

MULTIPLE SCLEROSIS QUALITY OF LIFE PROJECT
A TRI-COUNTY NEEDS ASSESSMENT

INTRODUCTION

Multiple sclerosis, a debilitating and chronic neurological disorder, presents unique challenges to patients, their families and health care providers. Very often resources in communities are inadequate to meet the short and long term medical, psychosocial and spiritual needs of these people. This tri-county needs assessment was commissioned to study the population of people with multiple sclerosis (MS) in three counties of Central California to determine their needs for services and health care.

Multiple sclerosis is a neurological disease resulting in the destruction of the myelin sheath surrounding the nerve fibers in multiple locations in the central nervous system. There is no cure for MS and only since 1993, has there been FDA approved medications for the treatment of the underlying disease process. From an epidemiological standpoint, MS affects primarily young people profoundly affecting their productive years. Most people diagnosed with MS are between 20 and 40 years of age with women being affected 2-3 times more often than men. Geographically, MS is more common at the higher latitudes; in the US, MS occurs most frequently above the 37th parallel, which includes most of California.

In the US, there is estimated to be between 250,000 to 350,000 cases of MS. The Silicon Valley Chapter of the National Multiple Sclerosis Society estimates there are approximately 800 people with this condition in Monterey, Santa Cruz and San Benito counties, the geographical area in which this study was conducted.

The clinical course of this disease is highly variable and unpredictable. This fact combined with the young age of MS patients contributes to the difficulty in establishing appropriate health care services and resources for this unique population and their families.

STUDY PURPOSE AND OBJECTIVES

This tri-county needs assessment was designed and implemented by an independent group of health care professionals to begin to comprehensively define the needs of persons with MS in this area and to systematically address possible solutions. In particular, the study aimed to:

1. Quantify the extent of disability in the sample
2. Measure the financial and psychosocial burden experienced by people with MS
3. Examine the costs and types of medications commonly used by people with MS
4. Quantify the utilization, coverage and satisfaction with current health care services and existing community resources
5. Describe the various living arrangements experienced by people with MS
6. Measure the objective and subjective burden experienced by primary caregivers of people with MS
7. Quantify the perceived future needs of people with MS and their caregivers
8. Establish a data base of people with MS in the tri-county area

METHODOLOGY

Study sample:

A convenience sample of patients and caregivers were interviewed for this study. These were people who learned of the study through local agencies, the public media or their physicians and who volunteered their time and information. All participants signed an informed consent. Eighty (80) patients and 25 caregivers were interviewed.

Interview process:

All participants in the study sample were interviewed by trained health care professionals in their home or care environment. These professionals, 3 registered nurses and one physical therapist, all had a background in home health care as well as specific training for this particular needs assessment project. Each interview took from one hour to three hours to complete.

Data collection tools:

Data collection tools were selected after studying a previous needs assessment conducted by the Rochester, New York chapter of the Multiple Sclerosis Society under the direction of James Ahearn CSW, ACSW, Margaret Wyan RN, Ph.D and Ruth O'Brien RN, Ph.D. These tools included:

For the person with multiple sclerosis:

- Sociodemographic Data Collection Tool
- Multiple Sclerosis History and Current Status
- Social Support Questionnaire
- Assessment of Current Home Environment
- Use of Community Resources
- Instrument Activities of Daily Living Scale
- Functional Ability Scale
- Perceived Future Needs

For the caregiver:

- Sociodemographic Data Collection Tools
- Social Support Questionnaire
- Caregiving Experience Questionnaire
- Perceived Future Needs

DATA ANALYSIS:

The data from the sample of persons with multiple sclerosis (N=80) was analyzed as an entire group and then reanalyzed according to level of disability (ambulatory N=48 or wheelchair/bedbound N=32). Variations in findings according to functional deficits will be illustrated in this report.

FINDINGS---PERSON WITH MULTIPLE SCLEROSIS

SOCIODEMOGRAPHIC DATA

Eighty (80) people with MS were interviewed. Their mean age was 51.7 years with a range of 28 to 85 years. Seventy percent (70%) were female; 92.5% of this sample were caucasian. Forty-nine per cent (49%) of the patients were currently married with the length of relationship averaging 23.4 years. The remaining 51% of the patients were either single, divorced or widowed.

When comparing marital status according to functional ability, more of the ambulatory patients were in a married or partnered relationship (56.3%) than wheelchair/bedbound patients (37.5%) The majority of the wheelchair/bedbound patients were single, divorced or widowed (62.5% versus 42.7% for the ambulatory population).

LIVING ARRANGEMENTS: Nineteen patients (24%) lived alone, 13 patients (16%) were living and being cared for in a licensed facility and the remaining 48 patients (60%) lived with various family members, the most of whom (72%) were employed outside the home The majority of the patients (81%) were not employed.

Of the wheelchair/bedbound population, 40% of the sample were in a licensed care facility and 46% of them reported their primary caregiver being a paid person.

GEOGRAPHICAL AREA REPRESENTATION: This study was conducted in three counties of Central California (Table 1).

Table 1: GEOGRAPHICAL DISTRIBUTION OF PATIENTS

County	N	%
Monterey County	38	47.5%
Santa Cruz County	38	47.5%
San Benito County	4	5.0%

These figures are felt to be representative of the numbers of people with MS located in each particular county region.

FINANCIAL MEANS: These patients/families demonstrated enormous variability in terms of financial means. The mean yearly income was between \$30,000 to \$39,000 with a range of less than \$10,000 (N=15) to \$50,000 or more (N=26). Numerous additional sources of income were reported by 63 patients including social security (N=43), SDI (N=18), SSI, family/friends, rental income and savings. The median monthly additional income reported was \$1133 with a huge range from \$100 to over \$25,000 monthly.

Patients were interviewed about their knowledge of obtaining additional financial assistance. Sixty-two percent (62%) of the sample stated they knew how to get state aid, 57% stated they knew how to get federal aid and 45% stated they knew how to obtain a living trust. Examining patient's knowledge of additional financial resources based on disability groups revealed that the two groups were very similar in this respect.

HOUSEHOLD AND MEDICAL EXPENSES: Sixty-nine patients reported on monthly household expenses with a median of \$1700/month and a range of \$45 to \$5895 for rent, utilities, food, and transportation. The patients who did not report monthly expenses were living in care facilities. Household expenses remained highly variable between the two levels of patient population with no significant trends noted.

Monthly medical expenses were also reported by 65 patients and ranged from \$10 to \$6100 per month with a median of \$225. These expenses included paid caregivers, medical equipment, prescription and nonprescription medications, insurance premiums and non-covered physician appointments.

COVERAGE FOR MEDICAL CARE: Fifty-seven percent (57% or N=45) of patients in this survey had primary Medicare coverage either alone or in combination with Medi-Cal or private insurance. Forty one percent (41% or N=32) were covered by private insurers alone and 2 patients had single coverage with MediCal. One third of patients (30%) reported their insurance inadequate to meet their medical needs with 24% having been rejected for health insurance at some point in their illness. Eighty-two percent (82%) of this sample stated they had had insurance since their diagnosis.

For the wheelchair/bedbound patients, medicare/MediCal was the most common type of health care coverage (41.6%) with the ambulatory patients being covered primarily by private insurance (52.1%). Monthly medical expenses for the disabled group was exceptionally high in the caregiving expenses and the costs of prescription medications.

PERCEIVED FUTURE FINANCIAL RESOURCES: A significant question for this study was whether or not patients felt they could remain in their current living situation if their expenses increased or decreased. This is a central issue for people suffering a chronic debilitating illness that directly impacts cost of care and income earning ability. Thirty one percent (31%) of this population stated they could not maintain their current lifestyle if their income decreased or expenses increased and the majority (44%) of these respondents stated they did not know what they would do in that situation. Only one patient considered residential care as a possible solution to this question with most patients saying they would move in with family or sell their home.

MULTIPLE SCLEROSIS HISTORY AND CURRENT HEALTH STATUS

The purpose of this tool was to interview the participants in regard to their knowledge of their MS history and current status including level of disability, impact of the disease on their lives, use of prescription and over the counter medications, frequency and type of MD visits, use of complementary health practices and overall satisfaction with the quality of their health care.

By self-report, this sample of patients had the following classifications of multiple sclerosis (Table 2).

Table 2: CLASSIFICATION OF MULTIPLE SCLEROSIS

TYPE	Ambulatory		wc/bb		total	
	freq	%	freq	%	freq	%
Relapsing/remitting	21	43.8%	2	6.3%	23	28.8%
Primary progressive	12	25.0%	18	56.3%	30	37.5%
2ndary progressive	18	22.5%	7	14.6%	11	34.4%
Uncertain	8	16.7%	1	3.1%	9	11.3%

By observation, this sample had the following levels of disability (Table 3).

Table 3: LEVELS OF DISABILITY PER COUNTY

<u>Level of disability</u>	<u>freq</u>	<u>%</u>
AMBULATORY N=48		
Monterey County	25	52.1%
Santa Cruz County	21	42.1%
San Benito County	2	4.2%
WHEELCHAIR BOUND N=28		
Monterey County	11	39.3%
Santa Cruz County	15	53.3%
San Benito County	2	7.2%
BED BOUND N=4		
Monterey County	2	50%
Santa Cruz County	2	50%
San Benito County	0	0%
TOTAL POPULATION		
Ambulatory	48	60%
Wheelchair	28	35%
Bedbound	4	5%

Patients in this sample recalled having their first symptoms of MS an average of 23.4 years ago with the actual diagnosis made an average of 15.7 years ago.

SYMPTOM DISTRESS: Participants were asked to list the three symptoms that they found most disabling (Table 4).

TABLE 4: MOST DISTRESSING SYMPTOMS

<u>Symptom</u>	<u># of times reported</u>
Fatigue	33
Vision deficits	21
Weakness	21
Bladder/bowel changes	19
Spasm/Spasticity	18
Lack of Balance	16
Pain	16
Cognitive changes	12
Parasthesias	8
Tremors	6
Stiffness	5
Dizziness	4

Understanding these distressing symptoms can help to guide patient assessments and the development and implementation of patient education and support programs for MS patients and their families and caregivers.

QUANTIFYING CHANGES RELATED TO MS: In an attempt to quantify the extent to which multiple sclerosis has imposed changes in their lives, each patient was asked to rate the degree of change imposed by this disease on a scale of 0 to 10 (0=no change and 10=extensive change). The total sample reported a degree of change imposed by this disease on their lives at a level 8/10. As expected, the degree of change was greater in the wheelchair/bedbound group with a mean level of change at 9.0 (SD=1.3) compared to a level of change of 7.3 (SD=2.7) in the ambulatory group ($p=0.002$).

SPECIFIC CHANGES DUE TO ILLNESS: Respondents were asked to evaluate various changes imposed upon them by their illness as being positive or negative to their well being. Responses were analyzed for each of the two functional groups (Tables 5 and 6).

Table 5: AREAS OF CHANGE MOST NEGATIVE TO MY WELLBEING

<u>Ambulatory</u>		<u>Wheelchair/Bedbound</u>	
<u>Area of change</u>	<u>%</u>	<u>Area of change</u>	<u>%</u>
Employment	80.5%	Employment	87%
Leisure activities	72.3%	Leisure activities	83%
Personal changes	48.8%	Personal changes	56%

Table 6: AREAS OF CHANGES MOST POSITIVE TO MY WELLBEING

<u>Ambulatory</u>		<u>Wheelchair/Bedbound</u>	
<u>Area of change</u>	<u>%</u>	<u>Area of change</u>	<u>%</u>
Friends	57%	Functional	67%
Structural	54%	Structural	51%
Family	51%	Family	48%

Respondents offered many open ended comments about the degree and impact of the change they have experienced because of MS. Following is a summary of some of the comments related to each area of change.

EMPLOYMENT: Patients spoke about leaving jobs they really enjoyed and how that affected their sense of purpose and self-definition. Mention was made about the financial consequences of not working and their dependence on others.

LEISURE: Patients spoke of the great loss because of not being able to be physically active. Gardening, shopping, golf, triathlons, dancing, walking, dressing up were some of the activities that were no longer a part of their lives.

PERSONAL: Patients spoke about being unable to go to church, their sadness at not having children and intimate relationships with the opposite sex. One respondent described how frightening it is not to have any control over her life. Another remarked that her whole life now centered on herself and her day-to-day functioning. Fatigue contributed to lack of confidence and motivation to try new things. Another common personal theme was the lack of independence and how that contributed in a negative way to their day to day living and relationships with others.

FUNCTIONAL: Functional changes included the use of equipment. Patients often expressed ambivalence about their adaptive equipment, stating at first they resisted using it but then it became no big deal. One respondent stated that use of equipment indicates he is losing the battle but overall it helps him to be more active.

FAMILY/FRIENDS: Relationships were impacted both positively and negatively with several patients describing their lives as very lonely and expressing grief over the loss of relationship with people they care about. One mother said that her kids hate MS because I cannot take care of them. Several members of the sample reported that they were more sensitive to the needs of others and appreciated the little things in life more than before their illness.

STRUCTURAL CHANGES: These changes were largely viewed as positive because they contributed to enhanced independence. Ramps, enlarged doorways, bathroom remodeling, the use of specially designed vans and wheelchairs were beneficial changes. Computer technology and creative adaptive devices also allowed bed bound patients to dial a phone and participate in on-line activities.

HEALTH CARE TEAM: All patients in this study were under the care of a physician, primarily internists/family practice doctors (92.4%) and/or a neurologist (79.7%). Table 7 lists the other medical specialists named by this sample as participating in their care. Only 20% of this patient population reported receiving psychosocial support. No wheelchair/bedbound patient had a psychiatrist, psychologist or marriage family therapist (MFT) on their health care team.

Table 7. TYPES OF MEDICAL SPECIALISTS

Medical specialist	Ambulatory		Wc/BB		Total	
	freq	%	freq	%	freq	%
Internal medicine	23	47.9%	14	45.2%	37	46.8%
Family Practice	21	43.8%	15	48.4%	36	45.6%
Neurology	38	79.2%	25	80.6%	63	79.7%
Ophthalmology	18	37.5%	11	35.5%	22	27.8%
Urology	11	22.9%	11	35.5%	22	27.8%
Psychosocial	16	20.0%	0	0%	0	0%

Fifty-five (55) of the 80 patients reported seeing other health care providers (Table 8).

Table 8. OTHER HEALTH CARE PROVIDERS

Type of HCP	Ambulatory		WC/BB		Total	
	freq	%	freq	%	freq	%
Physical therapy	19	39.6%	9	29.0%	28	35.4%
Chiropractor	10	20.8%	2	6.5%	12	15.2%
Occupational therapy	0		3	9.7%	3	3.8%
Social work	1	2.1%	1	3.2%	2	2.5%

MEDICATION USE: Medication management is key to controlling symptoms of multiple sclerosis. Table 9 indicates the frequency of prescription medication use for specific indications.

Table 9: PRESCRIPTION MEDICATION USE

<u>Indication</u>	<u>Frequency of use</u>	<u>%</u>
Pain control	44	55%
Disease Modifying Therapy	39	48.7%
Spasm	38	47.5%
Depression	22	27.5%
Bladder Dysfunction	17	21.2%
Fatigue	11	13.7%
Bowel dysfunction	10	12.5%
Insomnia	8	10.0%
Nausea/vertigo	7	8.7%
Pruitis	1	1.2%
Other medical conditions	76	95%

Over the counter medications and marijuana use were also reported as used by this population, particularly the ambulatory patients (Table 10).

Table 10: NON-PRESCRIBED MEDICATION USE

<u>OTC Medication</u>	<u>Frequency of use</u>	<u>%</u>
Vitamins	39	48.7%
OTC pain medicines	22	27.5%
Herbal preparations	17	21.2%
Cannabis	9	11.2%

COMPLEMENTARY METHODS: In addition to medical care, the patients in this sample utilized a wide variety of complementary methods of healing including bodywork, mind-body techniques and diet modifications (Table 11).

Table 11: USE OF COMPLEMENTARY HEALING METHODS

Method	Ambulatory		WC/BB		Total	
	freq	%	freq	%	freq	%
Stretching	26	54.2%	11	35.5%	37	46.8%
Massage	17	35.4%	7	22.6%	24	30.4%
Meditation	13	27.1%	7	22.6%	20	25.4%
Acupuncture	14	29.2%	4	12.9%	18	22.8%
Yoga	14	29.2%	3	9.7%	17	21.5%
Dietary changes	13	27.1%	3	9.8%	16	20.4
Weightlifting	9	18.8%	5	16.1%	14	17.7%
Visualization	8	16.7%	2	6.5%	10	12.7%

SOCIAL SUPPORT DATA

SOCIAL SUPPORT WITH FAMILY AND FRIENDS: The persons with multiple sclerosis were asked about the availability of social support as a source of help in managing their care. The majority of patients in the total sample and in the smaller functional groups reported having adequate social support (Table 12).

Table 12. SOCIAL SUPPORT—FAMILY AND FRIENDS

Types of support	Ambulatory		WC/BB		Total	
	freq	%	freq	%	freq	%
Assist with chores errands						
Yes	35	74.5%	28	90.3%	63	80.8%
No	12	25.5%	3	9.7%	15	19.2%
People to guide and advise						
Yes	33	75%	23	74.2%	56	74.7%
No	11	25%	8	25.8%	19	25.3%
People to listen						
Yes	40	85.1%	24	80%	64	83.1%
No	7	14.9%	6	20%	13	16.9%

As expected, the one area of social support that showed a statistical significant difference between the two functional groups was the greater need of the wheelchair/bedbound patients to require help with personal care.

Table 13. SOCIAL SUPPORT-HELP WITH PERSONAL CARE

	Ambulatory		WC/BB		x ²	p-value
	Freq	%	freq	%		
Need help	3	6.7%	22	71.7%	34.4	.001

SATISFACTION WITH SOCIAL SUPPORT: Overall satisfaction was high with the perceived level of social support. On a scale of 1 to 10 (1=extremely dissatisfied, 10=extremely satisfied), ambulatory patients rated satisfaction with social support at level 9.0 (SD 1.4) and wheelchair/bedbound patients rated their level of satisfaction with social support as 8.6 (SD 1.9).

SOCIAL SUPPORT WITH OTHER PATIENTS WITH MS: The majority of patients in this sample felt it would be helpful to talk with other people with multiple sclerosis, although it was not an overwhelming sentiment. A significant percentage of the patients either were uncertain or perceived that kind of support as not helpful (Table 14). When asked how they felt about sharing living space with another person with MS, the response was much less positive, particularly among the ambulatory patient population (Table 14).

Table 14: SOCIAL SUPPORT-OTHER MS PATIENTS

Types of support	Ambulatory		WC/BB		Total	
	freq	%	freq	%	freq	%
Sharing feelings/concerns						
Helpful	27	58.7%	17	54.8%	44	55%
Not helpful	10	21.7%	7	22.6%	17	21%
Never met person						
With MS	7	15.2%	2	6.5%	9	11%
Don't know	2	4.3%	5	16.1%	7	9%
Sharing living space						
Yes	6	13.0%	10	35.7%	16	20%
No	9	19.6%	1	3.6%	10	12%
Certain conditions	23	50.0%	13	46.4%	36	45%
Don't know	8	17.4%	4	14.3%	12	15%

Patients were asked to comment on the circumstances or conditions that would make living with another person with MS a viable option. Most of the mentioned circumstances related to personal changes that would force them into a different living condition (e.g. if the current caregiver was gone or disabled, financial necessity). Circumstances related to the choice of living with other MS patients focused on the importance of compatibility in personality, interests, habits. Many of the patient's comments stressed the need for some privacy. Only one person commented on the difficulty of living with someone whose disease process was more advanced than their own.

ASSESSMENT OF THE HOME ENVIRONMENT

An extensive evaluation of the living environment of the home or care facility was done by the interviewer with the patient when possible. Specific areas of the living environment were evaluated in terms of meeting current and future needs, current needs only or meeting neither current or future needs. Generally, the majority of the sample stated their living environment met their current and future needs (Table 15).

Table 15: ADEQUACY OF LIVING ENVIRONMENT-SUMMARY OF CURRENT AND FUTURE NEEDS

Area of evaluation	Meets current and future needs	
	Ambulatory	WW/BB
Outside area Walkway, entrance Driveway, Steps	61% to 76%	83% to 88%
Main living room furniture, Doors Telephone, Lights Floor covering	76% to 91%	90% to 95.5%
Bath Door, Toilet, floor, sink Wheelchair turn space Grab bars	40% to 76%	61% to 95%
Kitchen Door, refrigerator, sink Wheelchair turn space Stove, cupboards, table Telephone, floor	62% to 91%	60% to 100%
Bedroom Door, bed, closet, drawers Wheelchair turn space Telephone, Floor coverings	73% to 87%	70% to 95%

Most problematic from a safety point of view was the inadequacy of the emergency exits in the home environments that were evaluated (Table 16).

Table 16: ADEQUACY OF EMERGENCY EXITS

	Ambulatory		WC/BB	
	Freq	%	freq	%
Meets current/future needs	17	37.0%	13	59.1%
Meets current needs only	9	19.6%	1	4.5%
<u>Meets neither current/future Needs</u>	20	43.5%	8	36.4%

SATISFACTION WITH HOME ENVIRONMENTS: The majority of patients in both functional groups were satisfied with their current living situation and neither group had significant concerns about their home environment as long as their disease remained stable. Yet both groups expressed concern about their living environment should their MS progress and their disability increase (Table 17).

Table 17: SATISFACTION AND CONCERN WITH HOME ENVIRONMENT

	Ambulatory		WC/BB	
	Freq	%	freq	%
<u>Satisfied with current environment</u>				
YES	43	89.9%	23	79.3%
NO	5	10.4%	6	20.7%
<u>Concern if MS remains stable</u>				
YES	6	12.5%	8	27.6%
NO	42	87.5%	21	72.4%
<u>Concern if MS progresses</u>				
YES	29	60.4%	18	64.3%
NO	19	39.6%	10	35.7%

USE OF COMMUNITY RESOURCES

The availability of community resources and the frequency of use is an important question in examining services for the disabled. In the tricounty area under study, there are various community agencies devoted to the MS client as well as other services for the disabled. Patients were interviewed about their use of and satisfaction with these services. As expected, the wheelchair/bedbound patient population reported statistically significantly greater use of community resources than the ambulatory patient group (Table 18).

Table 18: USE OF COMMUNITY RESOURCES

	Ambulatory		WC/BB		X2	p-value
	Freq	%	freq	%		
Overall Use						
YES	19	39.6%	21	67.7%	6.0	0.015
NO	29	60.4%	10	32.3%		
Use of specific services						
RIDES						
Program	8	16.7%	10	32.3%		
MS Community Services	6	12.5%	4	12.9%		
MS National Society (Silicon Valley)	7	14.6%	4	12.9%		
Home health Care	2	4.2%	5	16.1%		
Other	9	19.1%	13	41.9%		

None of the patients reported using the Center for Independent Living located in Gilroy, California, a significant driving distance from the geographical areas under study. Other community services utilized by these patients were support groups, adaptive PE programs. Lift Line and Meals on Wheels.

When asked if any community services were covered by insurance, most patients reported no (ambulatory=82.4%; wheelchair/bedbound=55%).

SATISFACTION WITH COMMUNITY SERVICES: Satisfaction with community services was rated on a scale of 1 to 10 (1=extremely dissatisfied, 10=extremely satisfied). Wheelchair/bedbound patients reported a satisfaction level of 6.1 (SD=2.8) while ambulatory patients reported a satisfaction level of 5.0 (SD=3.5).

ASSESSMENT OF ACTIVITIES OF DAILY LIVING AND FUNCTIONAL ABILITIES

Two tools were administered to the persons with multiple sclerosis with the goal of understanding how their current disease state impacts their ability to perform activities of daily living (ADL's) and their day to day physical and psychosocial strength.

The Instrumental Activities of Daily Living Scale (IADLS) measures eight tasks required for independent living. The patients were asked to quantify their ability to perform each task on a scale of 0 to 3 with 0 indicating full independence and 3 indicating total dependence on others. The IADLS combined score for all 8 items could range from 0 to 24.

The Functional Ability Scale (FAS) is a 16-item tool measuring specific limitations in physical function, energy, ability to fulfill one's role in society and deficits in mood and mentation. The patients were asked to quantify their abilities in each function on a scale of 0 to 4 with 0 indicating normal function and 4 indicating severe impairment/limitation. The FAS combined score for all 16 items could range from 0 to 64.

The IADLS and FAS were analyzed according to the two functional groups and as expected, the wheelchair/bedbound respondents reported significantly higher on the disability scales (Table 19).

Table 19. ACTIVITIES OF DAILY LIVING AND FUNCTIONAL ABILITIES

IADLS-Instrument of Daily Living Scale—Range 0-24

	N	Mean	SD	t-test	df	p-value
Ambulatory	48	2.5	3.9	-8.2	77	.001
WC/BB	31	13.2	7.7			

FAS-Functional Ability Scale—Range 0-64

	N	Mean	SD	t-test	df	p-value
Ambulatory	48	12.3	6.4	-11.6	77	.001
WC/BB	31	37.3	12.7			

As an aid to planning services for people with a wide range of disability from multiple sclerosis, the various ADL's and functional states were looked at individually with the goal of learning what items are most problematic to the cohort of patients interviewed. Table 20 illustrates the 8 activities of daily living studied and ranks them according to the frequency that patients reported total dependence on others.

Table 20. ACTIVITIES OF DAILY LIVING REQUIRING TOTAL DEPENDENCE ON OTHERS N=79

ACTIVITY (Score=3)	Freq	%
Housekeeping	24	30.8%
Laundry	23	29.5%
Food preparation	34	29.1%
Shopping	14	17.7%
Responsibility for medication	12	15.4%
Ability to handle finances	12	15.4%
Transportation	3	3.8%
Ability to use telephone	2	2.5%

The eight activities of daily living were then ranked in reverse order according to the frequency that patients reported having total independent capability (Table 21).

Table 21. ACTIVITIES OF DAILY LIVING PERFORMED WITH TOTAL INDEPENDENCE N=79

ACTIVITY (Score=0)	Freq	%
Ability to use telephone	69	87.3%
Ability to handle finances	60	75.9%
Responsibility for medication	59	75.6%
Laundry	51	65.4%
Transportation	51	64.6%
Food preparation	40	50%
Housekeeping	33	42%
Shopping	31	39%

Looking at activities of daily living from the dual perspective of total dependence and total independence, it is noted that housekeeping, laundry, shopping and food preparation are the biggest challenges for this sample of people with multiple sclerosis.

A similar ranking of the 16 functional ability items on the FAS tool gives added information on the most problematic physical, mental and social limitations reported by patients in this study (Table 22).

Table 22. FUNCTIONAL ABILITIES WITH SEVERE IMPAIRMENT
N=79

ACTIVITY (Score=4)	Freq	%
Stair Climbing	31	40.3%
Ambulation	29	36.7%
Chair/Bed transfer	14	17.7%
Bowel Function	14	17.7%
Dressing	14	17.7%
Toilet transfer	13	16.5%
Bathing	12	15.2%
Societal Role	12	15.4%
Fatigue	10	13.2%
Grooming	9	11.4%
Other physical conditions	8	10.3%
Feeding	6	7.6%
Bladder function	5	6.6%
Mood/mentation	5	6.6%
Vision	2	2.6%
Speech and hearing	2	2.5%

The sixteen functional abilities were then ranked in the order according to which abilities the patients reported they had total normal function/capability (Table 23).

Table 23: FUNCTIONAL ABILITIES WITH NORMAL CAPABILITY
N=79

ACTIVITY (Score=0)	Freq	%
Speech and hearing	67	85.9%
Feeding	56	70.9%
Grooming	49	62.0%
Dressing	38	48.1%
Toilet transfer	37	46.8%
Chair/bed transfer	37	45.6%
Bathing	35	44.3%
Mood/mentation	31	40.8%
Vision	20	25.3%
Ambulation	17	21.5%
Bladder function	15	19.7%
Bowel function	14	17.7%
Other physical conditions	11	14.1%
Stair climbing	9	11.7%
Societal role	8	10.3%
Fatigue	6	7.9%

Looking at functional ability from the dual perspective of severely impaired to totally normal, it is noted that fatigue, change in societal role and the physical limitations in ambulation and transferring present the biggest challenges for this sample of people with multiple sclerosis. In addition, less than 50% of this patient population reported having normal function in mentation, vision or ambulation.

ALTERNATIVES TO MEET CURRENT AND FUTURE NEEDS:

Respondents were asked twice during each interview to comment and rank the importance of various services to enhance their health care. The following four possible alternatives were described to the study participants:

LICENSED RESIDENTIAL CARE FACILITY: A home where 4-5 people with MS can live. Caregivers are present 24 hours a day to maintain the home and prepare meals. Each resident would need to provide for their physical care or need minimal assistance.

AN INDEPENDENT LIVING CENTER: A subsidized housing project of 20 to 40 apartment units in which people who are disabled by MS or other neurological diseases can live with their families.

AN ACHIEVEMENT CENTER: A non-residential day care center where people with MS of any stage can come for exercise, group support, education and other healing and restorative activities.

A MULTIDISCIPLINARY CLINIC: A regular clinic for people with MS. Different medical and health care specialists would staff this outpatient clinic with the goal of better coordination of a person's care.

Initially, each patient was asked to rank the four alternatives of care on a scale of 1 to 4 with 1 being ranked as the most important and 4 being ranked as the least important to their care.

Of the four possible alternatives, a multidisciplinary clinic was rated as the most valuable asset to their present care (Table 24).

Table 24: RANKING OF ALTERNATIVES FOR CARE

Program	N	Mean	SD
Monthly multidisciplinary clinic	79	2.2	1.1
Achievement Center Day care or respite care Non-residential	78	2.2	1.0
<u>Independent Living CTR Housing project of 20- 40 apts for people with disabling neuro diseases</u>	78	2.7	1.1
Licensed Home for 4-5 People with Disabling MS or other neuro diseases	78	3.0	1.1

At a later time in the interview, the patients were asked to imagine their future needs and to evaluate how important it might be to plan for various alternatives and enhancements for their health care and under what circumstances they would utilize such services. The importance of planning for each alternative was rated on a scale of 1 to 10 (1=not important and 10=extremely important). Once again the multidisciplinary clinic was valued the highest with the greater percentage of both functional groups stating they would use this service (Table 25).

Table 25: PERCEIVED FUTURE NEEDS-Importance of planning for care alternatives and willingness to use

MULTIDISCIPLINARY CLINIC

<u>Rating of Importance</u>	<u>N</u>	<u>Mean</u>		<u>SD</u>
Ambulatory	48	8.2		2.3
WC/BB	28	8.0		2.5
All patients	76	8.1		2.4

<u>Willingness to Use</u>	<u>ambulatory</u>		<u>WC/BB</u>	
	<u>freq</u>	<u>%</u>	<u>freq</u>	<u>%</u>
YES	41	87.2%	22	78.6%
NO	6	12.6%	6	21.4%

AN ACHIEVEMENT CENTER

<u>Rating of Importance</u>	<u>N</u>	<u>Mean</u>		<u>SD</u>
Ambulatory	48	8.3		2.4
WC/BB	29	7.4		2.8
All patients	77	7.9		2.6

<u>Willingness to Use</u>	<u>ambulatory</u>		<u>WC/BB</u>	
	<u>freq</u>	<u>%</u>	<u>freq</u>	<u>%</u>
YES	43	91.5%	23	82.1%
NO	4	8.5%	5	17.9%

AN INDEPENDENT LIVING CENTER

Rating of importance	N	Mean	SD
Ambulatory	48	6.0	3.4
WC/BB	29	7.0	3.1
All patients	77	6.4	3.3

Willingness to Use	ambulatory		WC/BB	
	freq	%	freq	%
YES	22	47.8%	13	46.4%
NO	24	52.2%	15	53.6%

A LICENSED HOME

Rating of importance	N	Mean	SD	t-test	df	p-value
Ambulatory	48	5.4	3.5	-2.2	75	0.029
WC/BB	29	7.1	3.2			

Willingness to Use	ambulatory		WC/BB	
	freq	%	freq	%
YES	22	48.9%	18	66.7%
NO	23	51.1%	9	33.3%

Patients once again offered open ended comments on the various conditions of use or problems they envisioned in each alternative.

MULTIDISCIPLINARY CLINIC: Patients said convenient location, high quality doctors and adequate insurance reimbursement were conditions of use for this clinic. Several respondents described the clinic as a way of providing integrative care with qualified professionals overseeing and coordinating their care. Others commented that having their specialists under one roof would save them energy and make their doctor visits more efficient for their families. Many of the patients said they would use this clinic now if it were available.

ACHIEVEMENT CENTER: Again location, accessibility and quality staffing were seen as conditions of use. It was suggested that evening hours would be helpful. Some patients expressed concern about being around people more disabled than themselves and didn't want the feeling that they were being "babysat". Overall, however, the respondents were enthusiastic about a program that would get them out of the house, provide socialization and an opportunity to learn new ways to help themselves in their wellness.

INDEPENDENT LIVING CENTER: Patients stated they would use only with deterioration of the condition to the point where they could not stay in their home or if they faced a financial crisis. One person said they didn't want to "be labeled like a leper". Other reported problems with this alternative were isolation, cost, lack of privacy, noise and psychological concerns.

LICENSED HOME: Several patients stated this would be a last resort to care, something they would consider because they had no other choice. One person stated he would rather "be 10 feet under" than live in a licensed home. People expressed concerns about being "institutionalized" and having little control over the quality of their caregivers. Other problems with this alternative was the separation from family, being lonely, affordability, location and compatibility with other residents.

FINDINGS—CAREGIVERS OF PEOPLE WITH MULTIPLE SCLEROSIS

SOCIODEMOGRAPHIC DATA

Twenty-five (25) caregivers of MS patients were interviewed. Their mean age was 57.2 years with a range of 32 to 78 years. The majority were female (14/25) and Caucasian (23/25). Twenty-one (21) of the caregivers were in a marriage or partnership relationship with 20/25 living with the patient. The majority were employed full or part time (15/25 and 24/25 rated their health from fair to excellent.

As with the patient sample, there was a wide variety in the reported yearly income of these families. Fifteen caregivers reported their annual income being greater than \$50,000.

SOCIAL SUPPORT

The majority of caregivers reported there were people in their lives who would help with household errands (18/25), advise or guide during uncertain situations (17/25) and listen nonjudgmentally (20/25). More problematic in terms of social support was naming people who could help with personal care of the patient (9/25) or who could take over for vacations (13/25).

Overall satisfaction was high with the perceived level of social support. On a scale on 1-10 (1=extremely dissatisfied, 10=extremely satisfied), caregivers rated satisfaction with their social support at level 8.7 (SD=1.5).

CAREGIVING EXPERIENCE

Caregivers were initially asked to describe the various tasks they were required to do as part of their caregiving responsibilities. Because this data was not analyzed by the functional ability of the patient, the results were highly variable and difficult to interpret according to level of disability. Table 26 ranks the tasks of caregiving according to frequency that the caregivers reported they had the responsibility.

TABLE 26: TASKS OF CAREGIVING

TASK	FREQUENCY (N=25)
Errands	17
Meal preparation	13
Housework/Home care	13
Laundry	12
Transportation	12
Personal Business	11
Medications	9
Special treatments	7
Wheelchair transfers	7
Bathing	7
Dressing	7
Bed transfer	6
Assistance with walking	6
Toileting	5
Feeding	5

The caregivers were asked to evaluate and rate the changes in their personal lives and in their relationship with the person with MS that they attribute directly to their caregiving responsibilities. Table 27 illustrates the level of change in personal life because of being a caregiver,

Scale:	1	2	3	4
5	_____			
a lot better	a little better	same	a little worse	a lot worse

TABLE 27: EFFECTS ON PERSONAL LIFE OF CAREGIVERS

EFFECT	MEAN	SD
Amount of personal freedom	3.8	1.2
Amount of vacation activity	3.7	1.2
Amount of personal time	3.7	1.1
Amount of privacy	3.6	1.2
Amount of personal energy	3.6	0.9
Amount of recreational/social time	3.6	1.0
Amount of money for expenses	3.4	1.1
Effect on your personal health	3.3	0.5
Effect on family relationships	3.0	0.7

In terms of the effect of caregiving on their relationship with the person with MS, caregivers were asked to evaluate the frequency of various feelings and thoughts about their current situation (Table 28).

Scale:	1	2	3	4
5				
Rarely/never most of the time	a little	sometimes	often	

TABLE 28: THOUGHTS AND FEELINGS ABOUT BEING A CAREGIVER

THOUGHT/FEELING	MEAN	SD
I feel I contribute to him/her wellbeing	4.4	1.2
I am pleased with my relationship with him/her	4.2	1.3
I feel useful in my relationship with him/her	4.3	1.2
It is painful to watch him/her with MS	3.5	1.3
I am fearful about what the future holds	3.3	1.2
I feel I don't do as much as I should for him/her	2.0	1.3
I feel like I am the only one he/she depends on	1.8	1.2
I feel strained in my relationship with him/her	1.7	0.9
I feel under appreciated	1.5	1.2
I feel guilty about my relationship	1.4	0.8
I feel manipulated	1.4	1.0
I feel nervous/depressed about our relationship	1.3	0.8
I feel he/she asks for more than he /she needs	1.2	0.7

USE OF COMMUNITY SERVICES

Caregivers were also asked about the utilization and satisfaction with available local community services for people with MS and their families. The majority of caregivers reported that they did not use local community resources (19/25). Table 29 lists the local resources used by the caregivers and whether or not these services were satisfactory.

TABLE 29: USE AND SATISFACTION WITH COMMUNITY SERVICES

SERVICE	FREQ	SATISFACTION	
		YES	NO
RIDES Program	6	3	3
Home health care	6	6	0
MS Community Services	2	1	1
MS National Society	1	1	0
Del Mar Caregivers	1	1	0
Meals on Wheels	1	1	0

Satisfaction with community services was rated on a scale of 1 to 10 (1=extremely dissatisfied, 10 =extremely satisfied). Caregivers reported an overall satisfaction level with community services of 6.1 (SD 2.9).

ALTERNATIVES FOR PERCIEVED FUTURE NEEDS

Caregivers were asked to comment and rank from four alternatives which services they felt were important to enhance the care of the person with multiple sclerosis. The four alternatives presented to the caregivers were identical to those discussed with the patient sample.

1. A multidisciplinary clinic
2. An achievement center
3. An independent living center
4. A licensed residential home

Although the comparison is not statistically significant, the data in Table 30 details the ranking of the alternatives among the patient functional groups and the caregivers.

TABLE 30: ALTERNATIVES FOR CARE—PATIENTS AND CAREGIVERS

SERVICE	AMBULATORY		WC/BB		CAREGIVERS	
	YES	NO	YES	NO	YES	NO
Multidisciplinary Clinic	41 87.2%	6 12.6%	22 78.6%	6 21.4%	24 96%	1 4%
Achievement Center	43 91.5%	4 8.5%	23 82.1%	5 17.9%	22 88%	3 12%
Independent Living Center	22 47.8%	24 52.2%	13 46.4%	15 53.6%	11 47.8%	12 52.2%
Licensed home	22 48.9%	23 51.1%	18 66.7%	9 33.3%	18 72%	7 28%

Caregivers offered open-minded comments on the conditions of use or perceived benefits/problems with each of the four alternatives.

MULTIDISCIPLINARY CLINIC: Concerns about a clinic related to location, accessibility, affordability, and the quality of medical specialists. Several respondents mentioned the possibility of a mobile van as a means of bringing quality health care to those unable to leave their homes. A number of caregivers stated they could use the service presently if it were available and would appreciate seeing experts in MS and having the care better coordinated and guided.

ACHIEVEMENT CENTER: Concerns about this alternative revolved around accessibility and cost, the quality of staff and issues about motivating the patient to participate. Some caregivers said they would benefit from classes on finances, resources and the disease process in addition to support groups specifically geared to their needs.

INDEPENDENT LIVING CENTER: Concerns about an independent living center focused on the cost, location and feelings of grief and sadness about having to leave their homes

due to the disease process. People felt they would choose this option only if personal financial resources and ability to provide care were totally exhausted.

LICENSED RESIDENTIAL HOME: Caregivers expressed despair when considering this alternative. Many stated this alternative was viable only if they died before the patient and could leave no financial means for providing care. The isolation from the family and focus on disability were negatives to some caregivers. Conditions of use centered around convenient location, the training and certification of caregivers. One caregiver stated his "pride" would not let him accept such an alternative for the person in his care.

DISCUSSION AND RECOMMENDATIONS:

From a historical perspective, the independent group that commissioned this study was considering the development of affordable and appropriate housing specifically for people with multiple sclerosis. There was---and still is---great concern about the plight of young people, in particular, with MS who end up in the nursing home system of this country for their care. However, there were several concerns regarding this proposal; cost of housing in this area of California is very high and this type of project would address the needs of a very small population of people.

The Multiple Sclerosis Quality of Life Project was designed then to more fully describe the care and housing needs of a larger population of MS patients in the hope that concrete recommendations could be made. Eight objectives were established to guide the data collection. All eight objectives were met and a large amount of data was generated by the study.

The data as analyzed in this study interestingly did not support a convincing immediate need for the development of housing for people with MS. Instead, a significant number of characteristics and other unmet needs were identified that would be better met through a **service/case management model**. The details of this approach are open for discussion but in principle would involve a proposal for hiring professional health care providers (e.g. MSW) to assist with care coordination and resource development and utilization for the people with MS in this tri-county area. The following discussion focuses on the data as it supports the recommendation for a service model of case management.

An analysis of the sociodemographics and health of the 80 respondents is critical to defining recommendations for care, services and housing. This was a convenience sample of people which means that the people interviewed volunteered for the project. This type of self selected sample often includes highly motivated individuals, people already involved in advocacy efforts or those who are overwhelmingly needy and who participate in hopes of having needs met through the process itself. Unrepresented in this convenience sample are those who feel totally disenfranchised from the system, minority populations and those with cultural or deeply personal barriers to participation.

The individuals in this sample varied greatly in many aspects including levels of disability, financial resources, quality and accessibility to medical care, services and local support systems. Added to the heterogeneity of this sample is the fact that the study was conducted in a geographical area that is highly diverse. It is well known that the 3 counties studied...Monterey, Santa Cruz and San Benito..are very different, each having distinct medical systems, cultural milieu, opportunities for employment and citizens with varying income and education levels. This diversity, rather than being a negative aspect of the study design, actually echoes the fact that the disease in question is also intensely variable and unpredictable.

Another significant characteristic of this sample was the fact that more than half of the entire population were either single, divorced or widowed with this statistic rising to 62.5% in the wheelchair/bedbound group. Forty percent of the sample lived alone or in a skilled nursing facility. Many of these patients had no one to advocate for them, no one but themselves safeguarding or proactively seeking improvements in their well being.

A unique feature of MS, born out by this study, is the delay in diagnosis that many patients experience. In this sample, patients recall having symptoms an average of 23 years ago with the diagnosis made an average of 8 years later. Again this is highly variable with a number of people reporting symptoms a full 20 years or more prior to the diagnosis being made. The time between symptoms and diagnosis were often filled with negative experiences with health care providers. This situation contributes directly to lack of trust and feelings of bitterness and anger with the established system of care that were expressed by a number of the patients interviewed.

The disease process itself exerted enormous impact on the lives of these patients. These changes involved all realms of their being....physical, mental, social, emotional and spiritual. When asked to quantify the level of change on their lives because of MS, the overall sample reported a change level of 8/10. As expected, the wheelchair/bedbound patients reported a statistically significant higher level of change than the ambulatory group (9.0 vs. 7.3, $p=0.002$).

Understanding the symptoms experienced by people with a specific disease is critical to designing programs and services. The three most distressing physical symptoms reported by the patients in this sample were fatigue, vision deficits and weakness. These symptoms are global and constitutional and essential considerations when designing recommendations for care and services.

A **service/case management model** potentially could make a significant impact on the issues described by the sample characteristics. Many MS patients are isolated because of being alone and because of barriers to seeking care which include being disillusioned with existing services, not trusting, being too fatigued or not knowing where to begin. One goal of a service/case management model would be to establish relationship with the individuals in the local MS community, bridging barriers, building trust and facilitating healthy partnerships. In addition, the service/case management model is perfect for meeting the diverse needs of the MS patient. It is evident that care and support of this patient in this geographical area must be individually assessed and designed. And most imperatively, suffice it to say that the profound changes wrought by this disease on all patients are much more than a housing project can address.

From the perspective of the financial impact of disease, the information was highly variable. No effort was made to verify the financial data provided; that was not the intention of this study. In both the ambulatory and wheelchair/bedbound groups, the change in their lives that was most negative to their well being was loss or change in employment. This obviously has a financial impact for many of the families and individuals coping with a chronic disability in addition to the psychological impact of leaving a job one really enjoyed and coping with a loss of purpose and self-definition.

A common concern expressed by among patients and caregivers was how they would manage if their income decreased or expenses increased; 46% reported they did not know what they would do in that situation. An advantage of the **service/case management model** would be to assist selective patients in maximizing their financial resources with an eye on the future knowing there is a likelihood that their financial situation will be affected by disease progression and changing resources.

In considering the financial coverage for medical expenses, the data also supports the value of a **service/case management model**. A wide range of out of pocket monthly medical expenses were reported (\$10 to \$6100). One might ask if each person was receiving maximum reimbursement or if there were other resources or benefits that were not being utilized. Over half of this sample are receiving medical care coverage solely through state and federal sources (MediCal or MediCare). It is a fact that these 2 systems are over extended at present with no immediate relief for the foreseeable future. In addition, these two systems are geared largely toward reimbursement for acute care and do not adequately cover the

ongoing health maintenance services and medications required by people chronically and progressively disabled. Complicating the reimbursement situation for the MS patient is the complexity of the bureaucracy. It requires cognitive stamina, visual acuity and energy to maximize reimbursement and benefits from paperwork intense systems. Frequently, even physically healthy people do not possess adequate personal resources to manage such a complicated system. The data supports the value of a **service/case management model** that could creatively and proactively maximize reimbursement for health care and have access to additional financial resources to meet noncovered costs.

The health care team of a person chronically ill is a key element in their care and adaptation to illness. Most patients had multiple medical specialists involved in their care. Patients and families are faced with the challenge of keeping the care coordinated. People with other chronic illness face similar problems as their physicians hone in on particular areas of interest and expertise. Often two things happen; first, the overall picture of the patient is lost in the segregated view and secondly, communication among specialists is often non-existent resulting in fragmented and uncoordinated care. Emphasizing once again that MS patients often experience fatigue and weakness, the availability of better coordinated care would be a benefit to their well being. Traditional case management models have emphasized the importance of medical care coordination resulting in increased financial savings and patient satisfaction.

Several of the patients in the skilled nursing facility spoke of a different concern regarding their health care team. Many specialists would not visit them in the facility and the medical director of the facility managed their care. Patients complained that they were deprived of choice in their physician selection and stated that several physicians had been in this role during their stay at the facility and few of them had much expertise in caring for people with multiple sclerosis. These patients would benefit also from a **service/case management model** by having someone to assist in advocacy and care management in an environment where medical services are not readily accessible.

Of particular note is the absence of psychiatrists, psychologists, social workers or marriage/family therapists on the health care teams of these patients. Only 20% of the entire sample reported having access to these professionals and they were all ambulatory patients. None of the wheelchair/bedbound population, the people most impacted by change due to illness, was receiving psychosocial support.

Nearly 30% of patients reported taking medication for depression. This presents a critical unmet need. Both ambulatory and wheelchair/bedbound patients reported that the changes most negative to their well being were in the areas of employment, leisure activities and personal changes/societal role. Meeting these specific unmet needs falls within the domain of the psychosocial experts not the medical professionals. It can be postulated that meeting these psychosocial needs will facilitate greater adaptation to chronic illness and progressive disability and assist patients in developing healthier and more effective coping skills. A goal of a **service/case management model** would be to facilitate strategies for meeting these profound needs in the MS patients and directly improving their quality of life and psychological health.

Medication management is a key component to controlling symptoms of MS and more recently, to directly treat the underlying disorder. Patients in this study self-reported on their prescription and nonprescription medication use. The interviewers did not ask to see the medication bottles or verify the prescriptions with the physician. Therefore, the data on medication use may be under reported. The three most frequently stated indications for using prescription medications were pain control (44/80), treatment of the underlying disease (39/80) and to relieve spasm and spasticity (38/80). Seventy-five percent of patients reported being independent in medication management.

Financial coverage for medication was variable with 9% of the ambulatory group and 26% of the wheelchair/bedbound group reporting they had no coverage for medications. Out of pocket expenses for prescription medications ranged from \$10 to \$575 per month for ambulatory patients (median=\$45) and \$10 to \$1300 per month for wheelchair/bedbound patients (median=\$87). This does not include the cost of over the counter medications, which were used more frequently by ambulatory patients and are not reimbursed. This cost of medications can be an enormous burden to patients and families.

The newer agents being developed to modify disease activity can cost \$1000 to \$3000 monthly. That cost is not expected to decrease even as newer agents are released. The technology to develop and market these drugs make them extremely costly. Every MS patient wants access to these drugs; they hold the hope of reversing or stemming the progress of their disease rather than just managing symptoms.

A goal of the **service/case management model** would be to carefully reassess the patient's medication regime and reimbursement. Patients can be coached and educated to speak to their physicians about potential medication adjustments based on unrelieved symptoms or new advances in treatment of the disease.

Resources for reimbursement must be a priority of a service model. Many options are available for patients including mail order and on-line pharmacy services; often their charges to the patient are significantly less than local providers. In addition, financial assistance can often be found for noncovered or poorly reimbursed medications by using appropriate substitutions, claim resubmission and through partnerships with pharmaceutical companies which have programs for supplying medications to low income and under served patients at no charge. Providing guidance in drug procurement and reimbursement to this population of patients will be a significant improvement in care.

A relatively small number of patients reported using complementary methods of healing (e.g. bodywork, mind-body techniques and diet modification). Although many stated that they had a desire to participate in these activities, less than 50% of the sample actually reported any utilization of these services. In particular, many of the wheelchair/bedbound patients in the extended care facilities were anxious for better services such as stretching and bodywork. Reimbursement constraints prevent these people from receiving physical therapy on an ongoing basis; yet they are aware of the benefits of regular assisted range of motion and stretching. These activities help chronically and incurably ill people feel as if they are doing something to maintain their health and function and perhaps slow the progression of disease.

A goal of the **service/case management model** would be to creatively integrate these services in the care of people with MS. Strategies would include could include simple 1:1 education tools for relaxation and visualization, teaching stretching techniques to patients and caregivers and proactively seeking funding for rehabilitation professionals, massage therapists and energy workers to provide 1:1 and group sessions. Potential outcomes of this goal of a service model would be decreased pain and spasm, increased energy and cognitive strength and enhanced satisfaction and self-esteem.

Another problematic area defined by this study is the under utilization of community resources reported by both patients and caregivers. The wheelchair/bedbound patients reported much higher

use of community resources than the ambulatory group, although it remains lower than one would hope. Satisfaction with the services when accessed was 6/10 for all groups.

A potential goal of a **service/case management model** would be to not only streamline patient access to community resources but also to assist the existing resources in providing services that are needed and desired. The liaison role between patients and families and the non-profit community agencies can help to enhance service and patient satisfaction. The advocacy aspect of this model can maintain the focus on the needs of the patient while providing feedback to the providers about quality and potential additional areas of service.

Both patients and caregivers evaluated their perceived support systems. Categories of support discussed included assistance with chores and errands and the presence of helpful people to advise and guide and to listen without judgment. Both groups reported fairly high levels of social support from family and friends (75% of the entire cohort of patients and caregivers indicated they had adequate social support). Both groups also expressed high satisfaction with the support they were receiving (rated 8/10 to 9/10).

This type of support obviously has considerable value. Yet it is evident from experience with other chronic and often incurable diseases (e.g. diabetes and cancer) that people also benefit from professionally guided support with the goal of teaching coping skills and facilitating adaptation to illness and disability.

Enhancing this support system can be a distinct benefit of the **service/case management model**. Challenges facing this model of care would be the implementation of support systems for MS patients by MS patients. The patients interviewed were ambivalent about being with other people with MS whose condition may be worse than theirs. In many situations, peer support can be extremely valuable despite being difficult. One key to the success of peer support is the availability and supervision of professional staff. Ideally, the staff members of this model would be required to have experience and expertise in the areas of individual and group support and be able to contribute in a variety of ways (groups, 1:1 support and peer support) to each patient and families' adaptation to this difficult and challenging experience.

The Multiple Sclerosis Quality of Life Project included a separate data collection for caregivers of people with MS. Most of the caregivers interviewed were women with a mean age of 57 years (range 32 to 78 years). Most were married to the patient and were employed outside the home either full or part time. This sample was small and included caregivers of patients who also had been interviewed. The data was not extensively cross-referenced nor was it analyzed according to the level of disability of the patient being cared for. If the role and impact of caregiving needed further delineation, these would be considerations in addition to increasing the sample size.

Despite those limitations, however, several issues emerge. The most common tasks provided by the caregiver were errands, meal preparation, housework/home care followed by laundry and transportation. When the patient sample was asked which activities of daily living (ADLs) that they needed the most assistance with, the same tasks were identified (housekeeping, laundry, food preparation and shopping). Caregivers reported that the greatest change in their personal lives because of this role involved their personal freedom, time and vacation activities. This change was described by the majority of the sample as "a little less/worse" than before they became a caregiver. The relationship of the caregivers with the patient for the most part was a positive one with the majority stating they often felt they contributed to the well being of the patient. The most difficult thoughts/feelings expressed by the caregivers centered around the pain of watching someone they care about suffer and fearfulness about the future and what it might hold for them.

Every chronic illness affects the entire family circle and the family must be the unit of care whenever possible. A **service/case management model** would naturally include the family in its assessment and plan of care. Strategies and resources could be identified to assist families in crisis with errands and other such tasks of caregiving plus respite care. The psychosocial component of this model would provide positive feedback and reward to caregivers for the difficult job they perform in addition to supporting them as they face an uncertain future and experience the despair of the effects of this life changing illness.

Because this study was commissioned with a concern about housing, an extensive evaluation was done of each patient's living environment. In general, the home environments of the patients studied met their current and future needs; this was particularly true of the wheelchair/bedbound group. The bath and the kitchen areas appeared to need the most consideration for both groups of patients. Areas of concern were the height of cupboards and sinks and the availability of space for wheelchair turn around. The adequacy of emergency exits were a serious concern for the entire group. The emergency exits did not meet either current or future needs of 43% of ambulatory patients and 36% of wheelchair/bedbound patients.

Most patients were satisfied with their home environments and had little concern about their living arrangements as long as their MS remained stable. However, 60% of the ambulatory group and 64% of the wheelchair/bedbound group expressed concern about how they would manage in their current living situation should their disease progress. This is a definite unmet concern that could be met by a service/case management model of care.

Obviously, most patients desire to remain in their homes if at all possible. A purpose of the **service/case management model** would be to evaluate and monitor the adequacy of each home environment and proactively guide families and patients in making modifications as needed to protect patient safety, independence and care at home. The service model could develop a resource list of reputable building contractors and carpenters who have interest and expertise in home repairs/modifications and who will charge reasonable fees to these patients.

Despite the best intentions, however, residential care and skilled nursing care will be a reality for the most severely disabled without adequate family/financial support. A short-term goal of the case management model could be advocacy and care coordination in the existing facilities. This may foster a long-term goal of improved care facilities with a holistic commitment to patients suffering chronic neurologic impairments.

A critical aspect of both the patient and caregiver interviews was the questioning about perception of their future needs and what service would they want to see developed in the local area. Although the trends were similar for the overall population of people interviewed, specific differences in desires existed among the three groups (ambulatory, wheelchair/bedbound and caregivers).

All people interviewed overwhelmingly perceived a need for services such as a monthly multidisciplinary clinic and an achievement center as opposed to housing such as an independent living center or licensed residential home. The mandate for these services was very strong and comprises the primary foundation of the proposal for a **service/case management model**. The open ended comments of the respondents give added insight to their rationale for needing additional services and the various conditions of use including accessibility and location. The respondents were specific in their desire for such services and there was an excitement in their conversations with the interviewers about these options.

Housing concerns were real, however and the wheelchair/bedbound patients and the caregivers expressed more interest than ambulatory patients in examining these options. This reflects a more realistic perception of what the future (or present) holds. It is imperative that a service/case management model continue to pursue improved quality in the existing local residential and skilled nursing care facilities. Developing and offering services to the facilities in addition to individual patients is a necessary component of the proposed model of care.

During the conduct of this study, a community of MS patients who live in assisted or skilled nursing facilities were identified in Santa Cruz. Many of these patients have chosen to live in this area because of the favorable climate and the existing community of people with neurological impairments. There are identified patient leaders in this area who are committed to assisting in improving quality of care through new programs. It is conceivable that the proposed service model of care could efficiently connect with this community and quickly begin to identify ways to improve care within the existing facilities. Success within this community could then be used to improve services for patients in residential and skilled facilities in the other areas of the county. This in a sense may accomplish a segment of the original goal of the independent group who commissioned this study...that of improving the housing of people with MS.

PERSONAL REFLECTIONS:

My professional work as an oncology nurse has given me a familiarity with the struggles faced by people with MS. Cancer patients also have a disease with a stigma, they face an uncertain future, their future story is disrupted as they live with a life changing and sometimes life threatening diagnosis. Families, finances, self-esteem, levels of energy and ability to perform activities of daily living are all impacted by malignancy. Patients struggle within a bureaucratic medical system and need to take responsibility for keeping their multiple doctors and health team organized. Many are intensely interested in complementary methods of healing to enhance their western medicine and to do something themselves to fight their illness. People with cancer often feel like they have no control and actively pursue opportunities to learn healthily and effective coping skills for managing the many changes they encounter daily for years after diagnosis.

A service model involving case management, education and support have been enormously successful tools in my work with people with cancer and their families. The presence of a professional person to act as a "coach" or "guide" through their experience with cancer definitely enhances their care. Most certainly, the patients and their support people express greater satisfaction and exhibit healthy coping and adaptation as a result of the interventions. Physicians also comment that their jobs are made easier by having the services of the cancer center with its ability to provide case management, education and support.

As the nurse in this position, I have been able to develop a wide base on support for my patients including additional funding sources for services that are not covered by insurance, high quality massage therapists, rehab specialists, psychosocial and spiritual support, social services, sliding scale legal and accounting services. As a result, the service model has grown to include others committed to the care and well being of people with cancer.

It is my personal observation that the process of interviewing all these MS patients and caregivers provides us with additional support for the service/case management model we are proposing. My colleagues in this project felt the same way. The majority of respondents were extremely receptive to sharing their story and information with a trained professional. It seemed like the individual assessment, personal contact and relationship with someone who cared about their situation and outcome was in and of itself

therapeutic. Although nothing really changed because of the interview itself, the patients and the interviewers often both felt that something was indeed accomplished.

From the point of view of the interviewers, the work of interviewing was often difficult because we didn't have any concrete solutions to offer or authority to make improvements. We did witness much sadness and anguish while at the same time celebrating courage and perseverance...often in the course of the same interview. We met a number of very exceptional patients...people who have managed to take their disability in stride, who have used the computer world to bring them into life outside the confines of their bed or wheelchair, people who have faced the inevitability of their circumstances and who have prepared as best they can and continue to live as joyfully as possible in the present moment. This reality is something worth striving for in any patient with MS.

