

## **IJMSC** Volume 5, Issue 2 June-Summer 2003

### **MS News**

*The following brief reports summarize research news recently published in the peer review literature.*

#### **Health Impact of MS and Parkinson's Disease**

Researchers in the United Kingdom found that measures of health status, such as the 36-item short form health survey (SF-36), can be useful in detecting areas of disease impact that may not be obvious from clinical investigation. Their report, published in the June Journal of Neurology, Neurosurgery and Psychiatry, compared 638 patients representing the full spectrum of multiple sclerosis (MS) and 227 patients with Parkinson's disease to 2,056 controls. Scores for the eight health domains of the SF-36 were compared between groups after controlling for age, sex, disease duration, mobility, social class, ethnicity, education, marital status, and employment status.

The investigators found that patients with MS and those with Parkinson's disease had significantly worse health than the controls on all eight domains of the SF-36. While the relative impact of MS and Parkinson's disease was similar, MS resulted in poorer scores on physical functioning and better scores on mental health than Parkinson's disease. The researchers added that patients with mild MS who walked without an aid also had significantly worse scores in all dimensions than did controls.

The results highlight both the utility of the SF-36 as a measure of disease impact and the need for further research into the aspects of health measured by the SF-36. While the information generated through such measures, when supplemented by additional investigations (such as assessment of health care needs) is capable of guiding subsequent disease intervention, it is important to remember that generic measures may fail to address clinically important aspects of the impact of a specific disease, they concluded.

Riazi A, Hobart JC, Lamping DL, et al. Using the SF-36 measure to compare the health impact of multiple sclerosis and Parkinson's disease with normal population health profiles. *J Neurol Neurosurg Psychiatry*. 2003;74:710-714.

#### **New T2 Lesions Enable Earlier Diagnosis of MS**

In clinically isolated syndromes, the new McDonald criteria for the diagnosis of MS require new gadolinium-enhancing lesions for dissemination in time at a three-month follow-up MRI scan. According to a report published in the May Annals of Neurology, the addition of new T2 lesions as an alternative for dissemination in time would increase the sensitivity while maintaining the diagnostic specificity for clinically definite MS at three years.

Researchers in the United Kingdom examined 56 patients (30 female) between ages 16 and 50 with clinically isolated syndromes suggestive of MS who had been followed clinically for three years after having an MRI at baseline. Patients underwent T2-weighted and gadolinium-enhanced T1-weighted brain MRI at baseline, three months, one year, and three years. During the course of the study, 20 patients developed new T2 lesions at three months; only 14 had new gadolinium-enhancing lesions, the researchers reported. The specificity of the McDonald criteria for clinically definite MS at three months was 95%, but sensitivity was only 58%. Eight patients who did not fulfill the McDonald criteria at three months developed clinically definite MS at three years.

The addition of new T2 lesions to the criteria of MRI dissemination in time at three months also had high specificity (92%) and better sensitivity (74%) than the McDonald criteria. Only five patients who failed T2-MRI criteria at three months developed clinically definite MS after three years. Regardless of the number of lesions on the baseline scan, a new T2 lesion was sensitive (84%) and specific (89%) for clinically definite MS, the researchers added. They proposed that, based on their findings, the McDonald MRI criteria for dissemination in time be expanded to include T2 lesions seen on three-month follow-up scans.

Dalton CM, Brex PA, Miszkiel KA. New T2 lesions enable an earlier diagnosis of multiple sclerosis in clinically isolated syndromes. *Ann Neurol.* 2003;53:673-676.

### **Epstein-Barr Antibodies Elevated Prior to MS Onset**

There is a relationship between Epstein-Barr virus and the development of MS, suggests a study in the March 26 JAMA. While previous research has associated the virus with an increased risk of MS, the temporal relationship between the two has remained unclear.

Researchers assessed the blood samples of more than three million military personnel whose blood was collected upon entry into the military and every two years thereafter since 1988 for various Epstein-Barr virus antibodies. For each of the 83 cases of personnel granted disability due to MS, the investigators identified the earliest available serum sample, plus two samples collected before MS onset and the first sample collected after onset. Each case was matched to two controls with the same sex and ethnicity, and similar ages and dates of blood collection.

All of the cases and 96% of the controls showed evidence of Epstein-Barr virus infection at baseline, and the mean time between initial blood collection and the MS onset was four years. The researchers found that "the baseline mean serum antibody titers to Epstein-Barr virus were consistently higher among individuals who later developed MS than among their matched controls." They noted that the lack of variation in antibody concentrations between blood samples collected six to 11 years prior to onset and those taken later suggests that "the increased antibody response to Epstein-Barr virus occurs early in relation to the pathological process that leads to demyelination and clinical disease."

Levin LI, Munger KL, Rubertone MV, et al. Multiple sclerosis and Epstein-Barr virus. *JAMA.* 2003;289:1533-1536.

### **Cost-Effective Management of MS**

The cost of treating MS is high, but it decreases with prolonged treatment, according to research in the March 8 BMJ. Researchers evaluated the cost-effectiveness of four drugs currently licensed for the treatment of relapsing-remitting and secondary progressive MS in the United Kingdom (three interferon bs and glatiramer acetate). Using a model to simulate the clinical course of the disease, they assessed the effect of each drug against conventional management during a 20-year period, measuring cost per quality-adjusted life year gained. The investigators calculated that the cost of each year of life saved or prolonged by using any of the four treatments ranged from approximately \$66,469 to \$156,800. Cost-effectiveness varied markedly between the four interventions, and price was the key modifiable determinant of the cost-effectiveness for each drug. For any intervention, the cost per quality-adjusted life year gained is unlikely to be less than \$64,000, they reported. The researchers emphasized, however, that uncertainty surrounding these estimates is substantial, largely due to the unpredictability of the disease and the difficulty in capturing all aspects of its impact on patients. Experience after stopping treatment (which usually occurred after 10 years) is a key factor in calculating long-term cost effectiveness, they noted.

Chilcott J, McCabe C, Tappenden P, et al. Modeling the cost effectiveness of interferon beta and glatiramer acetate in the management of multiple sclerosis. *BMJ.* 2003;326:522-525.

### **Validation of Diagnostic MRI Criteria for MS and Response to Interferon b1a**

The modified Barkhof imaging criteria supported by the McDonald diagnostic criteria for MS were tested for their predictive value for the progression to clinically definite MS by the Early Treatment of Multiple Sclerosis Study Group. Additionally, the researchers attempted to determine whether the Barkhof criteria were predictive of a response to weekly treatment with subcutaneous interferon b1a. The study results were published in the June issue of the *Annals of Neurology*.

MRI was performed on 309 patients enrolled in the randomized, double-blind, placebo-controlled Early Treatment of MS study as part of the prestudy screening and at the end of months 12 and 24. At baseline, all patients had supratentorial T2 lesions and 64% had infratentorial T2 lesions. Enhancing lesions were present in 59% of patients, and enhancing or nine or more T2 lesions in 94%. Most patients had either three (36%) or four (50%) modified Barkhof criteria present at baseline.

Overall, conversion to clinically definite MS within two years of follow-up occurred in 39.3% of patients. Conversion was more likely to occur in the presence of gadolinium enhancement or nine T2 lesions, with nine T2 lesions seeming to have a slightly more prognostic value, the researchers reported. In patients with multifocal presentation, the baseline MRI findings had no significant additional predictive value, whereas in patients with unifocal presentation, the baseline MRI findings did convey predictive value. Additionally, when the individual Barkhof criteria were fulfilled, the odds ratio for treatment effect was statistically significant. The effect of interferon b1a seems stronger in patients with a high number of positive MRI criteria, the researchers noted. However, the study was not of sufficient statistical power to render this significant, and further assessment is required.

Barkhof F, Rocca M, Francis G, et al. Validation of diagnostic magnetic resonance imaging criteria for multiple sclerosis and response to interferon b1a. *Ann Neurol*. 2003;53:718-724.

### **Two Perspectives of MS Disability**

MS patients' perception of change in disability differs not only quantitatively but also qualitatively from that of a physician, according to a longitudinal study published in the April *Journal of Neurology, Neurosurgery and Psychiatry*. Investigators aimed to characterize the relationship between one-year changes in neurologist ratings of exam abnormalities, measured by the Expanded Disability Status Scale (EDSS), and changes in the patient's perceived disability, measured by the Guy's Neurological Disability Scale (GNDS).

Two hundred fifty patients with MS were recruited from an outpatient clinic. The investigators found that the correlation between one-year changes in EDSS versus GNDS was significantly lower than cross-sectional correlations between the two scales at baseline and at follow-up. Interestingly, there were opposite changes in EDSS scores and GNDS scores in 8% of patients, they noted. In addition, the researchers also reported that "dependent on the criterion applied for significant change in the GNDS, 10% to 22% of the patients who have a significant worsening on the EDSS show a significant improvement in perceived disability." Three reasons given for the discrepancies in the change in scores were "differences in the change perceived by the patient and that measured by the physician, changes in many disability subcategories not leading to changes in EDSS, and the GNDS incorporating aspects of disability (for example, fatigue) that are not at all considered by the EDSS."

Hoogervorst ELJ, Eikelenboom MJ, Uitdehaag BMJ, Polman CH. One year changes in disability in multiple sclerosis: neurological examination compared with patient self-report. *J Neurol Neurosurg Psychiatry*. 2003;74:439-442.

## Guest Editorial Sexuality and Other Quality-of-Life Issues

**Deborah M. Miller, PhD, LISW**

This issue of the International Journal of MS Care includes an informative report of clinicians' attitudes toward addressing sexual dysfunction with their multiple sclerosis (MS) patients. A key point in the literature review of the Foley et al article is that sexual dysfunction is a common disorder among men and women with MS and that this impairment has a significant impact on patients' quality of life. The data reported in the article also make clear that a sample of MS clinicians are understanding of sexual dysfunction in their MS patients. They believe that most patients require professional intervention to address the issue and that there are useful treatments to help manage this condition. Nonetheless, these clinicians indicate that they seldom address this important topic. The primary reasons reported as to why they do not assess sexuality include limited time with patients, belief that assessment of sexual function is outside their domain, and being uncomfortable with addressing sexuality.

The regular use of patient questionnaires regarding sexuality and related concerns can be useful and practical in facilitating conversation during routine clinical transactions. Two such questionnaires, which patients can complete while waiting to see the health care professional, are the Derogatis Sexual Functioning Inventory,<sup>1</sup> a multidimensional measure of sexual functioning, and the five-item Sexual Satisfaction Scale,<sup>2</sup> which is a component of the Multiple Sclerosis Quality of Life Inventory. The questionnaire responses could be reviewed during the clinic visit, and if the patient has concerns, a plan can be developed to address them. This process would alleviate some of the issues identified by Foley et al. If patients are offered the opportunity but are not required to complete the questionnaire, they may be more comfortable revealing their concerns or may choose not to discuss the subject. Patients and clinicians could review the responses together and quickly determine if intervention is needed. As the treatment plan is developed, clinicians who are not comfortable managing sexual concerns can make appropriate referrals.

This process does not need to be limited to a review of sexuality. A range of patient concerns, including sexuality, is assessed in MS-specific quality-of-life measures such as the Multiple Sclerosis Quality of Life Inventory. The routine practice of having patients complete an MS-specific quality-of-life measure will encourage patient participation in the care process, allow for greater efficiency and meaningful interaction during the patient/clinician encounter, and provide another important data point for clinicians to use in the management of their patients.

### REFERENCES

1. Derogatis L, Melisaratos N. The DSFI: a multidimensional measure of sexual functioning. *J Sex Marital Ther.* 1979;5:244-281.
2. Nowinski JK, LoPiccolo J. Assessing sexual behavior in couples. *J Sex Marital Ther.* 1979;5:225-243.

## Multiple Sclerosis and Sexuality: A Survey of MS Health Professionals' Comfort, Training, and Inquiry About Sexual Dysfunction

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### Abstract

*When health care professionals were asked about their perceptions of, assessment of, and treatment methods for sexual dysfunction, they acknowledged that sexual dysfunction was a frequent problem for MS patients, although few addressed the issue with their patients. Most also believed that very few of the patients actually sought help for sexual dysfunction. In addition to comfort level and training as the strongest predictors determining inquiry behavior, respondents indicated that lack of time with patients was an important factor in not inquiring about sexual function. As a whole, the group had minimal training in human sexuality. This questionnaire-based study found that amount of training was a significant predictor of both comfort level in discussing sexual functioning and the frequency in which discussions were initiated with patients. The results suggest that more training would facilitate MS health care professionals' comfort and assessment behaviors of sexual dysfunction.*

Suggested citation: Int J MS Care serial on-line. 2003;5(2).

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Multiple sclerosis (MS) is a demyelinating disease of the central nervous system (CNS) resulting in a wide array of impairments that may include difficulties with gait, balance, sensation, pain, bladder and/or bowel control, vision, sexuality, and cognitive function.<sup>1</sup> Sexual dysfunction is reported to occur in more than 70% of persons with MS, a frequency greater than that reported with other chronic diseases.<sup>2</sup> In reports of men with MS, sexual dysfunction has ranged from 23% to 85%.<sup>1,3</sup> Women, who are diagnosed with MS at a ratio of 2:1 compared to men, report sexual dysfunction up to 85% of the time.<sup>1-3</sup> MS patients followed for a two-year period indicated that the prevalence of sexual dysfunction remained higher than 70%, with additional sexual complaints and worsening of previous symptoms.<sup>4</sup>

Sexual dysfunction in MS has multiple causes. Anatomically, it is thought that lesions that affect the thoracic spine and autonomic nerves are the main factors that affect sexual function in MS patients.<sup>5</sup> However, many of the problems of sexual dysfunction in MS patients are not directly related to disease processes. A model of the categories of sexual dysfunction has been

developed by Foley and Iverson.<sup>6</sup> Primary sexual dysfunction in MS is a direct result of demyelinating lesions in the CNS, which subsequently affect the sexual response and/or sexual feelings.<sup>3</sup> Primary sexual dysfunction may include a decrease or loss of libido, decreased or unpleasant genital sensations, or decreased orgasmic response in both men and women.<sup>3,6</sup> For men, there may be problems in achieving and maintaining an erection, and diminished frequency of ejaculation.<sup>7</sup> Women may experience reduced vaginal lubrication in addition to inorgasmia and a lowered sex drive.<sup>8</sup>

Secondary sexual dysfunction occurs when systems that are not directly involved in the neural pathways that connect to the genitals are affected. Symptoms of secondary sexual dysfunction occur as a result of bladder and bowel problems, fatigue, spasticity, muscle weakness, tremors, cognitive changes, and sensory paresthesias in nongenital parts of the body.<sup>3,7,8</sup> Secondary sexual dysfunction may also occur as a result of adverse effects from medications that either directly treat MS or treat symptoms of MS (eg, spasticity, depression, bladder dysfunction).<sup>7</sup>

Tertiary sexual dysfunction occurs as a result of disability-related psychosocial and cultural issues that affect sexual response or pleasure.<sup>3,7</sup> These issues may include changes in family roles, altered self-image, lowered self-esteem, depression, demoralization, fears of being rejected by one's partner, and feeling less attractive. As with many diseases that can create physical disabilities, sexual dysfunction can affect how others perceive the patient and can have a negative influence on the patient's sense of self-worth.<sup>9</sup>

In a study that examined the direct impact of MS on sexuality and relationships, McCabe et al<sup>1</sup> asked MS patients to fill out a questionnaire regarding perceived impact of MS on sexuality, social and intimate relationships, and various aspects of life, as well as coping strategies employed to deal with problems in these areas of life. Results indicated that 79.6% of the sample experienced problems in sexual functioning and, further, that the greatest area of difficulty was the level of satisfaction with sexuality. On a positive note, however, results suggested that if the relationship was already a strong source of social support, then it continued that way and appeared to be relatively unaffected by sexual dysfunction.

A second study examined the effect of sexual dysfunction on the quality of life of MS patients and their partners, as well as what mechanisms patients were using in order to deal with this problem. Dupont<sup>10</sup> found that both male and female patients' sex lives were significantly affected by MS. Results also showed that sexual dysfunction was not significantly correlated with the patient's age, duration of diagnosed MS, or the mood of the patient. Partners of MS patients, however, were found to have sexual dysfunction that was related to the patient's age, duration of illness, and the impact of the illness. It was clear that sexual dysfunction not only affected MS patients but also profoundly affected their partners.

It is evident that sexual dysfunction is a complex interaction of disease-related and psychological factors. The effects on the patient and his/her partner can be quite devastating. Two general responses tend to transpire in the wake of sexual dysfunction: reduced sexual activity and silence.<sup>11</sup> Couples merely stop engaging in sexual activities for fear of being rejected or because they feel incapable of performing at a satisfactory level, and then find it difficult to talk about these changes with their partners or their health care providers.<sup>6</sup>

### **The Doctor/Patient Relationship: A Brief Overview**

The interactions between patient and doctor are complex. They involve interactions between persons who are not in equal positions that are often nonvoluntary and emotionally charged, and that involve issues of great concern to the patient.<sup>12</sup> Different styles of doctor/patient interactions have been described. The first, known as "doctor/patient behavior," is goal-oriented and directed by the physician's hypotheses about what is wrong with the patient and what type of treatment should be instituted. The second, known as "patient-centered behavior,"

relies more on an egalitarian relationship between the doctor and the patient, where the patient is seen as vital in understanding the origin of the problem and what course of treatment is needed.<sup>13,14</sup>

Physicians employ a limited set of hypotheses when talking to patients and usually direct their inquiries according to these hypotheses.<sup>14,15</sup> The line of inquiry described in the literature most frequently chosen by doctors often leads to a prescription, referral, or a follow-up visit.<sup>16</sup> The dynamic that is created by this sort of interaction is one that is typically limited in time, which in turn restricts the content of most consultations and in fact may discourage the patient from asking about different health-related topics.

The patient affects the direction of the interactions as well. Several studies on doctor/patient communication have shown that patients are often left feeling as though they have not received enough information regarding their health.<sup>15-17</sup> In a study in which patients were asked to fill out a questionnaire regarding their interest in information, it was found that patients often had a strong desire for information that they were hesitant to ask their physicians about. Another finding of the study showed that patients were less apt to assume responsibility for medical decisions, placing that task upon the doctor.<sup>16</sup>

A review of doctor/patient communication is necessary to examine the role of health care professionals in discussing sexual dysfunction. It is important to know not only the patient's role in the doctor/patient relationship but also how the doctor or health care professional may view these interactions and their purposes. If doctors are primarily focused on diagnosis and treatment of disease, they may never find out from their patients that there are problems with sexual functioning—the doctors may not direct their questioning towards this sensitive topic. In turn, if the patients want their doctors to have more responsibility in treatment decisions, then they may not think to inquire about sexual functioning because their doctors are simply not asking questions about it.

Many health care professionals are hesitant to address sexual functioning with their patients, and oftentimes, the patient is too embarrassed to broach the subject.<sup>8</sup> The sensitive nature of sexuality and disability can lead to health care professionals either not asking about sexual functioning or believing that their disabled patients are asexual or have not had the desire to have sex since the onset of their disability.<sup>17</sup> The reluctance of health care professionals to talk about sexual concerns arises in part from feelings of being unable to solve this sensitive problem.<sup>18</sup> White et al<sup>8</sup> suggested that medical professionals ask about sexual functioning routinely, because treatment may be as simple as prescribing medication. Physicians are not the only health care professionals who can assist the MS patient with sexual difficulties. Occupational and physical therapists can address more practical concerns, such as positioning techniques or the use of sexual aids that may increase sexual response and/or pleasure.<sup>19</sup>

Sexual dysfunction research in MS has been sparse to date. Most of the sexual dysfunction literature in medical patients focuses on spinal cord injury rather than chronic diseases.<sup>9</sup> However, one recent small study demonstrated that cognitive behavior psychotherapy and sexuality-sensitive MS symptom management can improve marital communication, satisfaction, and sexual functioning in MS patients and their partners.<sup>20</sup> Although research on improving sexual dysfunction in MS is sparse, even less is known about health care professionals' inquiries and practice patterns regarding sexual dysfunction.

The purpose of the present study was to assess: 1) health care professionals' perceptions of the impact of sexual dysfunction on the MS patients' lives and relationships; 2) the extent to which they think patients would benefit from treatment of sexual dysfunction; 3) who is and who they think should be treating sexual dysfunction; 4) what methods of assessment and treatment are

being used; 5) the amount of training that the health care professionals had received in sexual dysfunction; and 6) their comfort level in addressing sexual functioning.

It was hypothesized that amount of training in sexual dysfunction as well as comfort level would predict the degree to which health care professionals ask their patients about sexual dysfunction. It was also hypothesized that there would not be any differences among the types of professionals (eg, physicians, nurses, physical and occupational therapists, social workers, and psychologists) in terms of how each perceived, assessed, and treated sexual dysfunction.

## Methods

### Questionnaire Development

The survey questionnaire was constructed following a thorough review of the literature. Questions were selected to sample relevant content domains, which included demographics, percent/time exposure to MS treatment, beliefs about MS and sexuality, training and comfort with discussions on the topic with patients, and practice patterns. Following the initial questionnaire development, it was distributed to nine MS health professionals (including two neurologists, three psychologists, and four nurses) for review. Two MS patients reviewed it as well and offered several suggestions for additional items. Questions were added or eliminated based on the qualitative input received, and the format was changed to improve clarity.

### Sample Description

The sample consisted of members of the Consortium of Multiple Sclerosis Centers attending a workshop on sexual dysfunction in MS (see Table 1 for a description of the sample members and the overall membership of the Consortium at the time of the survey). The current sample was compared to the membership database of the Consortium of Multiple Sclerosis Centers. A chi-square goodness-of-fit test was used to analyze whether the respondents provided an accurate representation of the distribution of the different professional groups making up the Consortium membership. The category "Other Professionals" was not present in the Consortium membership, and therefore was omitted from the analysis. As shown in Table 1, the sample did not accurately represent the overall Consortium membership. Physicians were underrepresented in the sample, while nurses were overrepresented [ $\chi^2(5) = 98.99, P < .001$ ].

**Table 1**  
**Description of the members of the Consortium and the sample as determined by health care profession**

<b>Profession</b>	<b>Consortium members</b>	<b>Membership percentage</b>	<b>Sample members</b>	<b>Sample percentage</b>
Physician	900	65%	12	17%
Nurse	230	17%	39	54%
Physical therapist	60	4%	4	6%
Occupational therapist	61	4%	2	3%
Social Worker	60	4%	7	10%
Clinical psychologist	70	5%	3	4%
Other professional	--	--	5	7%
Total n	1381	100%	72	100%

The majority of the sample were women ( $n = 65$ ), with most of the women being nurses ( $n = 39$ ). The men ( $n = 5$ ) in the sample were mainly physicians with one psychologist and one administrator. The mean age of the sample was 44.7 (SD, 8.9), with a range from 24 to 66. Most of the health professionals in the sample spent their professional time in the outpatient hospital clinic setting (65%), followed by "other" work setting (24%), inpatient rehabilitation hospital work setting (21%), inpatient acute care hospital setting (19%), an office or group practice setting (14%), or in community care agency work settings (3%). Work setting totals exceed 100% because some respondents indicated that they work in multiple settings. The mean percentage of time that the health care professionals spent in the clinical care of MS was 49.3% (SD, 4.3), while the average number of years experience working with MS was 8.4 (SD, .83).

## **Results**

### **Analysis of Variance**

One-way Analysis of Variance (ANOVA) was used to examine health professional differences for each question. Health professionals were divided into three groups: nurses, physicians, and other health care professionals. The other health care professionals category included social workers ( $n = 7$ ), physical and occupational therapists ( $n = 4$  and  $2$ , respectively), psychologists ( $n = 3$ ), and "other professionals," who were administrators ( $n = 3$ ).

### **Amount of Training in the Sample**

The "amount of training in sexuality" was evaluated in the sample to determine whether there were differences in health care professional groups on this factor. There were no significant differences for health care professionals ( $F_{2,71} = .420$ ,  $P = .66$ ).

### **Beliefs About the Prevalence of Sexual Dysfunction**

Although most of the sample had not received a great deal of training in human sexuality, the majority believed that at least 40% to 80% of MS patients experience changes in sexual function due to MS. There were no significant health professional differences in answering this question ( $F_{2,69} = 1.09$ ,  $P = .342$ ).

### **Beliefs About the Impact of Sexual Dysfunction on Intimate Relationships**

There were no significant differences among health professionals when answering about the impact of sexual dysfunction in MS on intimate relationships ( $F_{2,69} = 1.42$ ,  $P = .249$ ). The groups as a whole agreed that sexual dysfunction has a "moderate to large" negative impact on intimate relationships (86%).

Similarly, all groups of health professionals surveyed believed that there was a "somewhat to moderate" extent to which sexual dysfunction in MS contributes to divorce or separation in long-term intimate relationships.

### **Beliefs About the Need for Professional Care in the Treatment of Sexual Dysfunction**

Concerning the perception of respondents who estimated a patient's ability to cope with sexual dysfunction (without professional care), there were no significant differences among health care professionals ( $F_{2,67} = .377$ ,  $P = .687$ ). The overall sample believed that "few or none" to only "some" of the patients could cope with sexual dysfunction without the help of professional intervention (76%). Most of the sample reported that "many" to "very many" persons with MS could benefit significantly from professional help in dealing with sexual dysfunction (65%). There was a significant difference among health professionals when answering what percentage of persons with MS would significantly benefit from help ( $F_{2,69} = 4.07$ ,  $P = .02$ ). Tukey post hoc analyses revealed that physicians believed that a smaller percentage of patients (40% to 60%) would significantly benefit from professional care (mean, 1.9 ["many"] [SD, 1.0]), while both nurses and other professionals thought that a larger percentage of MS patients would

benefit from professional care (60% to 80%) (mean nurses, 2.6 ["very many"] [SD, 1.0]; mean other professionals, 2.9 ["very many"] [SD, .79]).

There were no significant differences among health care professionals in estimating the percent of persons with MS who actually seek professional help for sexual dysfunction ( $F_{2,68} = .530$ ,  $P = .591$ ). The majority of the sample (93%) thought that "few or none" to only "some" of persons with MS actually sought help for sexual dysfunction. Similarly, when asked about the percentage of persons with MS who are asked about sexual dysfunction by their health care providers, health care professionals answered "few to none."

### **Discussion of Sexual Concerns With MS Patients**

Most of the sample reported feeling "somewhat" to "very" comfortable in discussing sexual functioning with MS patients (64%). There were no significant differences among nurses, physicians, and other health professionals ( $F_{2,70} = .865$ ,  $P = .426$ ). However, when assessing the frequency of direct inquiry or initiating discussions about sexual functioning with MS patients, the majority of the sample answered "seldom."

### **Reasons for Not Inquiring About Sexual Functioning**

MS health care professionals' reasons for not inquiring about sexual function were limited time with patients (44%), "outside my role" (15.3%), patient discomfort (12.5%), lack of professional training or comfort (6.9%), other priorities (5.6%), limited medical coverage so they can't afford treatment (2.8%), and too intrusive for patients (2.8%); 8.3% of the sample did not answer the question.

### **Methods Used to Assess Sexual Dysfunction**

The sample reported that the most often used method to assess sexual dysfunction in MS patients was the informal report of the patient (54% of the time), followed by a neurological exam (13%), sexual function not assessed at all (8%), other primary assessment methods (7%), interview by a mental health professional (4%), a physical exam (3%), and psychological or personality testing (3%).

### **Who Is Responsible for Assessing and Treating Sexual Dysfunction?**

The sample endorsed the idea that the health care professional most responsible for the assessment, treatment, or management of sexual dysfunction was a urologist (32%), followed by a nurse (21%), and then a psychologist (18%). Only eight people in the sample indicated that a neurologist was the health care professional most responsible, with even fewer members of the sample indicating psychiatrists, other physicians, social workers, or physical and occupational therapists. Interestingly, the majority of the sample (71%), when asked if the person who assesses, treats, and manages sexual dysfunction was a consultant, answered no.

### **Interventions Used to Treat Sexual Dysfunction**

The two final questions asked respondents about specific types of interventions used to treat sexual dysfunction in their respective workplaces and the primary or most frequent treatment intervention used; responses are included in Table 2.

**Table 2**  
**Number and percentage of respondents reporting the use of various methods for the treatment of sexual dysfunction in MS**

<b>Treatment Method</b>	<b>Number of respondents using this method</b>	<b>Percentage of respondents using this method</b>
Medical sex education	22	30.4%
Oral medications	19	26.4%
Sexual dysfunction not treated	9	12.5%
Sex therapy	6	8.3%
Intracorporeal injections of meds for erectile dysfunction	3	4.2%
Noninvasive physical treatment for erectile dysfunction	2	2.8%
Surgery	1	1.4%
Other treatment interventions	1	1.4%
Did not answer the question	9	12.5%

### **What Predicts Professionals' Frequency of Discussion With Patients About Sexual Dysfunction?**

Hierarchical multiple regression was used to help determine what combination of factors predicted both "frequency of discussion" and "comfort level" (with discussing sexual function), respectively. Planned regression analyses were performed to minimize the number of analyses performed. The first analysis used "frequency of discussion" as the dependent variable. The first step in the hierarchical regression contained the control variables: sex, age, and number of years' experience working with MS patients. A second step in the regression included the primary independent variable of interest, "amount of training in sexual functioning." The results of the regression were that demographics did not predict frequency of discussion but "amount of training" in sexual dysfunction significantly predicted frequency of discussion, when the demographic variables in the first step were controlled ( $F_{4,64} = 6.35, P < .01$ ). Health care professionals who had received more training in sexuality asked about sexual dysfunction more often.

A second sequential regression analysis on the dependent variable "frequency of discussion about sexual dysfunction" was performed using the same demographic variables in the first step and comfort level in the second step. Sex, age, and number of years' experience did not predict frequency of discussion.

When the variances attributable to sex, age, and number of years' experience were controlled, comfort level predicted the "frequency of discussion" ( $F_{4,64} = 18.2, P < .01$ ). Health care professionals who had a higher comfort level asked their patients about sexual dysfunction more often.

### **What Predicts Professionals' Comfort Level About Discussing Sexual Dysfunction With Patients?**

A third sequential regression analysis was performed using "comfort level" as the criterion variable. The first step included sex, age, and number of years' experience with MS patients as control variables, while the second step included "amount of training," which was the

independent variable of interest. Sex, age, and number of years' experience did not predict health care professionals' comfort level with discussing sexual functioning. When the variances attributable to sex, age, and number of years' experience were controlled, "amount of training" significantly predicted the health care professionals' "comfort level" in handling sexual matters ( $F_{4,64} = 10.44, P < .01$ ). More training in human sexuality was associated with a higher level of comfort in talking about sexual functioning among the health care professionals in this sample.

### Are There Differences Among MS Health Care Professionals When Controlling for Amount of Training and Comfort Level?

Since the hierarchical regressions indicated that comfort level (with discussing sexual dysfunction) and training in sexuality predict practice patterns, further analyses were performed to evaluate potential differences in health care professionals' responses to survey questions while controlling for amount of training in sexuality and comfort level. Hence, Analysis of Covariance (ANCOVA) was performed on each question. Prior to performing ANCOVA, a test for homogeneity of the regression coefficient was performed to determine if the interaction between the covariant (amount of training or comfort level) and the independent variable (groups of different medical professionals), was significant for each comparison. Since the interactions were not significant, comparisons among the medical professionals were conducted while covarying out amount of training and comfort level.

Table 3 contains results of significant ANCOVAs with amount of training as a covariate. While controlling for the amount of training in human sexuality, a significant difference was found among health care professionals in the frequency of discussion about sexual functioning ( $F_{2,70} = 3.76, P = .03$ ). Nurses and physicians both reported asking about sexual functioning at a "fairly often" level of frequency, while other professionals only reported asking about sexual functioning occasionally.

**Table 3**  
**Significant survey questions with amount of training in human sexuality as a covariate**

Significant survey questions	Physicians mean (SD)	Nurses mean (SD)	Other health care professionals mean (SD)	F-statistic	P value	ETA squared
Frequency of discussion	1.8 (.31)	2.0 (.18)	1.4 (.24)	3.76	.03	.101
% who would benefit from professional care	2.0 (.27)	2.6 (.15)	2.9 (.21)	3.68	.03	.100

When amount of training was controlled, a significant difference was found among health professionals when responding to a question about the percentage of patients who would benefit significantly from professional care of sexual dysfunction ( $F_{2,70} = 3.68, P = .03$ ). When amount of training was controlled for, nurses and other professionals believed that a larger percentage of patients would benefit from professional care of sexual dysfunction (60% to 80%), while physicians believed that only 40% to 60% of patients would benefit significantly from professional care.

### Comfort Level

A second set of ANCOVAs comparing the health care professional groups' responses to each question was performed, controlling for comfort level. See Table 4 for significant results of ANCOVAs with comfort level as a covariate. Only two significant differences were found, and no other trends emerged from this analysis. While controlling for comfort level, a significant difference among health professionals was found in the frequency of discussion about sexual functioning ( $F_{2,71} = 8.34, P = .001$ ). Nurses reported initiating discussions about sexual functioning more frequently than both physicians and other health care professionals.

**Table 4**  
**Significant survey questions with comfort level in discussing sexual functioning as a covariate**

Significant survey questions	Physicians mean (SD)	Nurses mean (SD)	Other health care professionals mean (SD)	F-statistic	P value	ETA squared
Frequency of discussion	1.4 (.25)	2.1 (.14)	1.3 (.18)	8.34	.001	.19
% who would benefit from professional care	1.9 (.27)	2.6 (.15)	2.9 (.21)	4.77	.01	.12

While controlling for comfort level, a significant difference was found among health professionals in assessing the percentage of patients who would benefit from the professional care of sexual dysfunction in MS ( $F_{2,69} = 4.77, P = .012$ ). Nurses and other professionals reported that at least 60% to 80% of patients would significantly benefit from professional care, while physicians thought that 40% to 60% of the patients would significantly benefit from professional care.

### Discussion

Health care professionals who attended a workshop on sexual dysfunction at an MS conference were asked to complete a questionnaire that assessed their opinions regarding sexual dysfunction, its impact on the lives of patients with MS, and their practice patterns related to assessment and treatment. The sample was not completely representative of the distribution of professional membership of the Consortium of Multiple Sclerosis Centers, with fewer physicians proportionately to the organization membership.

Results demonstrated some significant differences among health care professionals in their perceptions, assessment, and treatment of sexual dysfunction. Regarding the effects of sexual dysfunction on the intimate relationships of MS patients, all health care professionals agreed that sexual dysfunction has a significant impact and contributes to divorce. When asked about the percentage of patients who experience changes in sexual functioning due to MS, there were no differences among health care professionals' answers. All indicated that a large percentage of MS patients were affected (40% to 60%). The MS health care professionals in this sample acknowledged that sexual dysfunction is not merely a minor problem but one that has a large impact on the lives of their patients. This is in keeping with another study in the general population that found that sexual dysfunction has a large impact on the quality of life.<sup>21</sup>

The survey found no significant differences among health care professionals in the amount of training that they had received in human sexuality. Most of the sample had received some

minimal training on human sexuality, such as attending a workshop or reading on the topic. Since the study found that amount of training was a significant predictor of both comfort level in discussing sexual functioning and the frequency in which discussions were initiated with patients, one could make the argument that more training would facilitate professionals' comfort and assessment behaviors of this symptom. Another conclusion from these results is that more training may be needed for all professional groups since no one group of health care professionals was better trained than another.

Although most of the sample believed that MS patients would benefit greatly from the treatment of sexual dysfunction, most also believed that very few of the patients actually sought help for sexual dysfunction, and the majority of the practitioners inquired "seldom" about this symptom. The sensitive nature of sexual dysfunction may contribute to this belief on the part of health care professionals; in their experience, perhaps, few patients had actually sought treatment for sexual dysfunction because of embarrassment or other medical priorities.

Results showed no significant differences in the sample in the comfort level in asking about sexual functioning. Most of the health care professionals reported feeling somewhat to very comfortable. However, the majority of the practitioners seldom initiated discussion, citing "lack of time," "outside my professional role," and "patient discomfort" as the three most frequent reasons for not inquiring about sexual dysfunction.

Respondents believed that the person most likely to be responsible for assessing and treating problems with sexual functioning is a urologist, with a nurse being the next most likely. Perhaps other health care professionals, such as occupational and physical therapists, social workers, and psychologists, may not ask about sexual functioning because they see it as a medical problem that is outside their scope of practice. However, the health care professional group that ranked third on the list of those responsible for assessing and treating sexual dysfunction was psychologist. Once again, there are many aspects to sexual dysfunction that need to be addressed, including medical, psychological, and emotional, as well as practical issues that can be handled by all groups of health care professionals, not just physicians, nurses, or psychologists.

As indicated in the results section, when asked directly about why they had not initiated discussions about sexual functioning, 44% of the sample said that they had limited time with patients. Sexual dysfunction may be considered more of a "quality-of-life" symptom, with disease progression and management of other disabling symptoms remaining as treatment priorities. According to the "cure" orientation of medical treatment, physicians prefer to steer treatment towards curing the patient or effectively managing symptoms. With sexual dysfunction there are few definitive cures, especially for women. Doctors and other health care professionals may simply ignore sexual dysfunction because it takes too much time or they feel that it cannot be helped and/or that addressing it is secondary to other medical needs.

In terms of who initiates discussion about sexual functioning, most health care professionals stated that they found out about their patients' problems through the patients' informal reporting. Once again, if health care professionals were trained to address this issue, they might feel more comfortable in bringing up the topic of sexual functioning.

The most popular treatment methods for sexual dysfunction endorsed by the respondents were "medical sex education" followed by "oral meds." While controlling for the amount of training in sexuality, physicians believed that a smaller percentage of MS patients would benefit from the professional care of sexual dysfunction, while nurses and other health care professionals believed that a larger percentage would benefit. Future research should investigate this difference in perception.

When comfort level in inquiring about sexuality was controlled for, nurses asked about sexual functioning more frequently than both physicians and other health care professionals. Perhaps the nurses asked more frequently about sexual dysfunction because they are often in the role of having more time with patients than physicians and can discuss a variety of issues. At the same time, the patients may in turn feel more comfortable with nurses because they are not as rushed as physicians and yet are capable of addressing medical and sometimes psychological issues. Perhaps other health care professionals do not see themselves in the role of asking about sexual dysfunction, although the reasons for these differences in inquiry among nurses, physicians, and other MS health professionals should be investigated in future research.

### **Limitations**

There were several limitations to this study. First, this was a cross-sectional survey with a limited number of participants that underrepresented MS-specialty physicians. The number of analyses reported was appropriate for an exploratory survey but inflated the statistical probability of finding results of "significance." Future research should acquire a larger, more representative sample and provide better experimental alpha protection.

### **Conclusion**

When health care professionals were asked about their perceptions of, assessment of, and treatment methods for sexual dysfunction, they acknowledged that sexual dysfunction was a frequent problem for MS patients. Since few addressed the problem with their patients, they may not have felt sufficiently comfortable or adequately trained to manage sexual dysfunction. In addition to comfort level and training as the most potent predictors determining inquiry behavior, respondents indicated that lack of time with patients was an important variable in not inquiring about sexual function.

The sample believed that sexual dysfunction was a complication of MS that could have deleterious consequences for the patients' relationships. The group had minimal training in human sexuality. Results from this study suggested that training of MS health care professionals in symptom management should include assessment and treatment of sexual dysfunction.

**Acknowledgments: Project funded by the Consortium of Multiple Sclerosis Centers, Teaneck, NJ**

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## The Needs of Caregiver

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### Abstract

*The Fairview Multiple Sclerosis Achievement Center (MSAC) is a maintenance rehabilitation program for those significantly affected by multiple sclerosis (MS). The MSAC offers a program that marries maintenance, physical, and occupational therapies to therapeutic recreation, support groups, and social services for persons with severe MS. A strong emphasis is also placed on caregiver support, in recognition of the critical role these individuals play in the lives of persons with MS. In addressing the needs of the caregivers, the MSAC focuses on sharing information on MS, providing listening and respite services, and developing a more effective care system for persons with chronic diseases.*

Suggested Citation: . Int J MS Care [serial on-line]. 2003;5(2).

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The Fairview Multiple Sclerosis Achievement Center (MSAC) opened in 1985. A component of the Fairview MS Center, under the medical direction of Randall T. Schapiro, MD, the MSAC is a maintenance rehabilitation program for persons with severe multiple sclerosis (MS). The MSAC offers a daylong (10:30 AM to 3:20 PM) program that marries maintenance, physical, and occupational therapies to therapeutic recreation, chaplain-led support groups, and social work services designed for persons with severe MS. Members attend one day per week.

### Program Goals

The MSAC works to achieve five goals:

- To keep people with MS as functional as possible against the backdrop of progressive disease.
- To prevent complications of MS as seen at this level of disease (eg, skin breakdown, depression, infections, contractures, choking).
- To assist with adaptation to changes from MS to keep the individual functioning as independently as possible at home.
- To enhance the quality of life for our members and their families.
- To prevent nursing home placement.

Another significant goal of the MSAC is directed not at persons with MS but at their caregivers. That goal is to provide a day of respite for caregivers, because it is the caregivers who are most responsible for enabling persons with severe MS to continue living in the community. Since its inception, the MSAC has sought to be a resource for caregivers, by offering the following types of support:

- A monthly caregivers support group facilitated by a chaplain.
- Information and equipment that would make life easier in the home setting.
- Physical therapy and occupational therapy extension services to train family members in the use of various equipment.

- Co-sponsorship of an annual celebratory event to honor caregivers.
- Family week at the MSAC.
- Promotion of MS Society programs and other community-based programs to meet the information and social needs of the whole family.
- Working with MS families and the MS Society to advocate at the state and national level for their needs.

### Caregiver Description

A description of the caregivers for the people who attend the MSAC is found in the table below. As reported by most studies on MS caregivers, the age of the caregivers ranges from 18 through the late 70s, with the average in the mid-50s.<sup>1,2</sup> At the MSAC, the average age of caregivers is 58, with a range from 18 through 91. More than half work outside the home as well as giving care. The average duration of caregiving among members of the MSAC is 14 years. The literature reports this figure at around 10 years.<sup>1,2</sup>

Spouse only	50
Spouse with outside paid help	26
Person living alone with outside paid help two to 14 hours/day	27
Person living in group home with paid staff	19
Person living with parent, or parent significantly involved	14
Person living with daughter/son, or daughter/son significantly involved	10
Person living alone (no help coming in, or help for less than two hours/week)	17
Person living with sibling, or sibling significantly involved	2
Person living in assisted living complex	8
Person with live-in nonrelative to assist with care	5

### Caregiver Tasks

Tasks performed by caregivers vary by the patients' symptoms and by what they cannot do for themselves because of their disease course. The most common caregiver tasks are:

- Transportation to social activities and medical appointments.
- Assisting with activities of daily living (eg, dressing, bathing, grooming, feeding).
- Physical assistance and support in bladder and bowel management, range-of-motion exercises, and transferring.
- Caring for children.
- Other tasks (eg, meal preparation, shopping, financial management, laundry, any special needs the person might have).
- Psychological and social support.

### Caregiver Stressors and Rewards

According to self-reports provided at MSAC caregiver support group meetings, the most troublesome stressors for caregivers are:

- Cognitive deficits and the problems such deficits cause in daily living situations (eg, memory problems, problems with judgment, initiation of activity, ability to process new information).
- Day-in and day-out physical cares, especially incontinence of bladder and bowel.
- Overwhelming sense of uncertainty.
- Issues regarding sexuality.
- Financial concerns (insufficient income or high MS-related medical costs).
- Worry about possible nursing home placement.

- Lack of own space.
- Lack of energy to do much else.
- Loss of friends.

Alternatively, caregivers also reported the rewards they receive from caregiving:

- The comfort of knowing they are really making a difference in the life of the person they love.
- The honoring of a marriage vow.
- The clear conscience associated with knowing they will not have regrets about how they handled this life situation.
- The realization that they are really doing something of great social importance.
- Recognition from others for their efforts.
- Earning the gratitude of the person they provide for.

### **Addressing the Needs of Caregivers**

In both the caregiving literature and the experience of the MSAC, the primary need of caregivers—be they family members or paid caregivers—is for information.<sup>3,4</sup> Caregivers desire and require as much information as possible on MS and its various symptoms and how to manage them. Paid caregivers must have training on various aspects of MS, both physical and cognitive, that they may encounter in the workplace, as well as on safe ways to move people about and how to support psychosocial needs in a healthy way.

Issues of particular import are dealing with cognitive deficits caused by MS and managing incontinence of both bowel and bladder. Caregivers also want information regarding the services available to meet the needs of the person with MS as well as their own needs, the costs of those services, and their accessibility. Likewise, information on specific aspects of living with MS, such as adaptive equipment or special types of transportation, is often desired, as is information on the numerous financial issues that occur in having a family member with a chronic disease. Finally, it is important to remember that caregivers should have opportunities to share information on coping strategies others have found useful and that their requirements for information will change. As new problems arise, so too will the need for new types of information.

The second most important need caregivers have is for someone to listen to their story and try to understand the things that they have been experiencing. Often the things they experience are very painful; an understanding listener can validate what they are going through and can show respect, honor, and support for their commitment to care for the person with MS.

There are numerous opportunities for empathic listening. For those involved in clinics, efforts can be made to include the caregiver in the regularly scheduled visit of the person with MS. During that visit inquiry can be made of the caregiver's emotional and psychological well-being. Taking the time to listen and support will pay dividends in the care of the person with MS.

Health care professionals can also support caregivers by having readily available any information on programs and/or resources from the local MS Society or other community support groups, by encouraging caregivers to attend support groups and to use respite, and by being sensitive to the tremendous psychosocial issues caregivers face.

### **Respite and Community Services**

Most professionals who work with caregivers cite respite care as a critical support service for caregivers, yet the literature reports that respite and other community services are not often used by caregivers of people with MS, with only one third to one fourth of caregivers taking advantage of these services.<sup>2,5</sup> Given the enormous importance of these services to caregivers, this is an issue that must be addressed. Is there an informational problem of people not knowing what's available in the community? Is there a financial problem; are people not able to

afford the service? Does the service not fit the needs of the people as they define their needs? Do caregivers feel guilty about expressing their own needs for respite or other services? Medical personnel and those involved with clinics and programs such as the MSAC should sit down with caregivers and explore the underutilization of respite and community services from the caregivers' perspective, and then develop specific, affordable services/programs that will meet the needs of caregivers as defined by themselves.

### Looking Ahead

I think the MS community could develop services that caregivers would use more frequently if we could set an agenda at our local, state, and federal levels that would value the care provided by individuals to their ill and/or disabled family members. There is an urgency for formal recognition of the family's caregiver role, with the provision of financial and other supportive resources—things like monies for in-home care; allowances for families with disabled members; reimbursement for respite care; good, accessible, handicap-equipped transportation services; incentives for home adaptations; funding for programs like the MSAC; and development of partnerships between government, family, and other community institutions. Above all, we should get rid of the current Medicare paradigm as the care model for those with chronic disease. The Medicare model, which is based on acute disease and acute rehabilitation, does not meet the needs of those with chronic disease. We must develop a separate chronic disease care system that delivers consistent care, seeks to prevent care crises, and supports the efforts of the informal caregiver as well as the person with MS.

On a more individual level, most of us who work in the MS area should provide care that encompasses the health needs of the caregiver as well as those of the person with MS. It may be as simple as communicating to caregivers that you are aware of the roles they play and how much they are valued. When working with the family over time, we have the opportunity to assess whether the caregiver is at risk for burnout; hopefully, we will have developed a trusting relationship where we can discuss this with the caregiver and suggest some resources that might be helpful.

As people who touch the lives of caregivers, as well as being caregivers ourselves, I think our greatest need is for hope; at the same time hope is the greatest gift we have to offer.

Hope is expressed in people's lives in many different ways, but one definition I like is that hope is the foundation that helps us know that all things in life work for the good. It is what allows us to see purpose and meaning in our lives. It is hope that allows caregivers to acknowledge the uninvited guest in their lives (MS), and it is hope that provides the strength to keep going and not give up when it seems that life has nothing good to offer.

It is up to us as people who work with caregivers, and with each other, to project hopeful attitudes through caring, support, listening, educating, and advocacy. If we can find ways to give hope, our own lives will be enriched.

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