

Impact of a Comprehensive Long-Term Care Program on Caregivers and Persons With Multiple Sclerosis

**EM Guagenti-Tax, DSW¹; TA DiLorenzo, PhD²; L Tenteromano, RN³; NG LaRocca, PhD⁴;
CR Smith, MD²**

¹National Multiple Sclerosis Society, Southern New York Chapter, Hawthorne, NY; ²New York Medical College, White Plains, NY; ³Helen Hayes Hospital, West Haverstraw, NY; ⁴National Multiple Sclerosis Society, New York, NY.

Abstract

The goal of this project was to evaluate a comprehensive model of long-term care in multiple sclerosis (MS). This model consisted of workshops designed to assist participants cope with caregiving demands; medical day care to provide rehabilitation and group therapy; home visits by a psychotherapist or nurse to assist with practical and psychological issues; and case management and liaison services.

Thirty patient-caregiver units receiving treatment were compared with 29 control subjects, with data being collected on 3 occasions over a 2-year period. Repeated measures analysis of variance found that physical functioning declined for MS subjects as indicated by Kurtzke score, Incapacity Status Scale score, and number of hospitalizations. The experimental group reported an increase in perceived cognitive deficits and decreased anxiety. Control subjects reported a greater decline in perceived health than experimental subjects as assessed by the SF-36 general health subscale. All caregivers reported increased overcommitment. Caregivers of controls reported significant decreases in perceived health and that health problems and caregiving activities interfered with social activities. Persons with MS in both groups reported increased satisfaction with caregiver help, while control subjects reported greater satisfaction with the timeliness of help received.

These results provide valuable information about effective ways to use and integrate community resources in the provision of long-term care for persons with MS.

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Introduction

The goal of this project was to develop, implement, and evaluate a comprehensive model of long-term care for individuals with multiple sclerosis (MS) and their caregivers. This comprehensive program was designed to provide individuals with MS and their families with the support, knowledge, and resources they need to live as comfortably as possible with a chronic illness. The program also sought to help caregivers maintain the family member with MS in the community as long as possible, while maintaining or improving the health status and quality of life of patients and caregivers.

MS is a chronic, progressive disease of the central nervous system. Its symptom profile differs widely from patient to patient but can affect virtually every body system. The outcome of MS is variable, with some individuals having a mild course with few symptoms and others having a more debilitating disease leading to significant disability.¹

Advances in symptom management and the treatment of acute complications have resulted in longer life expectancy for people with MS,^{2,3} leading to a growing population of chronically ill individuals requiring long-term care. This long-term care begins within the family setting, with a gradual shifting of roles and responsibilities within the family to accommodate the demands of the illness.⁴ In most instances, the care continues within the home until the demands become too great, and family caregivers are no longer willing or able to provide care at home.

Families differ significantly in their ability to cope with the challenges of chronic illness. This variation among families has significant implications for long-term care because "the manner in which families meet these challenges has a profound impact on family health, and on the patient's adjustment and rehabilitation course."⁵ It is therefore incumbent on health care providers working with these families to identify those who are likely to need support in their coping efforts.

Recently, more information about younger people with disabilities and their caregivers has been available. A study examining the caregivers of MS patients⁶ found them to differ from the typical caregiver of the frail elderly on a number of dimensions. Caregivers of MS patients tended to be spouses who were unassisted in caregiving activities. In addition to caregiving, the majority worked full time and had child care responsibilities. In contrast, caregivers of the elderly tended to be daughters who were not working and received assistance with caregiving. Another study of MS caregivers examined the use of respite services.⁷ Although caregivers felt that their regular activities had been curtailed by caring for their relative, only 55% had ever used any of the respite options available to them, including admitting the patient to the hospital, using day care programs, hiring assistants, or calling on family or friends for help. The reasons cited for not availing themselves of respite services included (1) lack of awareness, (2) lack of confidence in available resources, and (3) guilt and/or anxiety about letting go of any aspect of their family member's care. Unfortunately, this reluctance to use respite services limits their potential value in forestalling or preventing residential placement. These results highlight both the multiple demands placed upon MS caregivers and the support they need for respite care services.

One of the resources of greatest potential benefit to disabled individuals and their family caregivers is adult day health care (ADHC). ADHC refers to community-based programs that provide a range of coordinated social, health, and therapeutic services to the elderly and the chronically ill in order to maximize functional ability and well being.^{8,9} A central goal of ADHC is the promotion of optimal self-care and independence to maintain residence in the community and prevent or delay institutionalization. Of equal importance are the potential benefits for family members of periodic respite from the stresses of caregiving. The consensus is that adult day care has the potential to promote the health and independence of the patient, reduce the

stress on family members, and reduce the stress on the health care system by appropriately limiting the use of outpatient office visits and the need for hospitalization or institutionalization. However, little has been published about the effectiveness of these programs.^{10,11} Furthermore, it appears that few MS patients or their families make use of available services.

ADHC programs designed specifically for individuals with MS have been reported on in the literature. The MS Achievement Center (MSAC) is an ADHC program for MS patients designed to maintain individuals in the community. A primary goal is to ease caregiving responsibilities, thereby preventing or forestalling burnout and premature institutionalization. Participants attend 1 day per week for 5 hours, for at least 1 year. Services include physical therapy, occupational therapy, chaplaincy-led support groups, social work, therapeutic recreation, skin care programs, accident prevention programs, seating and positioning clinics, and nutritional education.

In program evaluation reports,^{12,13} subjects in the MSAC were reported to have fewer symptoms, less fatigue, and a lower rate of decline in physical function than a wait-list control group.¹³ In terms of quality of life, MSAC attendees had better outcomes than did controls on the energy/fatigue, social function, social support, and general health dimensions of the SF-36.¹² Participation in the MSAC was associated with less time spent caregiving and higher use of community services; however, no differences were found in caregiver well-being.¹⁴ These results provide support for the effectiveness of the MSAC in terms of participant, but not caregiver, outcomes. No data were reported on the impact of the program in terms of outside use of medical services (eg, long-term-care residential admissions). Because one of the underlying goals of MSAC is to prevent placement, it would be important to assess this variables in future studies.

The long-term-care program in the present study differs from that of the MSAC by having fewer day health sessions, but it provides individual case management services on a regular basis to both clients and their caregivers.

Method

Forty-three patient-caregiver experimental units participated in the comprehensive program, and 30 patient-caregiver units served as the control group. Data on medical, social, and psychological status at entry, 12 months, and 24 months after enrollment in the program, as well as data on the impact of the program on caregivers, were collected. This completed project represented the first randomized controlled trial of the impact of a comprehensive program of care for MS patients and caregivers.

The study utilized a 2-group, longitudinal design with both subjects and investigators unblinded. Randomization followed the Zelen (1979)¹⁵ "randomized consent" procedure for years 1 and 2 of the funded grant period. In this procedure, subjects who meet entrance criteria are randomized without their knowledge or consent to receive either standard care or a new form of treatment. The randomized consent design has frequently been used when a new treatment is being compared to standard care and when blinding is not possible because of the nature of the treatments. The underlying assumption of the design is that the vast majority of subjects will agree to participate. Following an intent-to-treat model, subjects who decline to participate in the new treatment must still be followed and remain part of the experimental group. The investigators considered a single-blind design, in which the assessments would be done by a staff person blinded to group assignment. However, this alternative was rejected for 2 reasons. First, the in-depth nature of the interview would make it extremely difficult to maintain blinding. Second, the cost involved in maintaining both blinded and unblinded staff in a study of this size would be prohibitive. In year 3 of the project, randomization was changed to

a conventional randomization rather than the Zelen procedure. This change was initiated because higher refusal rates were calculated for the experimental group.

Subjects randomized to the control group received the standard care available at 2 participating MS care centers and a local MS society chapter. Subjects randomized to the experimental group were invited to participate in the new long-term-care program. Both groups executed informed consent before entering the study.

The program targeted subjects with MS who required some assistance with basic life activities such as bathing, dressing, grooming, feeding, etc, and who lived with a caregiver. Eligible subjects included people with clinically definite or laboratory-supported definite MS, between 18 and 65 years old, requiring at least 4 hours per day of caregiving by a family member for at least 1 year, and with a Kurtze Expanded Disability Status Scale (EDSS) score between 6.0 and 8.5.

Instruments were administered to clients and caregivers by trained interviewers either in the client's home (n=69), at the caregiver's place of employment (n=3), at the MS center (n=2), or by telephone (n=2). To ensure confidentiality, clients and caregivers were interviewed separately. Interviews lasted from 2 to 4 hours, depending on the cognitive and physical abilities of the client-caregiver units. It was sometimes necessary to complete an interview in 2 parts.

The treatment program consisted of 4 coordinated components designed to provide a comprehensive response to the medical, educational, and psychosocial needs of severely disabled persons with MS and their family caregivers. They included (1) a twice-monthly medical day-care program, (2) a series of semiannual workshops for persons with MS and family caregivers, (3) monthly home visits by a social worker, nurse, or volunteer, and (4) case management and liaison services. These 4 components are described in detail below.

Medical Day-Care Program.

Only experimental subjects attended the medical day-care program, which was held 2 days per month for 12 months. The medical day care program provided group-based physical, occupational, and recreational therapy, group counseling with a social worker, socialization, nursing services as needed, and lunch. The goals of the program were (1) to maintain the current level of functioning, (2) to prevent secondary and tertiary complications, (eg, contractures, skin breakdowns, infections), (3) to provide respite for family caregivers, and (4) to maintain and strengthen marital and family relationships.

Group physical and occupational therapy sessions included energy conservation and stress reduction, upper body movement, range of motion and instructions for home exercises, cognitive exercises, adaptive equipment, and fall prevention. Topics of group psychotherapy included hidden fears, loss, grief and other emotions, relationship with one's doctor and health care providers, cognitive changes, positive solutions, changing negative patterns and behaviors, communicating with a care partner, charting support networks, and saying good bye to group members.

Workshops.

Family caregivers and persons with MS attended 10 workshops that addressed coping with social, psychological, and medical aspects of MS and their impact on the caregiver.

Social Work/Nurse Home Visit.

Once a month, the social worker or nurse conducted a home visit with the person with MS and/or the primary family caregiver to identify problem areas in the functioning of the patient-

caregiver unit; to assess the impact of the chronic illness on the family system and identify points of stress needing to be addressed; to facilitate communication between patient and caregiver; to teach coping strategies and improve problem-solving skills; to provide emotional support; and to help families learn how to recognize and make effective use of their available options.

Case Management and Liaison Services.

The social worker and nurse provided a wide range of assistance to experimental patient-care giver units, from obtaining medical care, home services, transportation, and health insurance to resume assistance and letters of recommendation.

Outcome Measures

Four sets of measures were used, covering medical, psychological, social, and economic factors.

Medical Measures for Persons with MS

1. The EDSS,¹⁶ which is a single index of severity of MS, in half-unit increments ranging from 0 (normal) to 10 (death);
2. The Incapacity Status Scale (ISS),¹⁷ which uses a 5-point Likert-type format to assess functional capacity in 16 areas of physical disability. Scores can range from 0 to 64, with higher scores indicating greater disability; and
3. The number of acute hospital admissions.

Psychological Measures for Persons with MS

1. The Perceived Deficits Questionnaire (PDQ),¹⁸ which assesses perceived cognitive deficits from the client's perspective. It contains 20 items that describe situations in which a person may encounter problems with memory, attention, or concentration. Clients indicate how frequently these events are experienced on a Likert scale ranging from 0 (none) to 4 (almost always). Higher scores indicate greater perceived cognitive impairment;
2. The Hopkins Verbal Learning Test (HVL),¹⁹ which tests verbal learning and memory. It consists of 3 trials of free recall of a 12-item, semantically categorized word list, followed by yes/no recognition. The test is used in patients too impaired for more comprehensive memory assessments and where repeated testing is necessary. Each patient was administered 3 forms of the HVL test;
3. The Mental Health Inventory (MHI),²⁰ which is a measure of overall emotional functioning. It is a valid measure of mood that evaluates both positive well-being and psychological distress. The instrument consists of 38 items that measure affect, depression, loss of behavioral/emotional control, general positive affect, and emotional ties. Clients are asked to rate the above-mentioned attributes on a scale of 1 (least) to 6 (most) over the past month.

Social and Economic Measures for Persons with MS

1. The social interaction subscale from the Sickness Impact Profile (SIP),²¹ which evaluates the impact of illness on role functioning;
2. The Revised UCLA Loneliness-Companionship Scale,²² which assesses quality of social relationships. It is a 20-item 4-point scale ranging from (1) "I have never felt this way" to (4) "I have felt this way often." The scale consists of 10 positively worded statements reflecting satisfaction with social relationships. Scores can range from 20 to 80. The higher the score, the greater the loneliness;

3. The Questionnaire on Resources and Stress (QRS)²³ (for caregivers only), which measures several dimensions of family stress associated with the care of a dependent family member. The QRS consists of 285 true/false items organized into 15 nonoverlapping subscales, such as "excessive time demands," "overprotection/dependency," "lack of social support," "overcommitment (martyrdom)," "limits on family opportunity," and "lack of financial support";
4. The Health Status Questionnaire of Client and Caregiver (SF-36),^{24,25} which includes 8 multi-item measures of functioning and well-being that represent physical and mental health status on the following dimensions: general health perception, physical function, energy/fatigue, emotional well-being, social functioning, bodily pain, role limitations due to emotional problems, and role limitations due to physical problems. All item scores are summed and transformed onto a scale of 0 to 100, with 0 representing the poorest and 100 the best health. The period of coverage by the SF-36 was the preceding 4 weeks;
5. Satisfaction With Care,²⁶ which is a 3-part scale. Part 1 includes questions regarding the client's satisfaction with his or her doctor and other health care providers in terms of health care, ability to get an appointment, and understanding his or her treatment plan. Part 2 involves satisfaction with personal care and help with client's daily routine provided by caregivers. Satisfaction With Care uses a Likert-type format ranging from "sometimes" to "always." The third part of the scale assesses client satisfaction with the caregiver;
6. Cost of health care and home assistance¹⁴ inquired about out-of-pocket costs due to MS;
7. Information about length of stay and reason for nursing home placement was obtained during the interview;
8. Demographic and financial information was obtained for both clients and caregivers; and
9. A Qualitative Final Program Evaluation was given to experimental subjects only on the last 2 sessions of the medical day-care program. Part 1 of the 1-hour client evaluation assesses the extent to which program services are (1) very helpful, (2) helpful, or (3) not helpful, regarding group occupational and physical therapy, recreation, psychotherapy sessions, case management and health care services, monthly home visits, workshops, volunteers, and nursing and social work services. Questions are also asked about how helpful program services are in terms of learning practical information, ways to cope with MS, providing closeness to other members, and identifying resources. Part 3 evaluates program components according to (1) excellent, (2) very good, (3) adequate, or (4) poor, regarding day and time of program, rest room and group room accommodations, and food quality. Three open-ended questions about program expectations and ways to improve the program are also included. The final question asks if participants would continue in the program, if they could.

Results

One hundred eighty-seven patient-caregiver units from a local chapter of the National MS Society and from 2 MS care centers were contacted. Groups were comparable at Time 1 (N=73); no statistically significant differences were noted between experimental and control groups on outcome and demographic measures. Differences on demographic measures were noted at Time 3 (N=59) (see control group results). Fourteen patient-caregiver units dropped out of the study. Five patient-caregiver units (35.7%) dropped out before the inception of the Medical Day Care Program, and 8 (57.1%) dropped out during program operation. Reasons for dropping out included death of the caregiver (n=1, 7.1%), death of the person with MS (n=4, 28.6%), disease progression (n= 4, 28.6%), and transportation problems (n=5, 35.7%). Reasons for nonparticipation of the majority of the sample were as follows: lived too far away (n=28, 24.6%), transportation problems (n=18, 15.8%), MS patient not interested (n=17, 14.9%), caregiver not interested (n=8, 7.0%), still working, part or full time (n=8, 7.0%), and no caregiver (n= 8, 7.0%).

Subjects

Experimental Group (Patients). Of the 59 patient-caregiver units who remained in the study at 24 months, the majority of MS clients were female (86.7%), with a mean age of 44 years (SD=8.4). Disease course, as rated by the client, was chronic progressive (66.7%). Sixty-three percent were married and 83% were Caucasian. Twenty-seven percent had no children, and 46.9% had children still living at home. The mean education was 14.4 years (SD=2.9). Financial information revealed that clients were receiving Medicaid, Medicare, and disability (6.7%, 70%, and 83.3, respectively).

Experimental Group (Caregivers).

Of the experimental group caregivers, the majority (56.7%) were female, with a mean age of 44.9 years (SD=13.0). Relationship to the client included spouse or partner (66.7%), parent (16.7%), sibling (6.7%), and child (10%). Eighty-three percent of the caregivers were Caucasian. Experimental group caregivers were receiving Medicaid, Medicare, and disability (6.7%, 10%, and 36.7%, respectively). Significant differences were noted for caregiver education, with experimental group caregivers having more education (experimental mean=14.7; control mean=12.8; $P = .03$).

Control Group (Patients).

The majority (69%) were female, with a mean age of 49 years (SD=10.4). Control group patients were significantly older ($P < .05$). Significant differences were noted on years since first MS symptoms appeared (experimental mean=12.9, control mean=18.3; $P = .03$) and years since diagnoses (experimental mean=8.9, control mean=14.2; $P = .013$), with the control group scoring higher. Seventy-two percent of the control group were married and 1 control group client-caregiver unit was a member of a religious order. The majority (89.7%) were Caucasian. Seventeen percent had no children, and 53.1% had children still living at home. Disease course, as rated by the client, was chronic progressive for the majority (86.2%). The mean education level was 13.4 years (SD=3.7). Clients were receiving Medicaid, Medicare, and disability (13.8%, 69%, and 69%, respectively).

Control Group (Caregivers).

Of the control group caregivers, the majority were female (51.7%), with a mean age of 51.8 years (SD=14.3). Relationship to client included spouse or partner (69%), parent (13.8%), religious order (3.4%), and child (13.8%). Eighty-six percent of the caregivers were Caucasian. Control group caregivers were receiving Medicaid, Medicare, and disability (13.8%, 10.3%, and 44.8%, respectively).

Table 1a. Demographic Information: Client (N=59)

Demographic Information	Experimental Group (%)	Control Group %
Gender Female	86.7	69.0
Age Mean (SD)	44 years (8.4)	49 years (10.4)
Ethnicity Caucasian	83.0	89.7
Disease course (client rated)		
Chronic progressive	66.7	86.2
Years since MS	12.9	18.3
	8.9	14.2

symptoms (mean) Years since diagnoses (mean)		
Education Mean (SD)	14.4 years (2.9)	13.4 years (3.7)
Financial information Medicaid Medicare Disability	6.7 70.0 83.3	13.8 69.0 69.0
Marital status Married	63.0	72.4
Children No children Children at home	27 46.9	17 53.1

Table 1b. Demographic Information: Caregiver (N=59)

Demographic Information	Experimental Group (%)	Control Group (%)
Gender Female	56.7	51.7
Age Mean (SD)	44.9 years (13.0)	51.8 years (14.3)
Ethnicity Caucasian	83.0	86.2
Education Mean (SD)	14.7 years (3.3)	12.8 years (3.3)
Relationship to client Spouse or partner Parent Sibling Child Religious order	66.7 16.7 6.7 10.0 —	69.0 13.8 — 13.8 3.4
Financial Information Medicaid Medicare Disability	6.7 10.3 36.7	13.8 10.3 44.8

Statistical Analysis

The analytic strategy of repeated measures analysis of variance (ANOVA) was used with SPSSPC/PC+ statistical software.²⁷ There was a single within-subjects factor, time. The between-subjects factor was group assignment. Significance tests were performed on the

between-subjects factor, the within-subjects factor, and the interaction. The level of significance for all tests was set at .05.

All Subjects (Main Effects).

Repeated measures ANOVA revealed that physical functioning declined for all MS subjects as indicated by the EDSS (F [2,114]=3.14, p=.047), the ISS (F [2,114]=9.22, P =.000), and the number of MS-related hospitalizations (F [2,114]=17.06, P =.000). The MS sample displayed an increase in perceived cognitive deficits (F [2,114]=3.87, P =.024) and a decrease in anxiety (F [2,114]=32.49, P =.000). Subjects with MS, as a whole, declined in verbal recall but improved in yes/no memory recognition, as evidenced by the HVL test. Their ability to recall verbally in 2 trials of free recall significantly decreased: Trial 1 (F [2,110]=4.57, P =.012) and Trial 3 (F [2,110]=7.54, P =.001). On yes/no recognition test, both groups made significantly better false-positive errors (F [2,110]=4.4, P =.014) and did not differ on the true-positive rate (F [2,110]=.20, P >.05). Overall, decision bias (the false-alarm rate for related and unrelated distractors) significantly declined for both groups (F [2,110]=4.48, p=.014). All subjects reported an increase in satisfaction with the help they received in their daily routine from their caregivers (F [2,114]=5.47, P =.005) and in getting help with their daily routine, within a reasonable time frame, when they needed it (F [2,114]=3.34, P =.039). On the QRS, caregivers reported an increase in overcommitment martyrdom (F [2,114]=8.73, P =.000).

Control Group (Interaction Effects).

A significant interaction was found on the SF-36 general health subscale, with control persons with MS reporting greater decline in perceived health (F [2,114]=3.35, P =.039). Caregivers of control group individuals also reported significant decrease in perceived health. Significant main and interaction effects on the SF-36 general health subscale (F [2,114]=6.49, P =.002) (F [2,114]=4.80, P =.010) were noted. Caregivers of the control group reported their physical health problems interfered with normal social activities over time. Their ability to carry out normal social activities with family, friends, or groups also significantly decreased. Significant interaction effects on social functioning (F [2,114]=5.74, P =.004) and role physical (F [2,114]=3.25, P =.042) were reported. Control group subjects reported greater satisfaction with getting help with their daily routine, within a reasonable time frame, when they needed it (F [2,114]=5.85, P =.004). Means and SDs of significant results are displayed in Tables 2a and 2b. Significant main and interaction effects are found in Tables 3a and 3b.

Table 2a. Client Mean Score by Outcome Measure and Experimental Condition (N=59)

Measure	Pretreatment Mean SD N	12 Months Mean SD N	24 Months Mean SD N
EDSS			
Experimental	7.06 .81 30	7.13 .92 30	7.25 .96 30
Control	7.24 .92 29	7.29 .95 29	7.34 .94 29
ISS			
Experimental	22.60 9.38 30	22.87 11.59 30	26.07 12.05 30
Control	28.93 9.14 29	29.66 11.22 29	33.04 11.20 29
Acute hospital MS hospitalization			
Experimental	2.80 2.75 30	3.67 3.22 30	4.67 3.83 30
Control	4.00 2.95 29	4.45 3.50	5.93 4.81

		29	29
SF-36			
General health	63.27 23.04	56.03 21.50	61.47 26.07
Experimental	30	30	30
Control	51.34 27.91	57.14 26.59	50.86 27.60
	29	29	29
Satisfaction w/care		3.33 1.75	
Help w/routine		30	4.43 .94 30
Experimental	4.27 .94 30	4.45 .87 29	4.48 .87 29
Control	4.34 1.04 29		
Help reasonable time		3.47 1.57	4.23 1.14
Experimental	4.10 1.06 30	30	30
Control	4.45 .78 29	4.28 1.22	4.38 .90 29
		29	
Mental health			
Anxiety	68.53 21.44	57.33 14.49	72.93 17.59
Experimental	30	30	30
Control	68.83 21.63	50.89 17.49	65.67 22.39
	29	29	29
PDQ	19.97 12.47	19.63 15.16	20.03 16.88
Experimental	30	30	30
Control	23.10 16.12	27.59 19.03	27.07 21.00
	29	29	29
HVL free recall	53.74 16.15	56.32 16.62	50.57 18.08
Trial 1	29	29	29
Experimental	50.00 14.87	47.62 16.64	41.67 17.71
Control	28	28	28
Trial 3			
Experimental	77.30 18.08	81.32 18.59	72.41 24.31
Control	29	29	29
False positive	66.37 18.07	72.32 20.92	63.69 21.78
Experimental	28	28	28
Control			
Decision Bias (BR)	.06 .04 29	.09 .10 29	.05 .03 29
Experimental	.09 .10 28	.10 .08 28	.06 .06 28
Control			
	.53 .12 29	.55 .15 29	.50 .09 29
	.57 .17 28	.52 .16 28	.44 .19 28

Table 2b. Caregiver Mean Score by Outcome Measure and Experimental Condition (N=59)

Measure	Pretreatment	12 Months	24 Months
	Mean SD N	Mean SD N	Mean SD N
SF-36 General health Experimental Control Role, physical Experimental Control Social function Experimental Control	80.10 13.76 30	77.13 18.62 30	78.63 20.37 30
	87.07 11.31 29	81.31 14.11 29	72.48 21.28 29
	80.00 34.99 30	95.83 14.80 30	86.67 28.42 30
	93.10 23.05 29	89.66 23.64 29	81.90 33.34 29
	87.92 19.55 30	82.08 24.27 30	93.99 15.39 30
	93.10 18.17 29	92.24 15.09 29	83.62 24.57 29
QRS overcommitment Experimental Control	3.77 1.17 30 4.24 1.02 29	3.9 1.39 30 4.4 1.32 29	4.8 1.05 30 4.6 1.29 29

Table 3a. Results of Repeated Measure Analysis of Variance for Client

Measure	Main Effect	Interaction Effect
Medical measures EDSS Acute MS Hospitalizations Incapacity Status Scale	F 2, 114 = 3.14 p=.047 F 2, 114 = 17.06 p=.000 F 2, 114 = 9.22 p=.000	N/A
Psychological Measures Perceived Deficits Quest. Hopkins Verbal Learning -verbal recall trail 1 -verbal recall trail 3 -false positive rate -decision bias Mental Health Inventory -anxiety subscale	F 2, 114 = 3.87 p=.024 F 2, 110 = 4.57 p=.012 F 2, 110 = 7.54 p=.001 F 2, 110 = 4.40 p=.014 F 2, 110 = 4.48 p=.014 F 2, 114 = 32.49	N/A

	p=.000	
Social Measures		
Health Status Quest.		
General health	F 2, 114 = 5.47 p=.005	F 2,114 = 3.35 p=.039
Satisfaction with Care		
Help with daily routine		
Help in reasonable time	F 2, 114 = 3.34 p=.039	F 2, 114 = 5.85 p=.004

Table 3b. Results of Repeated Measure Analysis of Variance for Caregiver

Measure	Main Effects	Interaction Effects
Social Measures:		
Health Status Quest.		
-general health	F 2, 114 = 6.49 p=.002	F 2, 114 = 4.80 p=.010
-role physical		F 2, 114 = 3.25 p=.042
-social functioning		F 2, 114 = 5.74 p=.004
Quest. on Resources & Stress	F 2, 114 = 8.73 p=.000	N/A
-over commitment/martyrdom		

Qualitative Final Program Evaluation of Experimental Subjects with MS

Medical Day Care Program. Ninety-seven percent of the experimental patients said they would continue in the program if they could, and 100% said the group was extremely helpful or helpful in providing a sense of closeness with other people. The majority of program participants had never participated in a formal day program (96.7%) and were extremely isolated. A great portion of their day, prior to attending the program, was spent tending to their activities of daily living (ADL) needs and watching television.

In group therapy sessions, many reported that they had lost their friends because of MS or that their social network significantly decreased when their disability worsened. Didactic group psychotherapy sessions, rated as extremely helpful or helpful by 100% of the participants, were originally scheduled for 1 hour; however, participants enthusiastically requested that the sessions continue for 2 hours. The nurse and volunteers also participated in these sessions. Family members were requested to participate on an as-needed basis. Group occupational therapy was rated as extremely helpful or helpful (90%). Group recreational services were rated as not helpful (72%).

Workshops for Persons With MS and Caregivers.

Workshops were rated by persons with MS as extremely helpful or helpful (90% of the sample). Further use of workshop presenter services occurred for 26 patient-caregiver units (87%); for example, family units used the services of an attorney (n=2), clinical psychologist (n=4), nutritionist (n=2), manicurists (n=2), computer technology specialist (n=5), occupational therapist and assistive technology specialist (n=5), exercise (n=2), and urology (n=3). Most

significant were the opportunities that family members had to meet with one another and the friendships that ensued.

Case Management and Liaison Services for Caregivers and Persons With MS.

Case management and health care services were seen as extremely helpful or helpful for nursing services (100%) and extremely helpful or helpful for social work services (97%). Case management services most frequently required for the day program by persons with MS were arranging ambulette, taxi, or car-pooling services (74%). It was necessary for the staff to be actively involved in this activity, which also entailed frequent telephone calls on the day before the program, to remind clients and caregivers of the actual program day and of the arrangements made. Feeding assistance (51%) and transfer assistance (51%) were an integral part of program activities. Informational MS educational sessions (58%) were led by the nurse, social worker, or occupational therapist during group therapy or before program activities.

Caregiver support service (44%) occurred during day program operation, during home visits, or by telephone by the social worker or nurse. Services included off-hour crisis intervention telephone calls, divorce mediation, couple's therapy, bereavement support, insurance company intervention, letters of recommendation, resume writing, medication information, doctor-patient intervention, transportation assistance, and respite services.

Benefits of the long-term-care program, as reported by 83% of the experimental program participants, included the following: enjoyed being with people with the same condition and discovered how they coped (76%), learned we were not alone (76%), made some friends (40%), being involved in many activities and got out of the house (28%), and staff was great (12%). Suggestions by 73% of the sample to improve the program included the following: provide transportation to the program (64%), weekly meetings instead of bimonthly (64%), change recreational activities (41%), more vigorous structured physical therapy (32%), increase length of the program with no ending date (32%), and not mixing more disabled persons in groups with the less disabled (5%).

Discussion

Modest beneficial effects were found for persons with MS in terms of anxiety reduction and satisfaction with caregiver interactions. Experimental subjects did not report a decline in perceived general health as did the control group. Important results were found for caregivers of persons with MS in the control group. These caregivers reported a greater decline in perceived health and that health interfered with social activities. It seems that participation in the program may have prevented similar decline in caregivers of individuals with MS.

The most serious limitation of the program is that the conclusions to the study as they are described are not supported by the experimental design and data analyses. Despite the limited results on scientific outcome measures, success of the program was demonstrated in other ways. As evidenced by the final program evaluation, experimental clients looked forward to attending the bimonthly program and made new and lasting friendships. Workshops were originally designed for caregivers only; however, participants wanted not only to attend but also to introduce their family members to the new friends that they met in the program. The bimonthly meetings served as mutual aide groups and provided a new opportunity for socialization. The groups provided a forum for persons with MS to discover that they are not alone, to share feelings, and to make new friendships to compensate for their many losses. The program was novel for staff as well, many of whom had little or no experience with MS. Because this was a new model, rehabilitation staff was resistant to program start-up. Once staff participated, they were impressed by the efficacy of the program and became knowledgeable about the ramifications of the disease process.

The volunteer department at the medical center was extremely helpful in recruiting dedicated and caring volunteers and social work students to assist in program activities. Volunteer services were rated as extremely helpful or helpful (90%). All volunteers remained throughout program completion, and the majority (98%) continued their relationships with clients and caregivers after the program was completed. It was not uncommon for volunteers to continue to visit in the home or at the medical center when clients were hospitalized or waiting for medical appointments. The volunteer department of the medical center also provided monetary grants for transportation, meals, holidays, and seasonal events. The most recent grant was awarded to an MSW student to continue social work intervention for 3 clients who needed transitional services.

MS educational sessions at the medical day-care program were beneficial. Clients frequently asked questions about medication, catheterization, urinary tract infections, and recent news proclamations. The nurse also involved participants in ongoing clinical trials at the medical center. The one-stop shopping approach was used. Neurologist visits, urology, dental, assistive technology, and speech and swallowing evaluations were arranged while the participant attended the day program. MS physicians and nurses frequently made drop-in visits at group therapy sessions and entertained questions.

In addition to the changes described above in study outcome measures, the success of the program can also be measured by the establishment, and ongoing success, of the 3-year running "graduate group," a newsletter (written by graduates), attendance by experimental patient-caregiver units at various MS Society-supported programs, peer support groups, other adult day programs, and the continued social interaction between program clients, caregivers, and volunteers.

The amelioration of loss and feelings of connectedness are invaluable results of the interventions provided by this research project. Further studies are needed using research measures that tap change in social support, socialization, knowledge of resources, and caregiver burden. Additionally, MS patients require services from many systems and service providers. It would be beneficial to initiate controlled studies that explore whether comprehensive case management services would ease the burden for patient-caregiver units. Ideally, case managers would be at the MSW level, capable of coordinating services and intervening therapeutically when necessary—for example, providing couple therapy, family therapy, and acting as a liaison between professionals and clients.

There are several important additional limitations to the study. First, denial is a primary line of defense to the reality of the disease.²⁸ Both the caregiver and the person with MS can unconsciously collude in denying the severity of the symptoms and the emotional and physical devastation caused by the disease. The self-report measures that were used in this study could be influenced by denial. The unconscious use of defensive denial by people responding to self-report mental health questionnaires can result in false-positive results.²⁹ More objective measures that evaluate disease process and mental status by means of professional evaluation and observation would perhaps be more accurate than the self-report measures used in this study. Second, a gender bias toward the interviewer may have influenced responses. It appeared that patients replied more honestly to sensitive questions from the female interviewers. For example, questions about sexuality, intimate relationship issues, and bowel and bladder functions appeared to elicit a differential pattern when asked by a male versus a female interviewer. Next, the standardized instruments did not capture the impact of the program, in particular, the decrease in isolation, the continued socialization and long-lasting friendships that resulted for subjects in the experimental group. Lastly, attrition was a problem. The sample consisted primarily of people who had chronic progressive MS. The original sample size was 73 patient-caregiver units; attrition resulted in a sample size of 59 patient-caregiver units. In fact, this mortality rate had the consequence of reducing statistical power of the data

analysis to below what was desired at the outset of the study. Given the severity of the disease and individuals eligible for the study, mortality was a contributor to attrition.

Conclusion

Development of effective programs to address progressive disabling conditions remains one of the most significant challenges for the field of rehabilitation. This challenge is most notably manifested in MS, where a seemingly unpredictable course can wreak havoc on many traditional intervention methods. In the future, the challenge will grow with the increasing number of people affected by other progressive conditions such as spinal cord dysfunction, arthritis, leukemia, acquired immunodeficiency syndrome, diabetes, and others. The majority of people disabled by MS have significant spinal cord dysfunction; therefore, the research that addresses problems of MS will also be applicable in many ways to people with spinal cord injuries and other causes of spinal cord dysfunction. The results of this project provided valuable information about effective ways to use and integrate community resources in the provision of long-term care for persons with MS.

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