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Evaluation of the effectiveness of professionally guided self-care for people with multiple sclerosis living in the community: a randomized controlled trial

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Objective: The aim of the study was to assess the efficacy of a patient-focused professionally guided self-care programme for the management of multiple sclerosis (MS) in the community.
Design: This was a single-blind randomized controlled trial.
Setting: The study was conducted with people with MS living in the community.
Participants: Two hundred and seventy-eight people with MS were invited to take part in the study. One hundred and eighty-nine people consented to take part (68%). Of these 183 began the study and 169 (92.3%) completed it. Seventy-three individuals were in the intervention group and 96 were in the control group.
Intervention: The intervention comprised discussion of self-care based on client priorities, using an information booklet about self-care.
Main outcome measures: These included the Barthel Index, a measure of mobility, the SF-36, and the Standard Day Dependency Record (SDDR) which measures the need for assistance with daily activities. Assessments were conducted at baseline and again six months later.
Results: Changes in health status were small. However, at follow-up the intervention group had better SF-36 health scores, in mental health ($p = 0.04$), and vitality ($p = 0.05$) and considered help with daily activities to be less essential, as measured by the SDDR ($p = 0.04$), than the control group. Participants in the intervention group had maintained levels of independence at follow-up ($p = 0.62$) while the control group showed a significant decrease in independence ($p = 0.001$).
Conclusion: This intervention could be a useful aid for health professionals who are supporting people with MS living in the community.

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Introduction

Multiple sclerosis (MS) is the most common neurological disease in young adults.[1] The disease course is very varied, but is progressive in nature in many people. 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.

The MS Society have produced a document about the standards of health care for people with MS in which it is asserted that current service provision is inadequate.[2] Furthermore, a recent UK 'cost of illness' survey demonstrated that the bulk of NHS costs in MS are associated with hospital inpatient and outpatient treatments, which generally relate to the management of acute phases in illness only.[3] It has also been noted that many people with MS and carers experience problems with obtaining appropriate information about MS.[4,5] Therefore, despite the efforts of voluntary agencies such as the MS Society and health professionals such as MS nurses, there would still seem to be an information gap.

This evidence indicates that many people with MS are frequently left to their own devices when dealing with day-to-day living with MS. For this reason self-care is a key part of the lives of people with MS.[6] Self-care has been variously defined, but in this study was 'things people do to help themselves because of their MS'. Despite the importance of self-care there is little research in this area.

Many self-care regimes may be harmful, thus people following such regimes could benefit from professional advice.[7] However, even when people with MS consult health professionals 'noncompliance' can be a problem, perhaps because their priorities and those of professionals are divergent.[8,9] Thus it would seem to be important to recognize the views and priorities of people with MS when giving such advice. In fact, the importance of recognizing the needs of all service 'consumers' is gaining increasing recognition in the NHS.[10]

The rationale for the conduct of this study was the recognition of the need for more research into self-care, coupled with the need for professional support and the importance of addressing the views of people with MS. To this end a Delphi study was conducted to identify the self-care views and priorities of a community population of people with MS.[6] A professionally guided programme, focusing on these priorities, was then designed. The aim of this study was to test the efficacy of this consumer-focused professional advice about self-care for a community population of people with MS. The hypotheses were that there would be significant improvements in (a) independence in daily living, (b) need for assistance with activities, (c) functional mobility and (d) quality of life in a group of people with MS receiving the professionally guided self-care programme, compared with a control group.

Method

The study was a single-blind randomized controlled trial. It was a community-based research study, which was approved by the appropriate local research ethics committees, and was conducted at the Centre for Research in Rehabilitation at Brunel University's Osterley Campus in West London from June 1996 until February 1999. Participants were volunteers with MS who were recruited through voluntary organizations, were community based and lived in West London and in counties contiguous with Greater London. The only selection criterion was that the diagnosis of MS was confirmed by the general practitioner. There were no exclusion criteria.

The intervention

Participants were invited to join the study and were accepted when informed consent had been given in writing. Power calculations, with 95% confidence intervals, indicated that 180 participants would be required to identify significant change in functional status between groups as measured by the mobility scale.[12]

Participants were randomized into control and intervention groups after baseline assessments. Those in the intervention group were invited to participate in the self-care programme as soon after baseline as possible. Those in the control group received no intervention, but were just assessed at baseline and follow-up. Follow-up

assessments were conducted six months after baseline.

The self-care programme primarily comprised a discussion of self-care strategies supported by an information booklet developed for the study in line with consumer priorities.[4] Participants in the intervention group were contacted by telephone, by a health professional employed for the project, and an appointment was made to discuss self-care strategies relevant to each individual and to introduce the information booklet. Individuals were assigned to group or one to one sessions by the health professional in consultation with each person, and based on their needs and wishes. Sessions were conducted either at participants' homes or in local therapy centres. The discussions lasted between 1 and 2 hours and were conducted on two occasions, over a one month period.

Topics in the booklet covered many domains of life from the physical (e.g. mobility and exercises) to the social and the psychological (e.g. strategies to cope with stress). As findings from the Delphi study highlighted the need for flexibility and responsiveness to individuals the format of the discussion focused on individuals' interests and concerns rather than on covering all the information contained in the booklet.[4]

Assignment and blinding

An independent person not involved in the study randomized each participant using random number tables, with odd/even number allocation to intervention/control group, with random draw. Each random number was written on paper and sealed in an opaque envelope prior to the start of the study. An independent person held the envelopes and had no contact with the assessors. The health professionals administering the intervention received the sealed envelopes from the independent person, in groups of ten, following the baseline assessments. Names of participants were written on the outside of the envelopes and then the envelopes were opened to reveal their assignment to control or intervention. Information concerning the intervention and the assessments were stored separately. The blind code was broken after the final follow-up assessments had occurred. Evidence for the success of the blinding was not gathered.

Main outcome measures

A range of physical and psychological scales was included in order to obtain a comprehensive evaluation of the intervention. Total scores on a postal version of the Barthel Index,[11] a scale measuring mobility,[12] the United Kingdom version of the SF-36[13] and one measure developed for the study; the Standard Day Dependency Record (SDDR), were the main outcome measures.

The SDDR was developed out of the MRC Standard Day Interview[14] and measures the extent to which people are assisted in activities of daily living. The scale comprises two subscales, with items summed to achieve total subscale scores. The first subscale, SDDRO, measures the number of occasions people have been helped in the last 24 hours in five key life domains, including personal care, mobility, household tasks, leisure and employment. 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 is. Possible scores range from 5 (help is not needed) to 15 (help is essential) in each life domain.

Data analysis

Scale scores on the outcome measures in the control and intervention group were compared in two ways. The clinical impact of the intervention was assessed using change scores and an effect size statistic. The change score was calculated by subtracting the average initial score from the final score, and the effect size statistic was calculated by dividing this by the standard deviation of the initial score.[15] A value of between 0 and 0.19 is considered negligible, 0.20 to 0.50 is small, 0.51 to 0.80 is medium and greater than 0.80 is large.[16] The statistical significance of the difference between scores was compared within and between control and intervention groups over time, in a two-factor, two-level, mixed design analysis of variance (ANOVA) or with nonparametric tests of significance, where appropriate. Although multiple statistical tests were used it was decided not to use the Bonferroni method to correct for possible type 1 errors. This was considered inappropriate because some variables such as the mobility scale, the Barthel and the physical function scale of the SF-36 were corre-

lated.[11–13] This meant that the Bonferroni would be too conservative and might miss real differences between groups.[17] Missing values on scales were replaced with group means for each outcome measure. It was not possible to perform an 'intention to treat' analysis as those individuals who declined the intervention also withdrew from follow-up and therefore did not complete any follow-up assessments.

Results

Two hundred and seventy-eight people with MS were invited to take part in the study. One hundred and eighty-nine people consented to take part (68%). Of these, 183 began the study and 169 (92.3%) completed it.

Figure 1 presents a flow diagram of the progress participants made through the study in the control and intervention groups. Six people dropped out before randomization. Following randomization, 13 withdrew or were lost to follow-up and one person was removed from the study because they did not have confirmed MS. The demographics of the people who were not randomized, withdrew or were lost to follow-up ($n = 19$) were compared with the rest of the sample. This subgroup were more likely to live alone (chi square 6.13, df 1, $p = 0.01$), and had MS for significantly longer than the rest of the sample (drop-outs: mean 18.21 years, SD 12.82, others: mean 11.82 years, SD 8.6, t-value –2.12, df 19.88, $p = 0.05$).

Seventy-three (43.2%) individuals in the intervention group and 96 (56.8%) individuals in the control group completed the trial.

Table 1 presents the demographics of the inter-

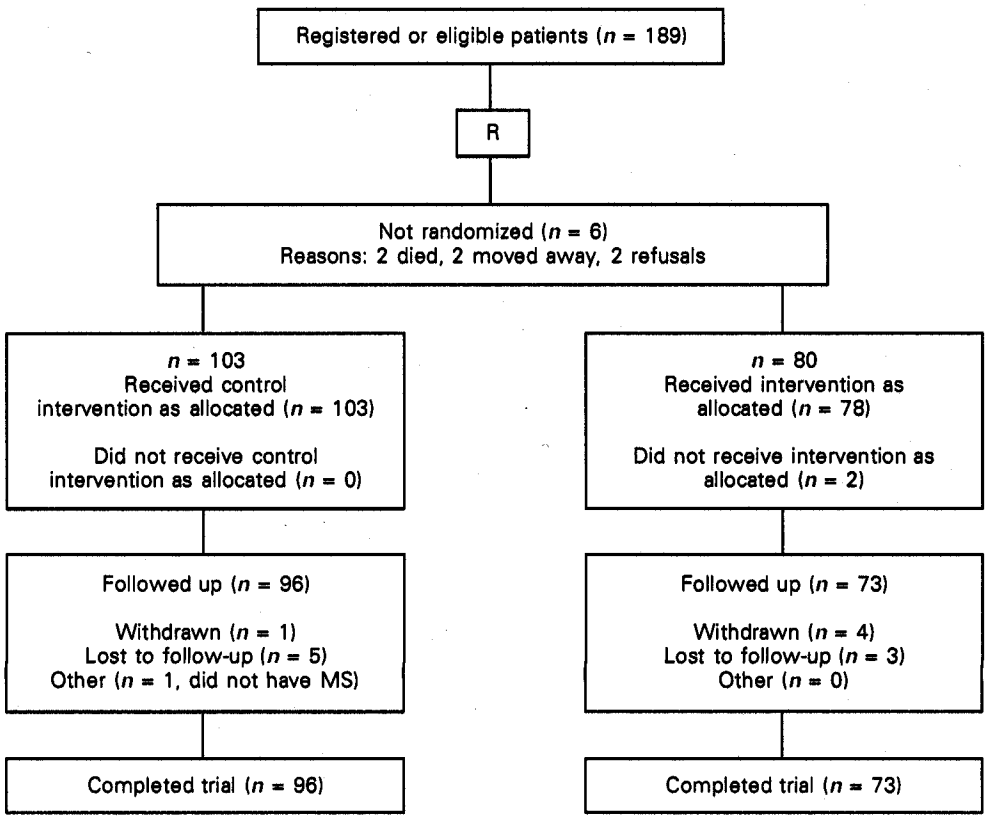

Figure 1 Profile of the trial

vention and control groups. There were no significant differences between the two groups in terms of demographics or illness-related factors at baseline. Furthermore there were no significant differences between the two groups, in the number of individuals who had experienced relapses, over the course of the study (chi square 0.16, df 1, $p = 0.69$).

Tables 2 and 3 present average scores, 95% confidence intervals and measures of dispersion for each group at baseline and follow-up. The baseline scores for the intervention and control groups were similar.

All of the SF-36 scores were lower than those in the general population.[18] This is indicative of the immense impact of MS on all aspects of health-related quality of life. The lowest SF-36 scale scores in this sample were for physical function and role, which reflects results in other studies of MS.[19] The low score for vitality may be indicative of fatigue, a common MS symptom.[20]

Table 4 presents the change scores, between baseline and follow-up, in the intervention and control groups. As might be expected, the change scores indicated that respondents in both groups deteriorated in mobility over time, however this

Table 1 Demographics of the sample

Demographics		Intervention ($n = 73$)	Control ($n = 96$)
Sex	Male	28 (29%)	23 (32%)
	Female	68 (71%)	50 (68%)
Age		Mean 52.5 SD 11.2, Range 28–79	Mean 50.4 SD 10.4, Range 30–81
Do you live	By yourself?	9 (12%)	10 (10%)
	With partner?	61 (84%)	82 (86%)
	With other adults?	3 (4%)	4 (4%)
With children?	Yes	11 (15%)	16 (17%)
	No	62 (85%)	80 (83%)
Marital status	Single	3 (4%)	3 (3%)
	Married	59 (81%)	81 (85%)
	Divorced	6 (8%)	10 (10%)
	Widowed	2 (3%)	1 (1%)
	Living with partner	3 (4%)	1 (1%)
Employment status	Full time	9 (12%)	8 (8.3%)
	Part time	9 (12%)	14 (15%)
	Voluntary work	5 (7%)	10 (11%)
	Not working	50 (69%)	63 (66%)
Education	None	13 (18%)	20 (21%)
	Primary	2 (3%)	1 (1%)
	Secondary	24 (34%)	38 (40%)
	Technical	16 (22.5%)	22 (23%)
	Tertiary	16 (22.5%)	15 (15%)
Years since diagnosis		Mean 11.3 SD 7.6, Range 1–38	Mean 12.2 SD 9.2, Range 1–44
Type of MS	Relapse remitting	32 (44%)	48 (51%)
	Chronic progressive	38 (52%)	44 (46%)
	Not known	2 (3%)	3 (3%)
Relapse in last six months? (at baseline)	Yes	24 (33%)	28 (30%)
	No	48 (67%)	67 (70%)
Relapse during study?	Yes	20 (27%)	29 (30%)
	No	53 (73%)	67 (70%)

difference was more marked in the control group. In contrast the median score on the Barthel remained stable.

There were mixed patterns of change in the SDDR scores in both groups over time. The mean number of occasions helped (SDDRO) increased slightly in the intervention group but increased somewhat more in the control group. The mean score for perceived necessity of help (SDDRE) decreased in the intervention group

Table 2 Descriptive statistics at baseline

Tool	Scale	Intervention ($n = 73$)			Control ($n = 96$)		
		Mean	95% CI	SD	Mean	95% CI	SD
Mobility		5.8	(5.0, 6.6)	3.7	5.8	(5.1, 6.4)	3.4
SDDR	SDDRO	5.5	(4.0, 7.0)	6.3	6.6	(5.1, 8.0)	7.0
	SDDRE	5.0	(4.0, 6.0)	4.3	5.2	(4.3, 6.0)	4.2
SF-36	Mental health	68.7	(64.0, 73.4)	20.1	69.2	(64.6, 73.7)	22.4
	Pain	60.8	(54.0, 67.6)	29.2	61.4	(56.0, 67.0)	27.1
	Physical role	34.5	(25.5, 43.5)	38.5	24.3	(17.3, 31.3)	35.7
	Physical function	25.6	(19.7, 31.5)	25.2	25.4	(20.7, 30.2)	23.4
	Role emotional	64.4	(54.3, 74.4)	43.2	57.8	(48.8, 66.8)	44.4
	Social function	60.1	(52.9, 67.3)	30.7	61.3	(55.8, 66.8)	27.2
	Vitality	38.9	(34.3, 43.6)	19.8	38.6	(34.0, 43.2)	22.8
	General health	42.7	(37.7, 47.7)	21.4	44.4	(40.7, 48.0)	18.0
		Median	95% CI	Range	Median	95% CI	Range
Barthel		17	(15.5, 18.0)	0–20	17	(16.0, 18.0)	0–20

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 less independence in the SDDRO, range 0–30, and SDDRE, range 5–15. 95% CI, 95% confidence interval; SD, standard deviation; SDDR, Standard Day Dependency Record; SDDRO and SDDRE, subscales of the SDDR.

Table 3 Descriptive statistics at follow-up

Tool	Scale	Intervention ($n = 73$)			Control ($n = 96$)		
		Mean	95% CI	SD	Mean	95% CI	SD
Mobility		5.7	(4.8, 6.5)	3.6	5.6	(4.9, 6.3)	3.3
SDDR	SDDRO	6.0	(4.4, 7.5)	6.6	7.4	(5.9, 8.9)	7.4
	SDDRE	4.8	(3.8, 5.6)	3.8	5.8	(4.9, 6.7)	4.3
SF-36	Mental health	72.4	(67.7, 77.0)	19.8	68.0	(63.4, 72.5)	22.3
	Pain	63.2	(56.0, 70.5)	31.0	60.3	(55.0, 65.7)	26.3
	Physical role	28.1	(19.9, 36.4)	35.3	23.7	(16.5, 30.8)	35.2
	Physical function	26.2	(19.6, 32.7)	28.0	24.1	(18.9, 29.2)	25.5
	Role emotional	60.2	(50.3, 70.1)	42.5	54.7	(45.4, 64.1)	46.1
	Social function	60.9	(53.6, 68.2)	31.3	58.0	(51.9, 64.2)	30.4
	Vitality	40.4	(35.2, 45.6)	22.3	34.4	(29.9, 38.9)	22.1
	General health	50.1	(44.3, 55.8)	24.6	49.2	(44.0, 54.2)	25.2
		Median	95% CI	Range	Median	95% CI	Range
Barthel		17	(16.0,18.0)	0–20	17	(15.0,18.0)	0–20

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 less independence in the SDDRO, range 0–30, and the SDDRE, range 5–15.

but increased in the control group. Thus there was some indication the intervention may have reduced the need for help and the perceived necessity of help.

It is noteworthy that responses on the SF-36 over time generally differed between the control and the intervention groups. Whereas respondents in the control group deteriorated over time (excluding general health), respondents in the intervention group improved over time (with the exception of scores on the physical role and role emotional scale). This indicated that participants might have had better health related-quality of life as a result of the intervention.

Table 4 also presents the effect sizes of the change scores. All the effect sizes were either negligible or small.

Table 5 presents the results of the interactions in the analysis of variance (ANOVA). There were three significant interaction effects, which means that there were significant differences at follow-up, between the intervention and control

Table 4 Changes in health status from baseline to follow-up

Tool		Intervention ($n = 96$)			Control ($n = 73$)		
		Change score	95% CI	Effect size	Change score	95% CI	Effect size
Mobility		−0.14	(−0.60, 0.32)	−0.04	−0.17	(−0.45, 0.12)	−0.05
SDDR	SDDRO	0.49	(−0.39, 1.37)	0.08	0.85	(−0.17, 1.88)	0.12
	SDDRE	−0.28	(−0.90, 0.34)	−0.06	0.65	(0.02, 1.28)	0.16
SF-36	Mental health	3.69	(0.37, 7.02)	0.18	−1.23	(−4.35, 1.88)	−0.05
	Pain	2.43	(−1.86, 6.72)	0.08	−1.12	(−6.43, 4.19)	−0.04
	Physical role	−6.38	(−15.10, 2.33)	−0.17	−6.17	(−7.98, 6.74)	−0.02
	Physical function	0.60	(−3.22, 4.42)	0.02	−1.35	(−4.97, 2.28)	−0.06
	Role emotional	−4.17	(−16.39, 8.06)	−0.10	−3.06	(−12.73, 6.60)	−0.07
	Social function	0.85	(−5.27, 6.96)	0.03	−3.29	(−9.00, 2.42)	−0.12
	Vitality	1.48	(−2.69, 5.65)	0.07	−4.21	(−7.92, −.51)	−0.18
	General health	7.38	(3.58, 11.19)	0.34	4.76	(1.22, 8.31)	0.26
Barthel		0.00	(0.00, 0.00)		0.00	(−1.00, 0.00)	

Negative change scores indicate worsening mobility, SF-36 and Barthel scores and improved independence on the SDDR.
95% CI, 95% confidence interval; SDDR, Standard Day Dependency Record; SDDRO and SDDRE subscales of the SDDR.

Table 5 ANOVAS: the interaction between group and time

Tool	Scale	Sum of squares	*F*	*p*-level
Mobility		0.02	0.01	0.91
SDDR	SDDRO	2.70	0.26	0.61
	SDDRE	17.95	4.17	0.04*
SF-36	Mental health	503.28	4.54	0.04*
	Pain	261.82	0.98	0.32
	Physical role	689.16	1.02	0.31
	Physical function	78.78	0.53	0.47
	Role emotional	25.18	0.02	0.88
	Social function	354.62	0.95	0.33
	Vitality	671.07	4.09	0.05*
	General health	142.24	0.99	0.32

*$p < 0.05$, df = 1, $n = 169$.
SDDR, Standard Day Dependency Record; SDDRO and SDDRE, subscales of the SDDR.

groups with baseline scores controlled for. The intervention group were less likely to consider help with activities of daily living to be essential, and were more likely to experience better vitality and mental health than the control group at follow-up.

There was no significant difference in independence in daily living, as measured by the Barthel, in baseline scores between the intervention and the control group (Mann–Whitney $U = 3459.50$, $Z = -0.14$, $p = 0.89$). However two Wilcoxon tests revealed that whilst there was no significant difference between baseline and follow-up Barthel scores in the intervention group, ($z = -0.49$, $p = 0.62$), there was a significant difference in the control group ($z = -3.41$, $p = 0.001$). This was surprising given that the median scores did not differ between groups or over the course of the study. However, an examination of the calculations for the Wilcoxon tests indicated that more individuals in the control group had declined in independence over time, and fewer had improved as compared with the intervention group (intervention group: negative ranks = 23 (32%), positive ranks = 21 (29%); control group: negative ranks = 45 (47%), positive ranks = 15 (16%)). Furthermore, an examination of the 25th and 75th percentiles revealed that individuals who were in the tails of the distribution of scores had apparently deteriorated more in the control group than in the intervention group (intervention: pre: 25th percentile = 14, 75th percentile = 20, post: 25th percentile = 13, 75th percentile = 20; control: pre: 25th percentile = 14, 75th percentile = 20, post: 25th percentile = 12.2, 75th percentile = 19). These findings indicated that, whilst levels of independence had deteriorated in the control group, independence was apparently maintained in the intervention group.

Discussion

This study has investigated the benefits of a low-intensity, low-cost, client-centred, community-based, professionally guided self-care programme for people with MS. Findings from this study indicated that this unique programme, which incorporated lay priorities, had statistically significant benefits for a community population of people with multiple sclerosis.

Clinical messages

- 'Self-care' is a key part of the lives of people with MS.
- Rehabilitation in MS should be based on consumer needs and priorities.
- The incorporation of self-care strategies into professional interventions can benefit people with MS.

Participants in the intervention group had significantly better mental health and less fatigue, as measured by the SF-36, than participants in the control group following the intervention. Poor mental health can be a major problem for people with MS,[23] as can fatigue,[20] thus the improvements in these two areas were particularly beneficial. Participants in the intervention group also reported that assistance with daily activities was less essential than individuals in the control group at follow-up. Thus the intervention appeared to reduce the perceived need for help by people with MS. However, although there was a general tendency for people in the intervention group to have better quality of life scores there were no significant differences between the control and intervention group on the other SF-36 scales.

Furthermore, there were no improvements in independence in daily living, mobility or a reduction in the number of occasions individuals were assisted with activities, as was hypothesized. Perhaps these were inappropriate goals for this low-intensity programme that had no physical intervention. Given that progressive deterioration is the norm, it could be argued that the findings that the programme appeared to slow down deterioration in self-reported independence, and reduce the perceived need for assistance, were important. Solari *et al.*[22] reported similar findings in a study evaluating the efficacy of a rehabilitation programme for people with MS. Although there were no significant differences, the loss of functional status appeared to be reduced in a treatment group compared with a control group.[22]

However, statistical significance does not assure clinical significance. The effect sizes of such changes was at best small, although this might be expected given the debilitating nature of MS.[21] It could also be argued that the meaningfulness of 'clinical impact' in relation to psychological measures such as the SF-36 is not clear.

A number of recent studies have provided evidence for the efficacy of various rehabilitation interventions for people with MS.[15,19,22] For example Solari *et al.* conducted an assessment of three weeks of intensive physical inpatient rehabilitation followed up for nine weeks.[22] However, these studies assessed interventions which were much more intensive and high cost than the intervention assessed in this study. Thus it could be argued that there are no similar published studies with which to compare our findings.

Of course the limitations of the study should be borne in mind when considering the implications of the findings. Cognitive impairment can be a problem in MS.[24] It was not assessed or controlled for in the study and may have affected results. In addition, participants were drawn from a convenience sample comprising members of voluntary groups such as the MS Society. Most participants had also had MS for many years. Findings cannot therefore be generalized to those who are not voluntary group members, and to the newly diagnosed. In addition, members of voluntary groups would be expected to be well informed already, thus it could be argued that providing more information and advice would be unlikely to have much of an effect. Perhaps this explains some of the nonsignificant findings and the low effect sizes in this study. Future research might investigate the impact of this intervention in the newly diagnosed, and in those who are not already members of voluntary groups. Furthermore, people with MS generally seek advice when they have specific problems. This was not the case with the study participants. It may well be that the observed benefits of the intervention would be greater in a 'real life' setting. Perhaps this should also be a focus for future research.

The design of this intervention attempted to address the problems of noncompliance and divergent t-values of professionals by incorporating lay priorities into the professional intervention and by concentrating on 'self-care' which is also of great importance to people with MS.[4] Most people with MS have limited access to intensive health care, generally in the form of inpatient and outpatient visits.[3] Research has also shown that the benefits of inpatient rehabilitation decline over time, reinforcing the need for continuity of care between the inpatient setting and the community.[19] Much of the burden of existing care falls on nonprofessional carers and on health professionals such as district and practice nurses and physiotherapists.[3] Perhaps one way of ensuring cost effective continuity of care, in a way that promotes client empowerment, might be to provide people with the information to pursue strategies which are beneficial to their health, through community health workers, who are likely to have most contact with them.

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