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**Predictive Value of SF-36 for MS-Specific Scales
of the MS Quality of Life Inventory**

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Background

The MS Quality of Life Index (MSQLI) is a modular health-related quality of life instrument consisting of the Health Status Questionnaire (SF-36) and nine MS-specific measures. The purpose of this study is to assess whether adding all the proposed MS-specific measures to the SF-36 is necessary to obtain a more comprehensive measurement of quality of life in MS.

Method

Eighty-eight persons with multiple sclerosis, 42 men and 46 women, with an average age of 52.5 ± 11 years, completed the MSQLI questionnaires. The predictive value of SF-36 items to MS-specific scales was low to moderate, with r^2 -values ranging between 0.02 and 0.57. The accuracy of the predictive models was not sufficient enough to replace the MS-specific scales with the SF-36 items.

Conclusion

Adding scales to the SF-36 may be valuable to obtain a more comprehensive view on the quality of life of people with MS. Int J MS Care [serial on-line]. 2003;5(1).

In recent decades, health-related quality of life (QoL) has become increasingly important as a measurement of the health status of people with multiple sclerosis (MS).¹ Quality of life has been defined by the World Health Organization² as the individuals' perception of their position in life within the context of the culture and value system they live in, and in relation to their goals, expectations, standards, and concerns. It is a broad-ranging concept, incorporating in a complex way a person's physical health, psychological state, level of independence, social relationships, personal beliefs, and relationship to salient features of the environment.

Health-related QoL can be considered a distinct component of QoL in general and has recently been defined as the functional effect of an illness and its consequent therapy upon a patient, as perceived by the patient.³ Similar to overall QoL, the health-related aspect is a complex concept, incorporating components such as physical and occupational function, psychological function, social interaction, and somatic sensation.

That QoL refers to the individuals' perception of their position distinguishes this parameter from more traditional measures of impairment, activity, and participation, where the scores are based on clinicians' perceptions. Studies have shown that health-related QoL provides additional information to clinician-derived data.⁴⁻⁶

Several scales have been developed to measure health-related QoL in MS. One of the most widely used scales is the Health Status Questionnaire Short Form with 36 generic items (SF-36).⁷ Several attempts have been made to extend the SF-36 with MS-specific scales to obtain a disease-specific measure for MS.⁸⁻¹⁰

The MSQoL-54⁸ incorporates the general items of the SF-36 as well as 18 MS-specific items, chosen on the basis of literature and clinical expertise. The disease-specific items relate to cognitive function (four items), health distress (four items), sexual function (four items), satisfaction with sexual function (one item), and overall QoL (two items). Freeman et al¹¹ investigated the psychometric characteristics of the MSQoL-54 to determine whether including the MS-specific measures would offer any advantage over the SF-36. A comparative analysis of the SF-36 and MSQoL-54 showed similar reliability and validity in 150 persons with MS, and similar responsiveness in 44 subjects. The authors concluded that the MSQoL-54 does not offer clear psychometric advantages over the SF-36.

In 1997, the Consortium of Multiple Sclerosis Centers published the Multiple Sclerosis Quality of Life Inventory (MSQLI),⁹ developed on the basis of the input of an expert panel and field tests with 300 persons with MS. This questionnaire includes 138 items organized in 10 scales—the SF-36 and nine MS-specific scales. The MS-specific scales relate to fatigue (21 items), pain (six items), sexual satisfaction (five items), bladder control (four items), bowel control (five items), visual impairment (five items), perceived deficits in cognitive function (20 items), mental health (18 items), and social support (18 items).

In a correlation analysis with the MS Functional Composite score⁵ and a study evaluating the effects of disease-modifying agents,¹² the MSQLI has shown promising results in terms of reliability, validity, and sensitivity, and Miller et al¹² concluded that QoL is a unique end point in the assessment of treatment effects. However, the relations between the general SF-36 items and the MS-specific scales of the MSQLI have not yet been examined.

Studies investigating treatment effects indicate that there is a need for including QoL as an outcome measure. However, the value of adding MS-specific items to general measures has not been clearly demonstrated. One disadvantage of the MSQLI is that it takes too long to perform (45 minutes on average). This issue may be relevant in terms of time constraints, particularly in the clinical setting. The purpose of the present study is to assess the predictive value of the general SF-36 to the MS-specific scales included in the MSQLI.

METHODS

Subjects

Beginning in June 2001, the first 100 patients consecutively admitted to the inpatient rehabilitation program at the National Multiple Sclerosis Center in Melsbroek, Belgium, were considered for inclusion in the study. Patients were eligible for participation if they had a definite diagnosis of MS and consented to participate in the study. Reasons for exclusion were serious cognitive or communication problems.

Out of the 100 eligible persons with MS, 88 (42 men, 46 women) answered all the scales of the MSQLI. If a person was unable to fill out the forms because of upper limb or visual impairment, the questionnaire was completed by the researcher in a face-to-face interview.

The average age of the subjects was 52.5 (\pm 11), and disease duration since diagnosis was 13.9 years (\pm 9.8). The average total score on the Functional Independence Measure was 84.4 (\pm 23.16) and ranged between 38 and 117. The median Expanded Disability Status Scale (EDSS) score was 7 and ranged between 2 and 8.5.

Multiple Sclerosis Quality of Life Inventory

The scales of the MSQLI, including the SF-36 and the nine MS-specific scales, are displayed in Table 1. The inventory contains 138 items and takes approximately 45 minutes to complete, either by self-assessment or by interview.

Table 1		
Scales of the MSQLI: Items of the SF-36 Health Status Questionnaire and Nine MS-Specific Scales		
Full name	Abbreviation	# of items
Health Status Questionnaire (Short Form Health 36-item Survey)	SF-36	36
General Health Scale	SF-GHS	5
Health Transition Item	SF-HT	1
Physical Functioning Scale	SF-PF	10
Role Physical Scale	SF-RP	4
Bodily Pain Scale	SF-BP	2
Vitality Scale	SF-VT	4
Social Functioning Scale	SF-SF	2
Role Emotional Scale	SF-RE	3
Mental Health Scale	SF-MH	5
Physical Component Summary Scale		
Mental Component Summary Scale	SF-MCS	
MS-Specific Scales		102
Modified Fatigue Impact Scale	MFIS	21
Medical Outcomes Study Pain Effects Scale	PES	6
Sexual Satisfaction Scale	SSS	5
Bladder Control Scale	BLCS	4
Bowel Control Scale	BWCS	5
Impact of Visual Impairment Scale	IVIS	5
Perceived Deficits Questionnaire	PDQ	20
Mental Health Inventory	MHI	18
Medical Outcomes Study Modified Social Support Survey	MSSS	18

Data Analysis

The predictive analysis between SF-36 and MS-specific scales was performed in three steps. First, a correlation matrix was built for the items of the SF-36 and the MS-specific scales. All items of the SF-36 with significant Spearman correlation coefficients ($P < .05$) were selected as predicting variables within a logistic regression. This analysis resulted in r^2 values, representing to what extent different SF-36 scores explained the variance of MS-specific scales. Finally, the

accuracy of the predicted models was determined by the Hosmer and Lemeshow Goodness of Fit test¹³ and an analysis of the specificity and sensitivity. All calculations were performed with SAS, version 6.12.

RESULTS

QoL Measures

Table 2 represents average scores and standard deviations for each of the items for the participants in the study. Scale values for the items on SF-36 range between 0 and 100, with a higher score indicating better health. The SF-36 scores with regard to social functioning (SF-SF), bodily pain (SF-BP), and vitality (SF-VT) are comparable to the results in the study of Freeman et al.¹¹ The physical and mental components scores, computed on the basis of z-scores referring to the scores of a general population, were comparable to the results in a study of Miller et al.⁵

Table 2		
Average	Scores	on
of the MSQLI	the	Different
in 88 Persons With MS	Items	SD
SF-36 items	Average/max score	SD
General Health Score	38.78/100	18.18
Health Transition	3.05/100	0.73
Physical Function	17.71/100	22.13
Role Physical	28.20/100	35.52
Role Emotional	61.63/100	43.24
Social Function	58.28/100	31.77
Bodily Pain	61.16/100	32.01
Vitality	44.06/100	22.76
Mental Health		23.39
Physical Components Score	28.86/100	7.84
Mental Components Score	47.64/100	13.82
MS-Specific Items		
Modified Fatigue Impact Scale	46.11/100	24.42
Pain Effect Scale	14.24/30	6.77
Sexual Satisfaction Scale	8.39/24	7.49
Bladder Control Scale	7.90/22	7.14
Bowel Control Scale	5.57/26	6.34
Impact of Visual Impairment Scale	3.34/15	3.77
Perceived Deficits Questionnaire	21.05/80	15.71
Mental Health Inventory	59.10/100	20.55
Modified Social Support Scale	65.39/100	22.13

For the MS-specific scales, no comparable data are available for MS patients. On all of these items, except for mental health inventory (MHI) and the modified social support survey (MSSS), a higher score indicates that the subject perceives more problems.

Correlation Between SF-36 and MS-Specific Scales

Table 3 represents the correlation between the SF-36 and MS-specific scales of the MSQLI on the basis of Spearman correlation coefficients. Since for the SF-36 items, higher scores indicate better health and for MS-specific scales (except MHI and MSSS), higher scores indicate more problems, most coefficients are negative.

The highest correlations were found between the MS-specific mental health index and mental health item of the SF-36 (r 0.84), the pain effect scale and bodily pain (r -0.71), and modified fatigue impact scale and vitality item of the SF-36 (r -0.69). For the other MS-specific scales, the maximal correlation coefficients ranged between 0.22 and 0.46. The MS-specific bowel control scale was not significantly related to any of the items of the SF-36.

Table 3
Correlation Between SF-36 Items (columns) and MS-Specific Scales (rows)
of the MSQLI (Spearman Correlation Coefficients) in 88 Persons With MS

	GHS	HT	PF	RP	RE	SF	BP	VT	MH	PCS	MCS
MFIS	-0.33	-0.05	-0.05	-0.53	-0.40	-0.34	-0.36	-0.69	-0.30	-0.37	-0.42
PES	-0.36	0.26	0.17	-0.48	-0.53	-0.54	-0.71	-0.48	-0.48	-0.35	-0.54
SSS	-0.11	0.22	-0.08	-0.16	0.02	-0.12	-0.08	-0.17	-0.20	-0.11	-0.10
BLCS	-0.11	-0.26	-0.08	-0.28	-0.07	-0.11	-0.03	-0.26	-0.19	-0.10	-0.20
BWCS	-0.04	-0.05	-0.17	-0.17	0.05	-0.17	0.01	-0.12	-0.17	-0.13	-0.09
IVIS	-0.16	-0.28	-0.15	-0.10	-0.02	-0.17	-0.04	-0.24	-0.14	-0.09	-0.17
PDQ	-0.16	-0.03	0.02	-0.22	-0.31	-0.33	-0.32	-0.46	-0.34	-0.14	-0.35
MHI	0.31	-0.12	0.006	0.40	0.58	0.49	0.32	0.54	0.84	-0.008	0.80
MSSS	0.16	0.17	-0.0003	-0.01	0.16	0.22	0.05	0.03	0.30	-0.06	0.27

Significant Spearman correlation coefficients ($P < .05$) are indicated in bold italic characters GHS, General Health Score; HT, Health Transition; PF, Physical Function; RP, Role Physical; RE, Role Emotional; SF, Social Function; BP, Bodily Pain; VT, Vitality; MH, Mental Health; PCS, Physical Components Score; MCS, Mental Components Score; MFIS, Modified Fatigue Impact Scale; PES, Pain Effect Scale; SSS, Sexual Satisfaction Scale; BLCS, Bladder Control Scale; BWCS, Bowel Control Scale; IVIS, Impact of Visual Impairment Scale; PDQ, Perceived Deficits Questionnaire; MHI, Mental Health Inventory; MSSS, Modified Social Support Scale

Predictive Value of SF-36 Items for MS-Specific Scales

The prediction analysis was performed on the basis of a logistic regression. Multiple regression was not used as the scores on the MS-specific measures were not normally distributed in the persons tested.

For each MS-specific scale, the predictive value of the best- predicting SF-36 item was determined on the basis of r^2 values (Table 4). The statistical significance of the predictive value is expressed on the basis of the P value of the χ^2 test, with $P \geq .05$ indicating that the specific SF-36 item has no statistically significant predictive value for the stated MS-specific scale.

The predictive value of the SF-36 was not increased by combination of SF-36 variables except for the prediction of the pain effect scale (r^2 0.44 on the basis of bodily pain and general health score combined).

MS-Specific Scale	SF-36 Item	r² Value	c² P Value
Modified Fatigue Impact Scale	Vitality	0.33	0.0001
Pain Effect Scale	Bodily pain	0.35	0.0001
Sexual Satisfaction Scale	Health transition	0.03	0.014
Bladder Control Scale	Role physical	0.08	0.01
Bowel Control Scale	Role physical	0.02	0.15
Impact of Visual Impairment Scale	Health transition	0.06	0.03
Perceived Deficits Questionnaire	Vitality	0.17	0.0005
Mental Health Inventory	Mental health	0.57	0.0001
Modified Social Support Scale	Mental health	0.06	0.03

Assessment of the Accuracy of Prediction

The Hosmer and Lemeshow Goodness of Fit test¹³ provides an indication of how well the predictive model fits the data. A P value of .05 or greater indicates that this condition is fulfilled.

The accuracy of the predictive model on the basis of sensitivity and specificity provides information on the percentage of correctly classified data for a certain P level ($P = .05$), with sensitivity referring to the ratio of correctly classified events over the total number of events and specificity referring to the ratio of correctly classified nonevents over the total number of nonevents. Within the frame of the present study, events refer to perceived problems and nonevents refer to the situation where the person does not perceive a problem in the specified domain. The analysis also provides information on false-positive prediction rates (number of nonevents incorrectly classified as events over the total number of events) and false-negative prediction rates (number of events incorrectly classified as nonevents over the total number of nonevents).

For all MS-specific scales, the Hosmer and Lemeshow Goodness of Fit test indicated that the predictive models on the basis of the SF-36 items were statistically sufficient.

Analysis of sensitivity and specificity indicated that the accuracy of the predictive models was highest for the prediction of the mental health inventory on the basis of the mental health item of the SF-36. The prediction was correct in 75.6% of the cases, implying that in 24.4% of the cases the prediction was not correct. The percentages in Table 5 demonstrate that 97.7% of the people who reported mental health problems in the SF-36 were also classified in the group with mental health problems on the basis of the MS-specific mental health inventory, but only 52.4% of the people who did not report mental health problems in the SF-36 were also classified in the MS-specific scale as having no mental problems. The number of false-positive and false-negative predictions was 31.7% and 4.3%, respectively.

Table 5
Accuracy of the Logistic Regression Models to Predict MS-Specific Scales of the MSQLI on the Basis of SF-36 Items in a Sample of 88 Persons With MS

MS	SF-36 item	p-LF	Correct %	Sensitivity %	Specificity %	False + %	False-%	
MFIS	VT	0.26	48.8	97.6	4.4	51.8	33.3	
PES	BP	0.08	57.5	100	11.9	45.1	0	
		BP+GHS	0.83	63.2	95.6	28.6	41.1	14.3
SSS	HT	0.46	50	97.7	0	49.4	100	
BLCS	RP	0.93	32.2	59.6	0	58.8	100	
BWCS	RP	0.10	27.6	51.1	0	62.5	100	
IVIS	HT	0.20	53.5	100	2.4	47.1	0	
PDQ	VT	0.61	53	97.7	5	47.5	33.3	
MHI	MH	0.50	75.6	97.7	52.4	31.7	4.3	
MSSS	MH	0.57	45.1	94.9	0	53.8	100	

p-LF, P-value resulting from the Hosmer and Lemeshow Goodness of Fit test; MFIS, Modified Fatigue Impact Scale; PES, Pain Effect Scale; SSS, Sexual Satisfaction Scale; BLCS, Bladder Control Scale; BWCS, Bowel Control Scale; IVIS, Impact of Visual Impairment Scale; PDQ, Perceived Deficits Questionnaire; MHI, Mental Health Inventory; MSSS, Modified Social Support Scale; VT, Vitality; BP, Bodily Pain; GHS, General Health Score; HT, Health Transition; RP, Role Physical; MHI, Mental Health Inventory

DISCUSSION

Our findings indicate that the general SF-36 measure has some predictive value for the MS-specific scales included in the larger MSQLI. However, the accuracy analysis of the prediction models demonstrates that the prediction of MS-specific scale outcome on the basis of SF-36 items was correct in a maximum of 75.6% of cases. This cannot be considered sufficient to conclude that MS-specific scales can be replaced by the general SF-36 items. The concern that a general health-related QoL measure may not capture all the relevant aspects of a specific illness such as MS10 is confirmed by the results of this study and points to the need to include MS-specific scales in QoL measures for people with MS. Future studies assessing the QoL in people with MS should thus include MS-specific scales in addition to a general QoL measure such as the SF-36.

The present study seems at odds with Freeman et al¹¹ where the MSQoL-54, including MS-specific items, was found to have similar psychometric properties with the SF-36. In Freeman et al,¹¹ the measures were compared in terms of psychometric properties; more specifically, their reliability, validity (comparison with other measures), and sensitivity. However, the similarity in the psychometric properties of different scales does not necessarily prove similar content. Freeman et al¹¹ stated that it would be wrong on the basis of their findings to conclude that disease-specific measures would not be necessary for clinical trials.

The present study used a different methodological approach—prediction analysis—to investigate the additional values of disease-specific measures to the SF-36. The first step in the analysis, building a correlation matrix, showed significant correlations for all except one MS-specific scale with at least one SF-36 item. Also, the logistic regression demonstrated that the SF-36 items selected from the correlation matrix had significant predictive value to the MS-specific scales.

The third step in the analysis, however, revealed that the predictive value of the SF-36 was not sufficient to actually replace the MS-specific scales with the relating SF-36 items.

The choice of a measure needs to be made according to the purpose of the study. Health-related QoL can be recorded either for descriptive purposes or to measure changes, for example, after an intervention. Time investment is an important factor to be taken into account, especially when the instrument is to be applied in the clinical setting. With its 138 items, the MSQLI remains a comprehensive measurement; however, it may not be applicable in routine clinical assessment. Further investigation on the predictive value of other, shorter measures would therefore be useful. An abbreviated version, including 81 items and taking about 30 minutes to complete, has been developed. If the predictive value of the abbreviated version proves to be satisfactory, the shortened version could be used for routine assessment, and an extended test could be performed for those items where problems were detected. It would also be useful to further investigate the relation of the MSQLI with other health-related QoL measures, such as the Functional Assessment of MS¹⁴ or the Illness Intrusiveness Rating Scale¹⁵

The MSQLI was not designed to yield one summary score because its creators believed that QoL is a multidimensional construct. Although one score for QoL may be easier to handle both in a clinical context and for research, one single score reflecting such a multifaceted parameter may be difficult to interpret and therefore may be a less sensitive measure. The MSQLI's many scales offer the advantage that the scales can be used separately according to the specific purposes of the measurement. Studies evaluating the effect of an intervention on a particular aspect of QoL, for example the impact of fatigue, may use the Modified Fatigue Impact Scale as such.^{16,17} Other studies evaluating an intervention with a presumed effect in several domains of QoL may include all of the scales and assess in how many of these a change has been detected.¹² The proper choice of a measurement is crucial to the interpretation of study outcomes.¹⁸ A measure can be psychometrically sound and yet totally useless when it does not cover the parameter of interest. The development of a multifaceted construct such as the MSQLI is valuable since it provides a flexible tool to work with.

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Ask-the-Nurse Program Study

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Abstract

This paper is intended to provide evaluative data designed to enhance nursing services to multiple sclerosis (MS) patients to benefit MS Society staff and stakeholders and to enhance the Ask-the-Nurse program. The Ask-the-Nurse program was initiated at the Michigan Chapter of the National Multiple Sclerosis Society in July 2001. A volunteer nurse knowledgeable in MS care is available via telephone to answer questions raised by MS clients statewide. Phone calls were tracked for 14 months to assess the needs of clients of the National MS Society–Michigan Chapter. Most calls concerned medication, basic clinical information ("Do I have MS?"), National MS Society programs and services, and information requests. It is recommended that other MS Society chapters institute Ask-the-Nurse programs, that Web-based data collection methods be implemented, and that more detailed evaluative data be collected.

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The Ask-the-Nurse program was initiated in July 2001 at the Michigan Chapter of the National Multiple Sclerosis Society. The program is designed to provide callers with information about multiple sclerosis (MS) and referrals, and support for those recently diagnosed with MS. A volunteer nurse is available via telephone to answer questions raised by MS clients in Michigan and to track these calls to assess client needs. A study of the program was initiated to provide client and programmatic evaluative data designed to enhance educational services to people with MS served by the National MS Society. An initial examination of the data found that callers include people with MS, their family members, and professionals from medical clinics. Clients sought information on medical issues (for example, "What impact does MS have on pregnancy?"), long-term care and insurance issues, and on National MS Society programs and services. A call analysis was conducted 10 months after the inception of the program. This paper provides a 14-month review and more detailed analysis of the data. This study recommends that other National MS Society chapters institute an Ask-the-Nurse program, that Web-based data collection methods be implemented, and that more detailed evaluative data be collected.

PROGRAM GOAL

The Ask-the-Nurse program study is intended to provide client and programmatic evaluative data designed to enhance educational services from the National MS Society to people with MS. The study has the following objectives:

- Assess the needs of clients of the National MS Society–Michigan Chapter.
- Determine the issues presented to enhance program and material planning.
- Provide recommendations regarding how the Ask-the-Nurse program may be made more

efficient and effective.

- Evaluate whether this program would be replicable in other National MS Society chapters.

METHODS

The study data were taken from calls received from July 2001 through August 2002. Records were kept of call issues as initiated by callers. It quickly became clear that simply recording call issues was insufficient. At this point, the study was begun and a formal data collection process was put into place, with an expanded list of call issues to assist in the data reduction process. While the volunteer nurse did not use call issues to direct callers explicitly, the expanded issue categories helped staff organize calls and assisted investigators in designing the study more effectively.

Prior to initiating the program, it was necessary to inform clients throughout the state of Michigan about the existence of the Ask-the-Nurse program. Marketing was done through self-help groups, notices in MSConnection (the quarterly Michigan Chapter newsletter), and via the Michigan Chapter Web site (www.nmssmi.org). When sufficient marketing had been completed, the program was initiated and evaluative data collection commenced.

Data Collection

Clients leave their name, phone number, and medical question on voicemail at a toll-free number. The Ask-the-Nurse volunteer is available one day per week to return calls. All contacts are recorded with the caller's name, the reason(s) for the call, diagnosis date, address, phone number, issues addressed during the call, response to the client, and follow-up. Each issue presented during the calls was recorded (as well as the number of actual calls). Repeat calls were noted but not included in the data for this study. Follow-up calls were made by the volunteer nurse as needed but have just started to be tracked.

In May 2002, call categories were expanded significantly by adding 14 specific symptom categories to the call database. Prior to this all MS symptoms were organized in a single category. This means that instead of determining the specific symptom being reported by the caller (eg, vertigo, tremors, speech difficulties), the only record made was that the caller had questions about a symptom.

Data Reduction and Analysis

At this point in the study (14 months, fall 2002), investigators are attempting to determine who is calling the Ask-the-Nurse program, why they are calling, and the direction of the data. Accordingly, call results were cross-tabulated, then organized into tables summarizing the frequency of calls, total calls by category, and the average number of calls per month. Once significant additional longitudinal data are collected (at least three years) more sophisticated data analysis will be possible.

LITERATURE REVIEW

Many studies exist regarding the effectiveness of MS treatment centered on the patients' subjective experience of treatment and the application of medical treatment modalities.^{1,2} Most of these studies are surveys of patients regarding the quality and value of treatment received. Moreover, the validity of surveys and studies measuring the effectiveness of public policy initiatives, of which medical policies play a major role, are firmly established.³ These evaluative tools take a "push" approach, meaning the survey is affirmatively directed to respondents, without the respondent having made an initial request.

Pioneering work by King⁴ that defined nursing as a scientific discipline, as opposed to a craft, demonstrated a high degree of internal and external evaluation and external analysis.⁵ King

recognized that valid and reliable measures of patient outcomes provide research data that demonstrate quality in nursing care.⁴ Gustafson and Andersson⁶ developed a four-staged model for evaluating nursing theory including description, analysis, critique, and support.

Moreover, patient education programs are now attempting to evaluate nursing services in a systematic manner.⁷ Welch et al⁸ have developed, implemented, and evaluated a worksheet being used by nursing faculty in a graduate clinical nurse specialist course to assist students in learning to estimate the cost-effectiveness of patient-education programs. This evidence-based nursing practice is the most recent iteration of outcomes-based nursing and indicates the relevance of gathering research data to document quality in nursing care.⁴

Advances in technology have led to innovative assessment and communications tools in many fields, including medicine. Most of these tools utilize a "pull" approach, meaning a response opportunity (phone bank, e-mail account, or Web site) is made available to patients and clients, and it is the responsibility of the patient or client to make the initial contact with the clinic. Examples include online pharmacies, on-call physicians, and Ask-the-Lawyer programs.

Individual physicians and clinics are now using e-mail both as a communications and an assessment tool. Doctors and patients who use e-mail consider it superior to the telephone for renewing prescriptions, making referrals, handling questions about minor ailments and symptoms, and relaying test results. Documentation of physician/patient exchanges is simpler and neater.⁹ Other studies found that e-mail may be a slower or less effective mode of communication. Physicians attempt to reply within 48 hours, while some do not use e-mail for fear of being overwhelmed.¹⁰ The American Medical Informatics Association (AMIA) has developed guidelines for the clinical use of e-mail with patients.¹¹ The AMIA recommends that care be taken before instituting a survey and research-oriented program, such as those described in this document. The AMIA suggests that a survey or focus group conducted among both staff and patients before instituting an e-mail policy will reveal important additional considerations innate to each venue. This implies that seeking buy-in from all users and stakeholders will foster maximal cooperation with the new directives.

With the advent of Internet- and e-mail-based programs, Web sites now may provide much useful evaluative data. They often support forms-based data entry, allowing the user to enter evaluative data into fields, such as address, job, problem, and issue. With an integrated database, the Web site itself collects data (eg, date, time, server, hits), allowing the managers and administrators to simply download data to their computers.

Technology is becoming a useful tool for assessing the needs and requirements of patients. Empire Blue Cross and Blue Shield recently debuted a Web portal for its network of more than 70,000 doctors. This site confirms patient eligibility, claims adjudication, class submission, and precertification procedures.¹² The portal has improved physician-client communications and greatly reduced claims processing time. The Stanford University Medical Group (www.med.stanford.edu/shs/smg/email.cfml) provides a Web site allowing for, among other things, physician follow-up with patients. Numerous Web portals exist to direct patients and clients to resources on the Web. Healthy.net (www.healthy.net), Fletcher Allen Health Care (www.fahc.org), the American Heart Association (www.americanheart.org), and the Mayo Clinic (www.mayoclinic.com) are examples of community-centered, health-based Web portals.

Nonmedical disciplines also provide mechanisms to communicate with professionals via phone and computer. The American Sleep Apnea Association (www.sleepapnea.org/lawyer.cfml) provides Web site and e-mail communication between clients and attorneys or doctors regarding the disease and legal and medical remedies. TECHWR-L, a Web site supporting the technical writing community, maintains an "Ask-the-Lawyer" Web page (www.techwr-l.com) addressing legal questions of interest to the technical writing community and provides

resources for finding more information. The Tenant Law Center (www.tenantlawcenter.com/askindex.cfm) provides online and e-mail support to tenants and landlords seeking legal support with respect to landlord/tenant disputes. Tenants and landlords from anywhere in the United States may post on the Internet or e-mail questions on a wide range of issues, including evictions, lease agreements, rent, security deposits, tenant selection, discrimination, and property disputes.

A consistent theme among these programs, regardless of discipline, is the lack of evaluative tools. Unlike the Ask-the-Nurse program, there is no attempt to track calls, e-mails, or Web posts by location, source, or other relevant criteria. There are a number of reasons why this is so. Most nonprofit organizations lack the resources and/or time to implement an effective evaluation system.¹³

Many medical clinics of various types have a nurse on staff in charge of patient education. While this is not a phone-, e-mail-, or Web-based program, there is the distinction of nursing staff providing educational and informational services rather than medical advice. The Ask-the-Nurse program at the Michigan Chapter of the National MS Society has made this distinction as well, and notification is made via a disclaimer read to clients by the volunteer nurse and also posted on any flyers and advertising of the program. Our Ask-the-Nurse volunteer nurse received customer service and information and referral training that provided her with all of the National MS Society resources available to share with clients.

Each of the primary MS drug companies has toll-free numbers for clients to call to get information from a nurse regarding their specific medication (eg, how to obtain the medication, how to administer the injections). Due to the for-profit, marketing focus of these services, they were not reviewed for the purpose of this study.

RESULTS

Table 1 outlines the results of calls for service from people in Michigan between July 2001 and August 2002 inclusive.

Category	Total	%
Disease-modifying therapy	94	14.3
Other medications	68	10.3
Symptoms	60	9.1
Neurologic referrals	58	8.8
Non-neurologic referrals	55	8.3
Other MS disease issues	52	7.9
Psychosocial issues	47	7.1
Books	36	5.5
Research	31	4.7
New diagnosis call	30	4.6
MRI questions	25	3.8
IV solumedrol therapy	21	3.2
Chemotherapeutic agents	19	2.9
Complementary therapies	18	2.7
Equipment	18	2.7
Insurance	11	1.7
Physician/professional calls	9	1.4
Employment issues	7	1.1
TOTALS	659	100

The Ask-the-Nurse program volunteer nurse handled 659 calls in a 14-month period. Of this total, 14.3% of callers asked about disease-modifying medications and 10.3% asked questions about other medications. The next highest percentage of calls was MS symptom management at 9.1%. In descending order of importance, other common issues raised by callers were neurological referrals (8.8%), nonneurological referrals (8.3%), other MS disease issues (7.9%), psychosocial issues (7.1%), books (5.3%), research (4.7%), and new diagnosis calls (4.6%). The charts reflect that calls were low in July when the program was being started. Calls were again low in December and January during the holiday season.

Clearly, most calls addressed MS symptoms and what can be done to mitigate them. The top three call categories (disease modifying therapies, other medications, and symptoms) directly addressed MS treatment and symptomatology. The bottom four categories (equipment, insurance, physicians or other professional calls, and employment issues) addressed issues secondary or tertiary to direct treatment and symptoms. In terms of frequency, many midlevel calls (psychosocial issues, books, research) referred to information gathering or interpersonal relations.

Interestingly, new diagnosis calls accounted for a small number (30) in the aggregate. It might be expected that newly diagnosed clients would account for a plurality, if not the bulk of Ask-the-Nurse calls. However, many newly diagnosed MS patients who are referred to the National MS Society by their physician reach the information and referral volunteers who are trained to provide researched information on MS. Those callers are usually directed back to their own physician at that point, if there are medical questions. Members of the National MS Society usually find out about the Ask-the-Nurse program from a flyer received in the first packet of information mailed to them or by reading the quarterly newsletter. Most callers are already aware that they have MS and are calling to receive additional information about the disease itself. Still others are health care professionals calling to receive literature and learn about resources to better understand the effects of MS.

DESCRIPTION OF CALL ISSUES

Neurological referrals—Calls from clients requesting a second opinion or change in treatment.

Non-neurological referrals—Calls from clients who needed occupational therapy, physical therapy, speech, psychiatric, or mental health referrals.

New diagnosis calls—Calls from clients who have been diagnosed within the last two years (Michigan Chapter guideline).

Physician or other professional calls—Calls from professionals requesting information on MS.

Disease-modifying therapy—Calls from clients requesting information on MS medications.

Chemo agents—Novantrone and chemo agent questions.

Intravenous solumedrol therapy—Inquiries as to the efficacy of intravenous methyl prednisolone (IVMP) therapy.

Other medications—Information requested about drugs.

Complementary therapies—Information requested about complementary therapies.

MRI—Callers requested information about the importance of MRI.

Symptom management—Callers discussed symptom management.

Other MS disease issues—Nonsymptomatic MS questions.

Psychosocial—Any questions relating to individual or family emotional and social support and improving communication skills.

Research—Inquiries related to new research in MS.

Equipment—Calls relating to how equipment can be obtained, used, and helpful in symptom management.

Insurance, employment, and books are additional issues that have been raised by callers since the start of this study. Some issues, for example “symptom management,” have been identified as needing to be broken down into more specific symptoms (such as fatigue, pain, vision, etc) to obtain more precise data. As the Ask-the-Nurse program continues, staff will be in a better position to identify exactly how these issues should be parsed.

The average call to the Ask-the-Nurse program was estimated at 30 minutes in duration, with a few calls as long as an hour and a half, though exact time was not recorded. Clients seemed to need someone to listen to them and to discuss issues in detail. The volunteer nurse spends much of the time educating clients regarding what questions to ask their doctor and how to work with health care professionals, and supplying research-based articles with information ranging from the importance of exercise to side effects of various medications to information on MS symptoms.

Though data gathered was by issue, callers seemed overall to want objective information and seemed relieved upon being able to discuss their concerns. Many callers asked the volunteer nurse whether or not she had MS, seeming to seek out peer support and understanding. Some of these callers were referred to the Friendly Listening or Peer Support programs.

In addition to the categories listed in Table 1, the MS Society has begun to collect a broad range of data relating to symptoms experienced by the MS client or to which the caller refers, including:

Pain	Decubiti
Cognition	Spasticity
Vertigo	Vision
Fatigue	Hormones
Neurogenic bladder	Edema
Tremors	Speech
Cold feet	Gait/balance

Most calls were from clients who are not seen at a National MS Society–affiliated clinic, of which there are six in Michigan. Referrals were made to neurologists, other health care professionals, and support groups. Callers asking about research were referred to the Consortium of Multiple Sclerosis Centers’ national NARCOMS Multiple Sclerosis Registry (information at www.ms-care.org), as well as given up-to-date research information. Literature was mailed to clients on research and other MS-related topics. Based on the number of calls (average, 11 per week), the variety of calls, and the issues addressed, it appears that there is a demand among clients for this type of service.

RECOMMENDATIONS

A number of structural changes are recommended to enhance the Ask-the-Nurse program’s effectiveness, including the use of Internet technologies, more effective use of in-house technology, and increasing the Ask-the-Nurse volunteer staff to optimize availability and provide for backup.

Use of Internet Technologies. The Ask-the-Nurse program communicates with clients via telephone only. When clients call, they may have to wait up to a week for a response from the volunteer nurse. This can lead to frustration on the part of the client and the volunteer nurse. As described earlier in this paper, both medical and nonmedical client response programs have successfully incorporated Internet technologies. These technologies would 1) allow clients to

contact the Ask-the-Nurse program at any time, 2) allow the nurse to respond at any time, and 3) allow nearly immediate response instead of causing clients to have to wait up to a week. These technologies could be established from a central location to serve one region or the entire country.

The Ask-the-Nurse program could implement a number of Internet-based client tools including:

- Ask-the-Nurse program Web page. This page would describe the Ask-the-Nurse program and ways that nurses would respond to clients.
- E-mail link. Having a linked Ask-the-Nurse e-mail address on the Web would allow a client to communicate directly with the program staff.
- E-mail listserv. The Ask-the-Nurse program could respond to clients with relevant information.
- Web-based form. An interactive form would allow the Ask-the-Nurse program to capture a host of data from the client and provide the client with a mechanism for precisely entering their symptoms or issues.

In-House Technology. A database of Ask-the-Nurse clients could be invaluable in helping the National MS Society understand the needs of MS clients. Currently, the National MS Society refers Ask-the-Nurse clients to an appropriate National MS Society program for services and support or to the Consortium of MS Centers' NARCOMS Multiple Sclerosis Registry. In-house paper files are the only record of communication between clients and the Ask-the-Nurse volunteer and staff. A simple database capturing personal and clinical information could replace the paper filing process. This would provide management information for National MS Society staff and allow for more effective evaluation of the Ask-the-Nurse program.

Increasing Volunteer Availability. Due to the volume of calls and the weeklong waiting period at this time, it is advisable to increase the number of volunteer nurses. Recruitment has begun for nurses with MS care experience. Volunteers are required to go through the National MS Society customer service and information and referral training as well. Increasing the number of volunteer nurses will allow for quicker response time and backup assistance.

Other Recommendations. Whether or not the Ask-the-Nurse program adds a Web component or institutes an e-mail response system, having a centrally located Ask-the-Nurse program would allow MS clients from around the country the opportunity to obtain information about MS. Further, National MS Society chapters would have the ability to determine easily how other chapters service clients with questions about issues related to MS. There is no logical reason why this cannot be done; the primary barrier is administrative and fiscal support. Alternatively, there are distinct advantages to having decentralized Ask-The-Nurse programs in regional offices. Regional staff is familiar with services, clinics, and physicians located in their area. Centralizing the Ask-the-Nurse program may cause services provided to be somewhat less personal.

The results of this study are being used in program planning for the National MS Society–Michigan Chapter. As a result, more books and videos are being purchased on specific topics from the lending library. An evaluation process was recommended and is being used by the Program Advisory Committee in planning. The evaluation process may be expanded to include a qualitative assessment of the reduction of anxiety among callers or of other specific focuses. The length of calls will be tracked as well. Increased advertising of the Ask-the-Nurse program will be done through mailings and the Michigan Chapter Web site.

The Ask-the-Nurse program could be a prototype for other National MS Society chapters or for a centralized program. Future studies could be done on the differences and similarities among chapter programs. Similarly, MS clinic staff could do studies on the differences and similarities among calls made to MS clinics.

SUMMARY

The Ask-the-Nurse Program was initiated at the Michigan Chapter of the National MS Society in July 2001. Based on the number of callers in a 14-month time span, there is clearly a demand for this type of service. Data collected for this study have been used in program planning and in budgetary decisions for material and literature ordering. An evaluation process was added and may be expanded.

This program could easily be replicated in other National MS Society chapter offices or in a centralized office. Careful setup of the program is important with qualified, licensed, and insured staff that are adequately trained and supported. Clarity is important in advertising that this is an educational program that does not provide medical advice. Ongoing and random evaluations of the program are important in ensuring professional services that continue to meet the needs of clients.

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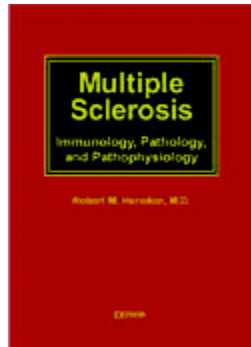
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Book Review

Multiple Sclerosis: Immunology, Pathology, and Pathophysiology

Multiple Sclerosis: Immunology, Pathology, and Pathophysiology, edited by Robert M. Herndon, MD, is a short text whose authors have been recruited from a small number of institutions—but they have been carefully chosen, as reflected by the book's superior quality. This work exceeds its stated purpose as a companion to Multiple Sclerosis: Diagnosis, Medical Management, and Rehabilitation (edited by Jack S. Burks and Kenneth P. Johnson), standing on its own as a contribution to the MS literature. It is well edited, as evidenced by its logical organization and minimal repetition, and, for a multi-authored, basic science text, it is uniformly well written and current. Data are presented objectively, and speculation, where it exists, is identified. It is difficult to find a poor chapter, although the reader can skip over areas of lesser interest without losing overall understanding. Many of the references date to within the past five years. Although the illustrations and tables are half-tones, they are instructive and clear. The index is well organized and user friendly.

This book is sufficiently readable to be recommended to anyone with an elementary background in science and a significant interest in MS. The clinical researcher with a desire to better understand MS will also find it informative, as will those involved in basic research.



Robert M. Herndon, MD, editor

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The reader first might wish to read this book through quickly in order to get an overview of the field. In doing so, it was apparent that although support for both the viral and the autoimmune etiology of MS was presented, the pathophysiologic mechanisms proposed for both were similar. Therefore, I was struck by the notion that these hypotheses might not be mutually exclusive, and that both mechanisms might apply to different patients or even to the same patient. Sections of interest might then be digested more slowly with the aid of the referenced material, especially when conflicting results are discussed. I look forward to the next edition and hope that it will be expanded while maintaining its high standard of scientific reporting.

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