistance and what form this assistance should take.



Introduction

Multiple sclerosis (MS) is the most common neurological disease in young adults.¹ Individuals with MS experience an array of symptoms and disabilities, which can place a major burden on those with MS and their families, as well as on health and social services and the voluntary sector. Although much has been done to improve standards of health care for people with MS and their carers in the UK, services and resources vary across different health regions, and in general, still leave much to be desired.^{2 3 4}

However, published research in this area is limited. All of the publications cited above are position papers rather than research reports with the exception of Compston et al.² who report findings from an unpublished study. Studies investigating the perceptions of people with MS and carers are particularly rare. Although some papers were identified from Australia, Canada, and America^{5 6 7} the only substantial sized study in the UK was conducted some twenty years ago by Elian and Dean.⁸ These researchers conducted interviews with 200 people with MS living in the community to investigate which health and social benefits they were receiving. At that time, major concerns were identified such as a lack of awareness of available services. In addition many respondents were not receiving essential services such as cash benefits, house alterations and home help. Of course, these findings cannot really be considered to apply to the present situation as many changes have occurred in health and social services provision since 1983. In addition, there is little published research to date, on the nature of informal care in MS in the UK. Examples of recent work are studies by Chipchase and Lincoln⁹ who conducted a postal survey of carers and demonstrated that carer strain was associated with memory problems experienced by people with MS and a qualitative study of carers, conducted for the MS society by Robinson and Hunter.¹⁰ The small amount of research in this area in the UK is arguably surprising given that informal caregivers, usually family members, play such a crucial role in



providing care and since there is a heavy reliance on them to allow those with long term illness to stay in the community. ¹¹

The overall nature of informal caregiving has gradually been receiving more attention in recent years and is now recognised as being a major component of community care. ^{12 13} It has been defined by Parker¹⁴ as the support and assistance provided on an informal basis to disabled and older people living in the community, usually by family members and close friends. While there is generally more understanding overall of the nature of caring, work remains to be done to understand how carers fit into the service system and show insight into particular situations.¹⁵ This is relevant to multiple sclerosis where further research is needed to update previous findings in relation to the level and quality of professional care, and to address a gap in research on informal care. The aim of this study is to address these areas of need and investigate the nature of informal and professional care in a community population of people with MS living in the UK, from the perspectives of people with MS.

Objectives

Specific objectives of the study were to: identify the incidences of care giving, the frequency of occurrences and the persons who provided the care: compare the nature of care provided by a health professional and an informal caregiver; characterise those people most in need of care by investigating relevant demographic, disease and psychological factors.

Method

The data were collected with a postal survey (for participants' self reports using questionnaires) and with a visit by health professionals (for assessment of mobility disability). There were no second mailing of questionnaires. This was a community based research study, which met the required standards of the appropriate Health Authority local research ethics committees.



Participants

Participants were volunteers with MS who were recruited through voluntary organisations, were community based and lived in West London and in counties contiguous with Greater London. The voluntary organisations were those specifying MS as a focus of their work. Participants gave informed consent to be involved, and a telephone help line was provided to deal with queries regarding the study.

The only selection criterion was that the diagnosis of MS was confirmed in writing by the general practitioner. There were no exclusion criteria. Two hundred and seventy eight people with MS were invited to take part in the study. Of these 169 (61%) completed it.

Insert Table 1 here

Table 1 presents the demographic profile of the sample. The ratio of women to men was just over 2:1, which approximates the pattern found in other studies, as does the average age of respondents. The majority of individuals were married and living with husbands or wives (83%) and were not in paid employment at the time of the study (76%). There was a good mix of people with varying levels of education, with the largest minority having at least secondary education (37%). On average, this sample were quite experienced with regard to living with MS (mean = 11.83). Approximately half the sample had the relapse remitting form of the disease (47%), half had chronic progressive MS (48%), and just under one third of the sample had had a relapse in the last six months (31%).

Measurement Tools

A range of physical and psychological scales were administered to participants. One measure developed for the study; the Standard Day Dependency Record (SDDR) was the main focus for analysis and discussion in this paper.



The SDDR

The SDDR was developed out of the Medical Research Council (MRC) Standard Day Interview by Lawson et al ¹⁶ and measures the extent to which people are assisted in activities of daily living in one 24 hour period. The scale comprises six questions. Question one asks about the number and type of people in a person's home in that time period. The categories of people include family members, friends and neighbours, health and social service staff and others. Questions two to six are concerned with the number of occasions people have been assisted in 5 life domains (rated from 0 to 5 or more), the type of person giving assistance and the degree to which this help was needed (rated essential, desirable, not strictly needed). The five life domains include personal care, mobility, household tasks, leisure and employment.

In addition, a number of items have also been combined into sub-scales with summing. The first sub-scale SDDRO measures the number of occasions people have been helped in the last 24 hours in all five life domains. Possible scores range from 0 to 30 with a higher score indicating the need for greater assistance. The second subscale SDDRE gives an indication of how essential this help was. Possible scores range from 5; help was not needed, to 15; help was essential in each life domain.

Other measures

Total scores on the Barthel Index ¹⁷, a scale measuring mobility ¹⁸, and the UK version of the SF-36 ¹⁹ were also administered to respondents.

Data analysis

Data were analysed with parametric and non-parametric descriptive and inferential statistics where appropriate.

Results

The incidences of care giving, the frequency of occurrences and the persons who provided the care were identified.



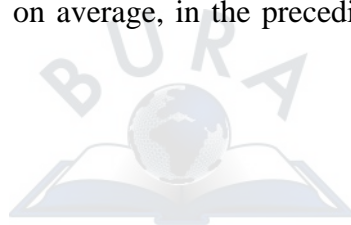
Insert Fig 1 here

Figure 1 presents histograms of the number of people in each category who visited respondents at home in the preceding twenty four hours. It is clear people with MS from this population are most likely to have contact with family rather than with either friends and family, health and social services staff or others. The median and modal score for this category was one, as compared to 0 for the other categories. Within the family category (a), most respondents had contact with just one person (79, 47%), and the majority had contact with four people or fewer (162, 96%). Just nineteen respondents had not been visited by any family members (11%). Within the friends and neighbours category (b) most respondents indicated they had no visits (106, 63%), and this was also the case in the other category (d) (140, 83%).

Graph c contains the histogram for the frequency of visits by health and social services staff. The majority of respondents had not had visits from either health or social service professionals in the preceding twenty four hours (144, 85%). Out of those twenty five individuals who had received such visits (15%), twelve received one visit (7%) and seven received two visits (4%), with the remaining individuals receiving between three and seven visits (6, 3%).

Insert Table 2 here

Table 2 presents descriptive statistics for the number of occasions people were assisted within each life domain. Mean scores indicate that respondents were assisted most often with household tasks, typically, approximately two and a half times in the preceding 24 hours (mean 2.64, s.d. 2.29). Mean scores indicated that respondents received help with decreasing frequency for mobility, personal care and leisure, on approximately one occasion, on average, in the preceding 24 hours (mean 1.27, s.d.



2.03, mean 1.13, s.d. 1.99, mean .86, s.d. 1.66 respectively). Finally, the mean score for employment was comparatively very low (mean 0.19, s.d. 0.80)

An examination of the patterns of frequencies of scoring in each domain is interesting. In total 127 received assistance with household tasks, 63 received assistance with mobility, 60 people received assistance for personal care, 57 with leisure and 13 with employment.

There was a good spread of scores for household tasks with one quarter of individuals receiving no assistance (n=42), 40% receiving assistance on between one and three occasions, and just over one third of respondents receiving assistance on four or more occasions (n=58). However, the majority of individuals, over 60% for personal care, mobility and leisure, received no assistance in these life domains in the preceding 24 hours (63%, 65% and 66% respectively), thus it could be argued, that modal and median scores, all zero, were the most representative measures of central tendency in this instance. It is noteworthy that most respondents did not receive any assistance with employment (92%). However, this figure may well reflect the fact that just 24% of the sample were in paid employment at the time of the study, rather than levels of assistance that were needed or available (n=40).

Insert Table 3 here

Table 3 presents descriptive statistics of the types of people providing assistance and how essential this assistance was. The statistics demonstrate that family and friends were providing most assistance within each domain. Family comprised from 58% of those providing assistance with employment to 84% of those providing assistance with household tasks. Health professionals were most likely to provide assistance with personal care (21%) and mobility (13%), and did not provide any assistance with employment. Help was considered to be essential for approximately 70% of individuals receiving help in each domain, with the exception of employment. Although only 12 individuals received assistance in employment, it is interesting that just 50% reported that this help was essential, whereas 50% reported that this help was desirable.



Insert Table 4 here

Table 4 presents descriptive statistics for the scales, SDDRO measuring number of occasions assisted, and SDDRE measuring how essential assistance was over all the 5 key life domains. The mean and median scores indicated most respondents were scoring towards the lower end of the scales. In fact the modal scores indicated that the most frequently occurring score was zero indicating that no assistance was given in any life domain.

The nature of care provided by a health professional and an informal caregiver were compared.

Insert Table 5 here

Table 5 compares the number of occasions those individuals who had health or social service professionals visit them in the preceding 24 hours received help in each life domain, with the number of occasions those who were not visited, received help. Just 25 individuals out of 169 (15%) received a visit from health or social service professionals in the preceding 24 hours. A comparison of the measures of central tendency reveal that the group who were visited by professionals, received more assistance on average, than the other group in personal care, mobility, household tasks, leisure and employment. For example, the group visited by professionals received assistance 3 times, as compared with 0.8 times in the other group. These figures appear to indicate that those most in need of assistance are most likely to be visited by health professionals.

However, a comparison of the patterns of frequencies for each domain in the health/social services professionals and the other group reveal, that there are some individuals who receive assistance on numerous occasions in each domain, who are not visited by health professionals. For example, there is a subgroup of thirteen individuals (9%), amongst those not visited by health professionals, who received assistance five or more times with personal care and mobility.



Insert Table 6 here

Table 6 compares those providing assistance in each domain, and how essential such assistance was, in the group visited by health/social service professionals in the preceding 24 hours with those who were not visited by health/social service professionals.

The pattern of findings with regard to the people providing assistance, confirms findings presented in table 3, that health professionals are most likely to provide assistance with personal care (12, 57%). Health professionals seem to take responsibility for assistance with tasks, that would otherwise be performed by family and friends, as family and friends provide over 90% of assistance with personal care, mobility and household tasks in the group not visited by health professionals, and with 88% of assistance with leisure and 60% of assistance with employment.

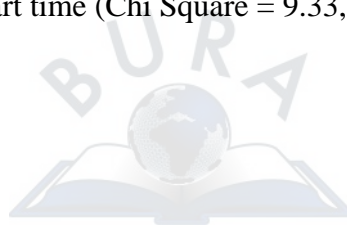
Insert Table 7 here

Table 7 presents measures of central tendency for SDDRO and SDDRE scales in the group visited by health/social service professionals, and those not visited by such professionals. Means, modes and medians indicate that, on average those visited by professionals, are assisted more, and consider assistance to be more essential than the group who are not visited.

Those people most in need of care were characterised by investigating relevant disease, demographic and psychological factors.

Insert Table 8 here

Table 8 compares the demographic profile of those 32 respondents in the top third of the distribution on the SDDRE scale indicating help was most essential, with a random sample of 32 respondents from the rest of the sample. The only demographic variable for which there was a significant difference between groups was employment status. Respondents in the “essential” group were significantly less likely to be in paid employment, either full or part time (Chi Square = 9.33, df 1, p= 0.01).



Insert Table 9 here

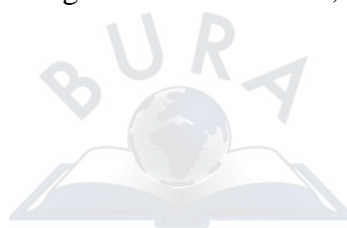
Table 9 compares mean scores on a range of physical and psychological variables between the group for whom help was most essential, and a random sample of similar size, from the remainder of the original sample.

Comparison of the measures of central tendency in the two groups indicates that those in the “essential” group not only considered help to be more essential, but also had more assistance in all life domains, were less mobile and independent and had lower quality of life scores on all eight scales in the SF-36. Independent samples t-tests were computed to test the significance of the difference between scores for all measures except the Barthel which was assessed with a Mann Whitney U Test. Findings were that the “essential” group not only considered help to be significantly more essential but also required assistance on significantly more occasions as measured by the SDDR ($t = 13.01$, $df = 622$, $p < 0.001$, $t = 10.38$, $df = 36.47$, $p < 0.001$ respectively). In addition the “essential” group were significantly less mobile and less independent than the “less essential” group ($t = -8.16$, $df = 62$, $p < 0.001$, $U = 76.50$, $p < 0.001$ respectively). Finally, participants in the “essential group” had significantly worse quality of life in terms of physical and social function ($t = -4.87$, $df = 56.34$, $p < 0.001$, $t = -2.30$, $df = 62$, $p = 0.03$ respectively).

Discussion

The aim of the study was to address an identified gap in existing research in the UK by investigating the nature of informal and professional care in a community population of people with MS living in the UK. This was investigated primarily by asking people with MS about the nature of care received in the preceding twenty four hour period.

The first specific objective was to identify the incidences of care giving, the frequency of occurrences and the persons who provided the care. Many people in this community sample of people with MS did not receive any assistance, for example over half the sample in this study had not received any assistance with personal care, mobility or leisure in the preceding 24 hours. However, where assistance was given, it



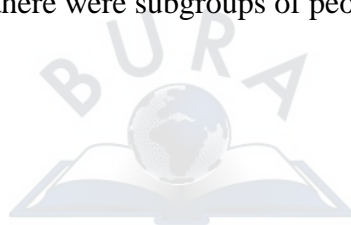
was most likely to be in the domain of household tasks, with respondents receiving assistance approximately 2 and a half times, within that time frame. This finding is consistent with Canadian research, in which household tasks were identified by people with MS as being an area in which they were most frequently in need of assistance.⁶

Respondents in this study were most likely to be assisted in all domains of care including personal care, mobility, household tasks, leisure and employment by family, rather than health or social service professionals, friends or “others”. This finding is again similar to that of Aronson et al⁶ who found that the primary care giver was most often a family member and was the sole caregiver in 42% of situations. The assistance was considered to be essential by approximately 70% of respondents in this study (with the exception of assistance with employment for which the figure was slightly lower). This finding is also consistent with the results of a UK study of people with MS by Freeman and Thompson³ where many people with moderate or severe disability failed to receive assistance from community care services.

The second objective of the study was to compare the nature of care provided by a health professional and an informal caregiver. Just 15% of respondents in this survey had received visits from health/social service professionals in the preceding 24 hours. This percentage is quite similar to the number reported to receive care from health professionals and “other Organizations” in a large scale Australian survey⁵.

Research findings indicated that health professionals were most likely to provide assistance with personal care and mobility. This may reflect a number of approaches such as the current remit of community health services or an emphasis on nursing and therapy provision or access to and knowledge of availability of services. These issues need further investigation. Freeman and Thompson²⁴ found in their study that for those people with MS who received health services the provision was also from nurses and therapists.

On average individuals in the group visited by health professionals received more assistance than those not visited by health professionals and considered assistance to be more essential, however, there were subgroups of people in the group not visited



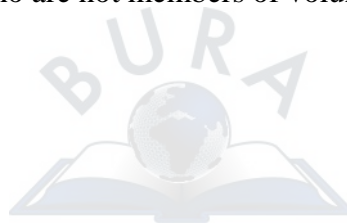
by health professionals who also received frequent assistance. These results suggested that there was a subgroup of individuals who may well have been in need of support from health or social service professionals, but who were not receiving it. It would seem that, as was the case in the UK in the 1980s not everyone who is “entitled”, or in this case, is in need, is in receipt of health and social care services. ⁸

The third and final objective of the study was to characterise those people most in need of care by investigating relevant demographic, disease and psychological factors. This was investigated by comparing those individuals who reported help was most essential, identified by selecting individuals scoring 10 to 15 on the SDDRE, with a random sample of the same size from the remainder of the sample. The only difference in the demographic profile of the two groups was that those in the “essential” group were significantly less likely to be in paid employment. Previous research has demonstrated that the ability to maintain a paid job is related to the severity of the disease and cognitive function. ²⁰

Findings from this study indicated that those in the “essential group” were significantly less mobile and independent and received significantly more assistance than those in the “less essential” group, as well as perceiving assistance to be more significantly more essential. These findings suggest that this group may have had a more severe form of MS. Once again these findings support those of research from other countries. For example Aronson et al ⁶ found that those with greater frequency and duration of assistance also had reduced mobility and more severe MS symptoms. In this study this increased physical disability also had negative implications for mental health. This was because the “essential” group had significantly poorer health related quality of life in terms of physical and social function as measured by the SF-36 than the “less essential” group. ¹⁹

As with any research this study had limitations which should be taken into account when considering the conclusions made.

Firstly, the sample comprised community based, self selected, members of voluntary organizations, thus findings may not be generalized to other MS populations such as those in hospitals or those who are not members of voluntary organizations. People



with MS who participate in research may also be quite different from those who choose not to participate. Schwartz and Fox ²¹ found that participants in their study were more often disabled from work, lived a moderate distance from where the trial took place, and had higher incomes than those who did not participate in a randomised controlled trial of two psychosocial interventions. The problem of sampling error is also hard to overcome given that, a representative sample can only be obtained when an exhaustive list of all possible subjects is available, and this is not the case in MS, at least in the UK. In addition of course, all ethical studies require participants to consent to being involved and to co-operate.

Secondly, the SDDR was developed for the purpose of this study. Although the results of this research, for example apparent links between the SDDR scores and levels of independence, provide some evidence for the convergent validity of the scale, further work is necessary to investigate its reliability and validity for this population.

This study focused on the perspective of people with MS. Future research might examine investigations from the perspectives of carers as previous research has found that caregivers consistently rated assistance as being given significantly more frequently and for longer duration, than did people with MS. ⁶

The research undertaken by Elian and Dean ⁸ twenty years ago demonstrated that several respondents with MS did not always receive and were not always aware of essential services. The research reported here has found similarities to Elian and Dean⁸ and shown that care needs today are still not always met and of concern there may be subgroups of people with MS not reaching vital services at all. Questions need to be asked about real improvements in service delivery for people with chronic conditions such as MS, living in the community. Although we now have policies in place to deliver care in the community the findings raise important questions about the delivery of this care to groups needing assistance and what form this assistance should take.

Guidelines on the management of MS in primary and secondary care have recently been published by the National Institute of Clinical Excellence (NICE)²⁵. These



guidelines specify recommendations on how services can meet the needs of people with MS and their carers in the areas of personal support, mobility, activities of daily living, leisure, employment and social activity. The research reported here has highlighted the need for implementation of the NICE Guidelines and provides a baseline of information against which future improvements may be measured. Future research will be required to evaluate the effectiveness of services in delivering the recommended support and care from the perspective of the service users.

Acknowledgements

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Table 1 Demographic profile of the sample

Sex	Males	51 (30%)	females	118 (70%)
Age	mean 51.33, SD 10.75		minimum 28	maximum 81
Do you live?	by yourself	19 (11%)	with husband/wife	137 (81%)
	with partner	6 (4%)	with other adults	7 (4%)
With children?	yes	27 (16%)	no	142 (84%)
Marital status	single	6 (4%)	married	140 (83%)
	divorced	16 (9%)	widowed	3 (2%)
	living with partner 4 (2%).			
Employment status	Full time	17 (10%)	part time	23 (14%)
	not working	113 (67%)	voluntary work	15 (9%)
Education	none	33 (20%)	primary	3 (2%)
	secondary	62 (37%)	technical	38 (22%)
	tertiary	31 (19%)		
Years since diagnosis	mean 11.83, SD 8.57		minimum 1	maximum 44
Type of MS	relapse-remitting	80 (47%)	chronic progressive	82 (48%)
	Gp's didn't know 7 (4%)			
Relapse in the last 6 months?	yes	52 (31%)	no	115 (69%)



Figure 1 Type and number of people in respondents' homes (N = 169 respondents)

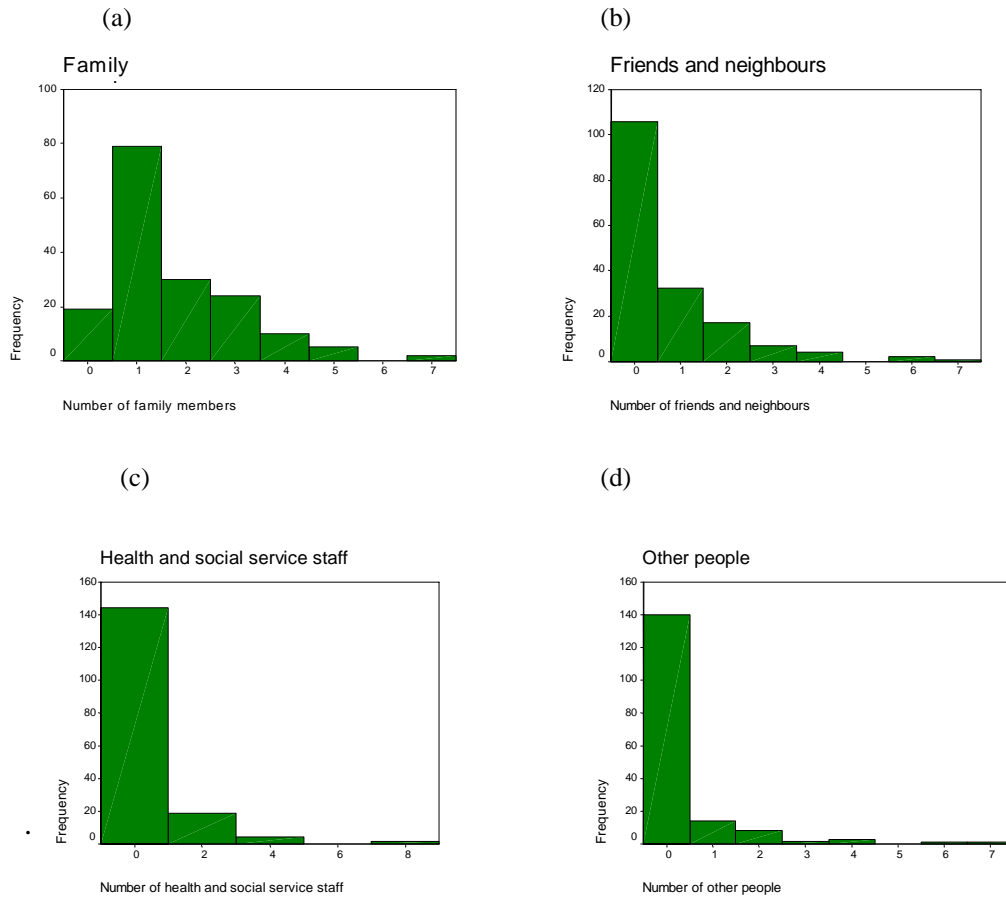


Table 2 Number of occasions assisted in each life domain

Life domain	Mean	SD	Frequencies (%)						
			0	1	2	3	4	5	5+
Personal care	1.13	1.99	109 (65)	21(12.5)	10 (6)	5 (3)	4 (2)	1 (.6)	19 (11)
Mobility	1.27	2.03	106 (63)	12 (7)	15 (9)	11 (6.4)	5 (3)	1 (.6)	19 (11)
Household tasks	2.64	2.29	42 (25)	26 (15)	26 (15)	17 (10)	12 (7)	6 (4)	40(24)
Leisure	0.86	1.66	112 (66)	29 (17)	6 (4)	6 (4)	3 (2)	3 (2)	10 (6)
Employment	0.19	0.80	156 (92)	4 (2)	5 (3)	2 (1)	0	0	2 (1)

Modes and medians for each domain were zero.



Table 3 People providing assistance and how essential assistance it was.

Domain	People providing assistance (%)				Was assistance essential ? (%)		
	Family	Friends	Health/ Soc. Serv	Others	Essential	Desirable	Not strictly needed
Personal care	44 (76)	0	12 (21)	2 (3)	42 (70)	17 (28)	1 (2)
Mobility	49 (79)	2 (3)	8 (13)	3 (5)	50 (79)	13 (21)	0
Household tasks	105 (84)	3 (3)	9 (7)	8 (6)	90 (72)	30 (24)	5 (4)
Leisure	46 (81)	4 (7)	4 (7)	3 (5)	39 (68)	16 (28)	2 (4)
Employment	7 (58)	3 (25)	0	2 (17)	6 (50)	6 (50)	0

Total numbers receiving assistance: Personal Care: 60, Mobility: 63, Household tasks: 127, Leisure: 57, Employment: 13.



Table 4 Number of occasions assisted, and how essential assistance was over all domains.

Scale	Mean	Mode	Median	S.D.	Range
SDDRO	6.1	0	3	6.7	0-30
SDDRE	5.1	0	3	4.2	0-15

N = 169



Table 5 Number of occasions assisted in each domain by those visited by health professionals and those who were not.

Group		Personal care (%)	Mobility (%)	Household Tasks (%)	Leisure (%)	Employment (%)
Health pros n=25						
Mean		3.0	3.1	4	1.3	1.16
Median		3.0	3.0	5.0	1.0	1.0
Mode		6.0	6.0	6.0	0.0	0.0
S.D.		2.2	2.2	2.3	1.8	1.3
Frequencies	0	4 (16)	5(20)	3 (12)	10 (40)	23 (92)
	1	5 (20)	2 (8)	3 (12)	10 (40)	1 (4)
	2	2 (8)	3 (12)	1 (4)	1 (4)	0
	3	4 (16)	4 (16)	3 (12)	1 (4)	0
	4	3 (12)	4 (16)	2 (8)	0	0
	5	1 (4)	1 (4)	2 (8)	1 (4)	0
	5+	6 (24)	6 (24)	11 (44)	2 (8)	1 (4)
Not Health pros n=144						
Mean		0.8	1.0	2.4	0.8	0.2
Median		0.0	0.0	2.0	0.0	0.0
Mode		0.0	0.0	0.0	0.0	0.0
S.D.		1.8	1.8	2.2	1.6	0.7
Frequencies	0	105 (73)	101 (70)	39 (27)	102 (71)	133 (92)
	1	16 (11)	10 (7)	23 (16)	19 (13)	3 (2)
	2	8 (6)	12 (8)	25 (17)	5 (3)	5 (4)
	3	1 (0.5)	7 (5)	14 (10)	5 (3)	2 (1)
	4	1 (0.5)	1 (0.5)	10 (7)	3 (2)	0
	5	0	0	4 (3)	2 (1)	0
	5+	13 (9)	13 (9)	29 (20)	8 (6)	1 (0.5)



Table 6 People providing assistance and how essential assistance it was for those who were visited by health professionals and those who were not.

Domain	People providing assistance (%)				Was assistance essential ? (%)		
	Family	Friends	Health/ Soc. Serv	Others	Essential	Desirable	Not strictly needed
Health Profs.	N = 25						
Personal care	8 (38)	0	12 (57)	1 (5)	19 (90)	2 (10)	0
Mobility	9 (45)	1 (5)	8 (40)	2 (10)	19 (95)	1 (5)	0
Household tasks	10 (45)	1 (5)	8 (36)	3 (14)	21 (95)	1 (5)	0
Leisure	9 (60)	0	4 (27)	2 (13)	10 (67)	4 (27)	1 (6)
Employment	1 (50)	0	0	1 (50)	1 (50)	1 (50)	0
Not Health Profs.	N = 144						
Personal care	36 (97)	0	0	1 (3)	23 (59)	15 (38)	1 (3)
Mobility	40 (95)	1 (2)	0	1 (2)	31 (72)	12 (28)	0
Household tasks	95 (92)	2 (2)	0	6 (6)	69 (67)	29 (28)	5 (5)
Leisure	37 (88)	4 (10)	0	1 (2)	29 (69)	12 (29)	1 (2)
Employment	6 (60)	3 (30)	0	1 (10)	5 (50)	5 (50)	0



Table 7 Number of occasions assisted, and how essential assistance was over all domains.

Scale	Mean	Mode	Median	S.D.	Range
Health professionals					
SDDRO	11.5	6 ^a	12.0	6.8	0-30
SDDRE	9.2	12	9.0	3.6	0-15
Not health professionals					
SDDRO	5.1	0	3.0	6.3	0-26
SDDRE	4.4	0	3.0	3.9	0-13

^a Multiple modes exist, others were 10,12 and 14 (n=3).



Table 8 Demographics of those most in need of assistance, compared with those less in need.

Demographic variables	Essential n = 32	Less essential n = 32	Chi Square/ *T –test, df	Significance (2 tailed)
Sex Male Female	11 (34%) 21 (66%)	13 (41%) 19 (59%)	0.27, 1	p = 0.61
Age	Mean 54.8 SD 11.6, Range 28-81	Mean 51.2 SD 10.6, Range 34-79	* 1.32, 62	p = 0.19
Do you live ? By yourself With partner With other adults	4 (13%) 26 (81%) 2 (6%)	2 (6%) 28 (88%) 2 (6%)	4.75, 3	p = 0.19
With children ? Yes No	4 (2%) 28(88%)	5 (16%) 27 (84%)	0.13, 1	p = 0.72
Marital Status Single Married Divorced Widowed Living with partner	1 (3%) 28 (88%) 2 (6%) 1 (3%) 0	1 (3%) 24 (75%) 3 (9%) 1 (3%) 3 (9%)	3.51, 4	p = 0.48
Employment ^a Status Fulltime Part time Voluntary work Not working	1 (3%) 0 1 (3%) 30 (94%)	6 (19%) 2 (6%) 2 (6%) 22 (69%)	6.33, 1	p = 0.01
Education None Primary Secondary Technical Tertiary	1 (34%) 11 (34%) 6 (19%) 7 (22%)	4 (12%) 0 14 (44%) 8 (25%) 6 (19%)	2.54, 4	p= 0.64
Years since diagnosis	Mean 11.67 SD 7.8, Range 4-40	Mean 11.71 SD 9.1, Range 1-44	*-0.02, 59	p = 0.98
Type of MS Relapse remitting Chronic progressive Not known	10 (31%) 21 (66%) 1 (3%)	17 (53%) 14 (44%) 1 (3%)	3.22, 1	p = 0.07
Relapse in last six months ? Yes No	8 (25%) 24 (75%)	(31%) (66%) 1missing	0.41, 1	p = 0.52

^a Recoded into is/is not in paid employment for Chi Square



Table 9 Comparison of the psychological and physical profiles of those most in need of assistance and those less in need of assistance.

Tool	Scale	Assistance essential		Assistance less essential		t, df	Sig. (2 tailed)
		Mean	S.D	Mean	S.D.		
SDDR	SDDRE	11.72	0.96	4.00	3.21	13.01, 62	p<0.001
	SDDRO	16.81	5.39	4.09	4.36	10.38, 36.47	p<0.001
Mobility		2.03	1.93	6.91	2.77	-8.16, 62	p<0.001
*Barthel		10.50	0-20	18.00	12-20	76.50	p<0.001
SF-36	Physical function	6.70	16.85	31.58	23.40	-4.87, 56.34	p<0.001
	Physical role	19.02	24.72	25.78	40.40	-0.81, 51.36	p=0.42
	Pain	52.97	32.54	64.03	24.90	-1.53, 58.04	p=0.13
	General health	40.59	16.39	45.91	20.35	-1.15, 62	p=0.25
	Vitality	33.25	21.26	39.49	22.77	-1.13, 62	p=0.26
	Social function	45.70	28.86	62.89	30.86	-2.30,62	p=0.03
	Role emotional	49.72	43.10	64.58	46.33	-1.33,62	p=0.19
	Mental health	59.75	26.22	71.41	21.21	-1.96,62	p=0.06

Barthel descriptives = median and range, significance test = Mann Whitney U.
 Higher scores mean more mobility, range 0-11, better quality of life in the SF-36, range 0-100, and more independence in the Barthel, range 0-20. Higher scores mean more assistance required in the SDDRO, range 0 –30, and SDDRE, range 5-15. N = 32 in each group.



References

- ¹Minden SL. Neuropsychiatric aspects of multiple sclerosis. *Current Opinion in Psychiatry* 1996, **9**: 93-97.
- ²Compston DAS, Evans CD, Feneley RCL, McLellan DL, Pentland B, Roberts MHW, Wiles CM. *Multiple Sclerosis: A working party report of the British Society of Rehabilitation Medicine*. London: BSRM, 1993.
- ³Freeman J, Johnson J, Rollinson S, Thompson A, Hatch J *Standards of healthcare for people with MS*. London: The MS Society, The National Hospital for Neurology and Neurosurgery, 1997.
- ⁴Nodder D, Chappell B, Bates D, Freeman J, Hatch J, Keen J, Thomas S, Young C. Multiple sclerosis: care needs for 2000 and beyond. *Journal of the Royal Society of Medicine* 2000, **93**: 219-224.
- ⁵Black DA, Grant C, Lapsley HM, Rawson GK. The services and social needs of people with multiple sclerosis in New South Wales, Australia. *Journal of Rehabilitation* 1994, **60**: 60-65.
- ⁶Aronson KJ, Gleghorn G, Goldenberg E Assistance arrangements and use of services among persons with multiple sclerosis and their caregivers. *Disability and Rehabilitation* 1996, **18**: 354-361.
- ⁷O'Brien RA, Wineman NM, Nealon NR. Correlates of the caregiving process in multiple sclerosis. *Scholarly Inquiry for Nursing Practice: An International Journal* 1995, **9**: 323-342.
- ⁸Elian M, Dean G. Need for and use of social and health services by multiple sclerosis patients living at home in England. *The Lancet* 1983, **1**: 1091-1093.
- ⁹Chipchase SY, Lincoln N B. Factors associated with carer strain in carers of people with multiple sclerosis. *Disability and Rehabilitation* 2001, **2**: 768 – 776.



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- ¹⁰ Robinson I, Hunter M, Neilson S. *A dispatch from the frontline: The views and needs of people with multiple sclerosis about their needs: A qualitative approach*. A report for the Multiple Sclerosis Society, Brunel MS Research Unit, London. 1996
- ¹¹ Dewis MEM, Niskala H. Nurturing a valuable resource: family caregivers in multiple sclerosis. *Axone* 1992; **13**: 87-94.
- ¹² Caring for People : Community Care in the next decade and beyond. HM Stationery Office, 1989.
- ¹³ Carers (Recognition and Services) Act. HM Stationery Office, 1995.
- ¹⁴ Parker G. *With Due care and attention : a review of research on informal care..* London. Family Policy Studies Centre, 1990.
- ¹⁵ Twigg J, Atkin K. *Carers Perceived*. Open University Press, 1994
- ¹⁶ Lawson A, Robinson I, Bakes C Problems in evaluating the consequences of disabling illness: The case of multiple sclerosis. *Psychological Medicine* 1985, **15**: 555-579.
- ¹⁷ Gompertz P, Pound P, Ebrahim S. A postal version of the Barthel Index. *Clinical Rehabilitation* 1994, **8**: 233-239.
- ¹⁸ De Souza L. The development of a scale of the Guttman Type for the assessment of mobility disability in multiple sclerosis. *Clinical Rehabilitation* 1999, **13**; 476-481.
- ¹⁹ Medical Outcomes Trust. SF-36 Health Survey Scoring Manual for English Language Adaptations. Boston 1994
- ²⁰ Hakim EA, Bakheit AMO, Bryant TN, Roberts MWH, McIntosh-Michaelis SA, Spackman AJ, Martin JP, McLellan DL (2000) The social impact of multiple sclerosis – a study of 305 patients and their relatives. *Disability and Rehabilitation* 22(6), 288-293.



²¹ Schwartz CE, Fox B. Who says yes? Identifying selection biases in a psychosocial intervention study of multiple sclerosis. *Social Science and Medicine* 1995, **40**:359-370.

²² Donohoe KM, Wineman NM, O'Brien RA. Are alternative long-term care programmes needed for adults with chronic progressive disability? *Journal of neuroscience nursing* 1996, **28**: 373-380.

²³ McNally S, Ben-Shlomo Y, Newman S. The effects of respite care on informal carers' well-being: a systematic review. *Disability and Rehabilitation* 1999, **21**: 1-14.

²⁴ Freeman JA, Thompson AJ. Community services in multiple sclerosis: still a matter of chance. *Journal of Neurology Neurosurgery Psychiatry* 2000, **69**: 728-732.

²⁵ National Institute for Clinical Excellence (NICE) Multiple Sclerosis: Management of Multiple Sclerosis in Primary and Secondary Care. Clinical Guideline 8. National Institute for Clinical Excellence Publications London 2003



