

Multiple Sclerosis Counseling Points™

Enhancing Patient Communication for the MS Nurse

ENDORSED BY THE INTERNATIONAL ORGANIZATION OF MS NURSES

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MANAGING PATIENT EXPECTATIONS *A Roundtable Discussion*



www.iomsn.org

The last decade has seen the introduction of a number of agents that offer hope for patients with MS. These disease-modifying drugs (DMDs) have been demonstrated to reduce the frequency and severity of relapses and slow disease progression. However, because these agents do not cure MS, it falls to health professionals involved in the care of patients with MS to help manage expectations.

Nurses are at the frontline of MS care. They participate in all facets

of patient management and thus, play a major role in educating the patients about the benefits of DMDs, while managing patient expectations.

Developing the therapeutic relationship

The first step towards setting realistic expectations is establishing a positive therapeutic relationship. The desired outcomes for this relationship are for patients to have an increased awareness and knowledge about MS, DMDs, and the

rationale for treatment. In addition, the need to be educated on injection techniques and strategies to handle the impact of side effects are important facets of patient education. Not only is it important to establish a relationship with the patient, but it is also important to establish a relationship with the family.

It is crucial to develop a sense of connection and lay the groundwork for sustaining a long-term relationship in which the lines of communication are always open.

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Patricia Kennedy has received honoraria for consulting and lecturing for Biogen Idec, Serono and Teva Neuroscience. She has also lectured for and received honoraria from Berlex.

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WELCOME TO MS COUNSELING POINTS™

Dear Colleague,

Multiple sclerosis (MS) is a chronic immune-mediated disease of the central nervous system with an unknown etiology that may affect a variety of physical and cognitive functions. Over the last two decades, extensive research has resulted in wide-ranging treatment options to address the deficits associated with MS. In many cases, treatment regimens are complex and involve parenteral medications.



Nurses involved in the management of patients with MS play a major role in maximizing outcomes. Whether they are addressing the physical or psychosocial needs of patients, nurses must establish a solid, potentially long-term relationship with patients and their families.

In *MS Counseling Points*™, nurses with many years experience in treating patients with MS share their expertise on a variety of topics ranging from managing patient expectations to bowel and bladder care regimens.

In each issue, as well as focusing on a specific topic, we will include abstracts from the literature highlighting nursing initiatives aimed at improving the care of patients with MS.

It is hoped that the information contained in this series will help nurses with and without in-depth experience with MS to enhance their skills and optimize outcomes for patients.

Your comments are important to help us plan future issues of *MS Counseling Points*™. Please take a moment to complete the survey on page 11 and fax back to us at 201-612-8282. We thank you in advance for your support.

I would also like to thank Teva Neuroscience for providing the grant necessary to support this program and for their continued commitment to multiple sclerosis nursing.

Amy Perrin Ross

Amy Perrin Ross, APRN, MSN, CNRN, MSCN (series editor)
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When initiating a conversation about DMDs, timing is everything. Frequently, early after diagnosis patients are so overwhelmed that they are not able to comprehend or remember what they are told about therapeutic options.

It is important to clarify a newly diagnosed patient's knowledge about the disease before introducing the subject of disease-modifying therapy. Patients will seek information about the diagnosis and also about treatments from various sources; however, the nurse must help sort through this information to assist patients with their understanding of the disease process. Having accurate information about the disease is helpful when discussing treatments and expectations of the treatments.

It is important to clarify a newly diagnosed patient's knowledge about the disease before introducing the subject of disease-modifying therapy

It can be useful to ask patients what websites or other resources they have used to find information about MS. Doing this allows you to identify what particular slant they have on MS and treatment options. It is also an invitation for patients to express their fears and concerns.

Nurses must realize that if a patient initially declines self-injected treatment for MS, it may be a sound judgment based on their knowledge level, expectations, support system and emotional state. The basis of the therapeutic relationship is understanding the emotional state and physical condition of the patient. Knowing this, the nurse can work with the patient and hopefully move towards the initiation of a disease-modifying therapy. Sometimes, it is up to the nurse to help patients realize that they are not ready to make the decision to start treatment. MS is a life-long disease, but a week or month either way is not likely to have a huge impact on the long-term outcome. Readiness to begin therapy will assist patients with long-term adherence.

Available DMDs

Avonex® (interferon beta-1a, Biogen Idec)

Administered once weekly via intramuscular injection

Betaseron® (interferon beta-1b, Berlex Laboratories)

Administered every other day via subcutaneous injection

Copaxone® (glatiramer acetate injection, Teva Neuroscience)

Administered daily via subcutaneous injection

Novantrone® (mitoxantrone, Serono Inc.)

Administered monthly intravenously

Rebif® (interferon beta-1a, Serono Inc. and Pfizer Inc.)

Administered three times weekly via subcutaneous injection

Patients frequently indicate that before they make any decisions, they would find it useful to talk to other patients with MS. Often the nurse can direct patients to a source where patients have been identified who are willing to share their story.

Setting realistic expectations

Nurses see patients in a variety of settings. In some cases, they have been involved with particular patients from the time of diagnosis and in others they are seeing patients with established MS for the first time. There is often limited time to discuss individual concerns and provide counseling. In addition, some nurses may not be as familiar with the MS treatments. Thus it becomes paramount for

It becomes paramount for nurses in practice to know the resources that can help patients understand the realistic expectations of MS treatments

nurses in practice to know the resources that can help patients understand the realistic expectations of MS treatments.

The media as well as direct to patient advertising are powerful information tools. However, they can also promote unrealistic expectations. It is possible for persons with MS, as well as health care providers, to get swept along with the general wave

The basis of the therapeutic relationship is understanding the emotional state and physical condition of the patient

of hype when a new product shows promise in clinical trials or is newly approved. Hope for the treatment is appropriate, but it must be realistic hope.

Nurses must stress that although DMDs can reduce exacerbations and slow disease progression, they are not cures. If patients believe that they will never have another relapse once they start a DMD, they are more likely to be disheartened and non-adherent when a relapse occurs. It is best to be straightforward when a patient has unrealistic expectations, and attempt to clarify what is realistic and what is not.

Identifying a patient's understanding of relapses and the appearance of new lesions on magnetic resonance imaging scans (MRI) is very important. These indicators can also play a part in patient expectations as well as adherence to treatments.

Factors that influence treatment choice

When counseling a patient on which agent is best for them, it is important to take into consideration lifestyle, stage or severity of disease, and ability to adhere to therapy.

Patients may be prescribed a drug before seeing an MS nurse and have questions as to why a particular drug was chosen for them. They often want to know if they have been prescribed the "best" therapy. It is likely that a particular medication was chosen based on both MS-related and lifestyle factors. Patients should realize that all of the therapies are effective, but that individual response

may vary. Thus, if patients have suboptimal response to the first agent they are prescribed it should not be perceived as a "failure." In this scenario, different treatments might be prescribed.

Frequently treatment decisions are driven by something that a patient tells his or her doctor. If a patient is concerned about flu-like side effects, the doctor may prescribe Copaxone® (glatiramer acetate injection, Teva Neuroscience). On the other hand, if a patient expresses concern about frequent injections, Avonex® (interferon beta-1a via intramuscular injection, Biogen Idec) may be prescribed.

Because the most commonly used DMDs (the interferons and glatiramer acetate injection) require self-injection, it is essential that patients are familiar with proper injection techniques. Nurses can help ensure that patients are armed with the

Readiness to begin therapy will assist patients with long-term adherence

skills and knowledge they need. Developing an injection education program, as described in an accompanying abstract, can lay the foundation for long-term adherence to an injectable agent.

Managing side effects

Each of the available agents may cause side effects that may make adherence difficult.

It is important to discuss with patients the potential side effects of the drug they are prescribed. It is preferable to have a patient call and report that the side effects were not as bad as expected, than have them say the side effects were a surprise. Patients must feel that they can report side effects and their concerns.

There are multiple ways to manage specific side effects. For example, the injected medications, interferon beta-1b (Betaseron®), interferon beta-1a (Rebif® and Avonex®) and Copaxone® have

specific injection site reactions associated with their use. All can cause discomfort and erythema. Interferons rarely cause skin breakdown and local necrosis at the injection site. Local necrosis is not usually associated with Copaxone® use. However, lipodystrophy has been seen with the use of Copaxone®. Prevention of these site reactions is possible with meticulous site rotation.

Pain at injection sites can be managed with the brief (2 minutes or less) use of ice pre-injection or the use of a topical anesthetic.

Flu-like symptoms related to the use of any interferon are best managed by initial dose titration,

Identifying a patient's understanding of relapses and the appearance of new lesions on magnetic resonance imaging scans (MRI) is very important

evening injections, and the pre/post injection use of analgesic/antipyretics such as acetaminophen, naproxen sodium or ibuprofen. It is important to counsel patients that flu-like symptoms generally dissipate over the first few months of interferon treatment.

Fortunately, the manufacturers of each of the MS therapies have support networks that provide patients with advice on how to manage side effects. Websites for these networks are provided on page 6 of this publication. Since some neurology practices do not have a nurse on staff, industry-sponsored websites provide a valuable service for patients, allowing them to connect with nurses who can answer their questions.

Long-term safety

Patients frequently have questions about the long-term safety of DMDs. The currently marketed MS

About the International Organization of MS Nurses

The mission of the International Organization of MS Nurses (IOMSN) is the establishment and perpetuation of a specialized branch of nursing in multiple sclerosis; to establish standards of nursing care in multiple sclerosis; to support multiple sclerosis nursing research; and to educate the health care community about multiple sclerosis; and to disseminate this knowledge throughout the world.



The ultimate goal of the IOMSN is to improve the lives of all those persons affected by multiple sclerosis through the provision of appropriate healthcare services.

Nurses who are interested in finding out more about the IOMSN or joining the organization should go to <http://www.iomsn.org>.

treatments appear to be relatively safe in the long term. Those initiating treatment often like to know how many patients have been treated with a particular drug and for how long. Hearing these numbers provides them with a feeling of confidence in their medication.

Nurses should discuss the potential risks of DMDs with patients, but remind them when the risks are acceptable in relation to the benefits. In addition, patients should be aware that risks can be monitored.

For patients self injecting interferons, hematology and liver function must be monitored on a regular basis. When possible, patients should be asked to assume the responsibility of ensuring that they have the tests performed regularly. Sometimes

Frequently treatment decisions are driven by something that a patient tells his or her doctor

patients may be seen only once a year by the neurologist, so the patient should make sure they have their hematology and liver function monitored as prescribed.

Adherence issues

Over the long-term adherence becomes a major issue. It is difficult for patients to be 100% adher-

ent the longer they are on a particular medication. For example, there are patients who have been on therapy for 10 or more years who find it harder and harder to find a suitable injection site because their skin has become so tough and thickened.

Older patients, in particular, seem to think that once they are in their 50's or 60's the disease has

Nurses should discuss the potential risks of DMDs with patients, but remind them when the risks are acceptable in relation to the benefits

run its course and they no longer need to take a DMD. Some neurologists or primary care physicians actually tell their patients that they need only take the medication until they are 50 because after that the disease burns itself out. This is not true, the disease can be active at any age.

Patients sometimes stop taking the medication for reasons not specific to the drug itself. People may change jobs and lose their insurance coverage or lose a spouse who had been administering the injections.

There are signs that indicate patients may not be adhering to therapy. In some cases, patients try to act as if everything is going well or they avoid giving direct answers. It is up to the nurse to be aware of these signs and to be able to assess what is really going on.

Frequent and consistent follow-up may be helpful in improving adherence to treatments. In addition,

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research has shown that those individuals

Resources

Patient oriented

<http://www.avonex.com>
<http://www.mspathways.com>
<http://www.mswatch.com>
<http://www.novantrone.com>
<http://www.mslifelines.com>
<http://www.nationalmssociety.org>

Health professional oriented

<http://www.mscares.org>
<http://www.iomsn.org>

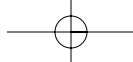
who have high self-efficacy and have a good relationship with their health provider will be more

Frequent and consistent follow-up may be helpful in improving adherence to treatments

likely to adhere to therapy. Thus, a therapeutic nurse-patient relationship can create the best environment to foster improved self-efficacy.

Conclusions

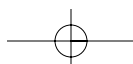
The bottom line is to remind patients that living with MS is, as the saying goes, a marathon, not a sprint. Before patients are prescribed a therapy, it is essential that he or she have a basic understanding of the MS disease process. By establishing an open relationship with patients and families early after diagnosis, nurses can ensure that patients feel comfortable with the therapy they are prescribed and are able to communicate their concerns and problems freely.



MS COUNSELING POINTS™

Managing Patient Expectations

- Establish and maintain a therapeutic relationship
- Nurses should become familiar with MS and DMDs prior to counseling patients
- Educate patients about MS before prescribing an agent
- Allow patients and families time to incorporate the disease into their lives
- Encourage early initiation of therapy, but be aware that when initiating a conversation about DMDs, timing is everything
- Set realistic expectations for patients
- Stress that while DMDs can reduce the frequency and severity of relapses and slow disease progression, they are not a cure
- Identify a patient's emotional tolerance level for relapses and the appearance of new lesions on magnetic resonance imaging scans
- Take into consideration lifestyle, subtype or severity of disease, and ability to adhere to therapy when choosing a medication
- Discuss potential side effects openly with patients
- Educate patients on how to manage side effects
- Discuss the potential for long-term risks in relation to long-term benefits
- Be aware of signs of non-adherence and be prepared to address patients' concerns and problems as they occur by reinforcing the importance of continuing therapy
- Refer to pharmaceutical company telephone support lines
- Encourage consistent follow-up





In the Literature

THE INFLUENCE OF RESOURCES ON PERCEIVED FUNCTIONAL LIMITATIONS AMONG WOMEN WITH MULTIPLE SCLEROSIS.

Clingerman E, Stuifbergen A, Becker H.

The purpose of this longitudinal investigation was to identify the effects of external resources (i.e., education, marriage, employment, social support, economic status) on the trajectory of perceived functional limitation among women with multiple sclerosis (MS). We hypothesized that these resources would have a long-term influence upon MS-related functional limitation. As part of a longitudinal study of health promotion and quality of life among persons with MS, we tested hypothesized relationships using data obtained at five

Nurses and other healthcare professionals are in an optimum position to observe and assess the resources of women with MS

time points, using repeated-measures MANOVA. We found that functional limitation scores increased over time for all participants. In general, women who were unemployed as a result of MS consistently had higher functional limitation scores, and employed women consistently had lower functional limitation scores. Women with lower social support scores consistently perceived greater functional limitation than those with higher social support scores. Women with lower perceived-economic-adequacy scores consistently had higher functional limitation scores than women with higher perceived-economic-adequacy scores. Nurses and other healthcare professionals are in an optimum position to observe and assess the resources of women with MS. They can use presence, listening, and observational skills to identify verbal and nonverbal cues of resource depletion. In addition, they can act as advocates for women with MS and speak out on policy issues and legislation at the local and national levels. Healthcare professionals can thus influence the presence of

resources for those who are particularly vulnerable to resource loss, so they can participate successfully in work, recreational, and home environments.

J Neurosci Nurs. 2004;36(6):312-21.

AGING WITH MULTIPLE SCLEROSIS.

Finlayson M, Van Denend T, Hudson E.

Although multiple sclerosis (MS) does not typically reduce life expectancy, there has been relatively little systematic investigation of the experiences and health-related concerns of people aging with this disease. A current search of the database CINAHL produced no articles when the search terms “multiple sclerosis,” “nursing” and “aging” were used. To initiate more dialogue about the role of nurses in addressing the issues and concerns of people aging with MS, a cross-sectional descriptive study was conducted using both qualitative interviews and the administration of standardized instruments to elicit information about the health concerns and service needs of 27 people with MS 55 years of age and older. Qualitatively, participants perceived that they had less freedom and required more assistance than same age peers who do not have MS. Scores from standardized instruments support these perceptions. Participants expressed unmet needs in the areas of

Neuroscience nurses need to be aware of and sensitive to the challenges of aging with MS

housework, physical therapy, MS support groups, religious service attendance, information and referral, check-in services, assistive technology use, social activities, personal care, and care coordination. To address these perceptions and needs, neuroscience nurses need to be aware of and sensitive to the challenges of aging with MS. In addition, nurses must be prepared to discuss and provide infor-

mation, resources, and referrals on a wide range of health, social, and wellness-related services.

J Neurosci Nurs. 2004;36(5):245-51, 259.

RETHINKING COGNITIVE FUNCTION IN MULTIPLE SCLEROSIS: A NURSING PERSPECTIVE.

Halper J, Kennedy P, Miller CM, Morgante L, Namey M, Ross AP.

Cognitive impairment is a common problem in multiple sclerosis (MS); up to 65% of patients exhibit some neuropsychological dysfunction during the course of their disease. It is a major contributing factor to unemployment, accidents, impairment of daily functioning, and loss of social activity in those affected by MS. The areas of cognition typically

Despite its prevalence in MS, cognitive dysfunction often goes undiagnosed or is misdiagnosed as depression, stress, stubbornness, lack of intelligence, or psychosis

impaired are memory, attention, information processing, executive functions, and visuospatial skills. Cognitive dysfunction is independent of disease duration and level of disability; cognitive decline may begin in the earliest stages of MS before patients become even mildly disabled. Structural brain imaging studies show a positive correlation between the extent of brain atrophy and cognitive dysfunction. Despite its prevalence in MS, cognitive dysfunction often goes undiagnosed or is misdiagnosed as depression, stress, stubbornness, lack of intelligence, or psychosis. Because nurses play such an important role in the care of patients with MS, they are in a position to identify patients with cognitive dysfunction, educate patients and their families on ways to cope with cognitive deficits, and counsel patients on available treatment options. Practical guidelines help nurses identify and care for cognitively impaired MS patients.

J Neurosci Nurs. 2003;35(2):70-81

THE MEANING OF FATIGUE FOR WOMEN WITH MULTIPLE SCLEROSIS.

Olsson M, Lexell J, Soderberg S.

AIM: This paper reports the findings of a study that aimed to elucidate the meaning of fatigue for women with multiple sclerosis (MS). BACKGROUND: Living with chronic illness can involve giving up

The feeling of being an outsider and lacking the ability as a healthy person is interpreted as a form of suffering

usual activities. MS is a chronic autoimmune disease of the central nervous system. Fatigue is a common experience among people with MS; however, little is known about the meaning of fatigue experienced by women with this condition. METHOD: Ten women with MS were interviewed about their experience of fatigue. A phenomenological hermeneutic method influenced by Ricoeur was used to interpret the transcribed interviews. FINDINGS: The findings were presented in two major themes with five subthemes; experiencing the body as a barrier and experiencing a different absence. Fatigue seemed to give rise to an experience of being absent and divided into two parts. This also led to a feeling of not being able to participate in the surrounding world. The feeling of being an outsider and lacking the ability as a healthy person is interpreted as a form of suffering. Although the fatigue had a great impact on the women's daily life, the women still hoped for some relief. Fatigue seemed to imply that instead of working as an implement to manage in the world the body has become an

This study highlights the importance for nurses of understanding how women with MS experience fatigue, which is a prerequisite for communication based on a shared understanding

enemy of survival. CONCLUSION: This study highlights the importance for nurses of understanding how women with MS experience fatigue, which is a

prerequisite for communication based on a shared understanding. This awareness would enhance nurses' opportunities to alleviate suffering. More research is needed to investigate what kinds of interventions can help these women to manage their everyday lives and to maintain a sense of normality despite their fatigue and illness. Such interventions should be subject to empirical evaluation research.

J Adv Nurs. 2005 Jan;49(1):7-15. Related Articles, Links

HUSBANDS AND WIVES LIVING WITH MULTIPLE SCLEROSIS.

Courts NF, Newton AN, McNeal LJ.

Multiple sclerosis (MS) frequently is diagnosed in young adults. Coping with symptoms of MS is challenging not only for the person with the disease, but also for his or her spouse. The well spouse often assumes the caregiving role. The purpose of this qualitative research was to investigate the experi-

Men attempted to protect their wives' energy, intervening for them. Wives encouraged independence in their husbands

ences of persons whose spouses have MS. Twelve people participated in a 2-hour focus group: 8 men and 4 women. The husbands were, on average, 50 years old, and the wives averaged 55 years old. The length of time since diagnosis ranged from 2 to 11 years for the husbands and from 3 to 13 years for the wives. The focus group discussions were audiotaped and transcribed verbatim. Participants talked freely. Four major themes emerged: caregiver roles, need for information, relationship changes, and barriers. Men attempted to protect their wives' energy, intervening for them. Wives encouraged independence in their husbands. Spouses need information about MS, complementary interventions, and support. They want increased public awareness of invisible symptoms and awareness in the workplace of continuing capabilities of persons with MS. Role reversals were challenging for the women who felt that "MS is the third person in a marriage." Spouses

need help to maintain appropriate boundaries. Limitations of the study include the small, economically homogeneous sample and the single encounter with the subjects. A longitudinal intervention study is needed.

J Neurosci Nurs. 2005 Feb;37(1):20-7. Related Articles, Links

LONGITUDINAL ANALYSIS OF ILLNESS UNCERTAINTY, COPING, HOPEFULNESS, AND MOOD DURING PARTICIPATION IN A CLINICAL DRUG TRIAL.

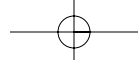
Wineman NM, Schwetz KM, Zeller R, Cyphert J.

The purpose of this longitudinal study was to examine the relationships among illness uncertainty, coping effectiveness, hopefulness, and mood in persons with chronic, progressive multiple sclerosis (MS) during participation in a double-blind clinical drug trial. The similarities and differences in the pattern of relationships among variables were investigated within each of four data collection time frames and across time. The convenience sample comprised 52 participants with clinically definite MS who participated in a 2-year trial using methotrexate to treat progressive MS. Participants with more severe disability were found to be less hopeful and more emotionally distressed. Participants with higher levels of hopefulness used more effective coping strategies and had more positive moods, and those with greater uncertainty about their MS were likely to experience less hopefulness and more negative moods. The pattern of relationships among uncer-

The findings may be used as a foundation for planning nursing interventions with patients involved in drug studies

tainty, coping, hopefulness, and mood did not change throughout participation in the drug trial. The findings may be used as a foundation for planning nursing interventions with patients involved in drug studies.

J Neurosci Nurs. 2003;35(2):100-6.



MS COUNSELING POINTS™

Managing Patient Expectations

TELL US WHAT YOU THINK

We are anxious to hear your comments about this premier issue of *Counseling Points™*. We would also like you to share any suggestions you may have for future issues.

Please take a few moments to fill out the evaluation form below and fax it to the Delaware Media Group, LLC at 201-612-8282. Thank you for your time and interest in *Counseling Points™*.

Program Evaluation

Using the scale below, please complete the program evaluation so that we may continue to provide you with high quality educational programming:

Excellent ⑤ Good ④ Satisfactory ③ Fair ② Poor ①

HOW WOULD YOU RATE THE:

Overall quality of the *Counseling Points™* ⑤ ④ ③ ② ①

Readability of *Counseling Points™* ⑤ ④ ③ ② ①

Usefulness of the information presented in *Counseling Points™* ⑤ ④ ③ ② ①

Value of the *Counseling Points™* summary (page 7) ⑤ ④ ③ ② ①

Do you believe you will be better able to communicate with patients after having read the information presented in *Counseling Points™*?

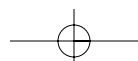
Yes No

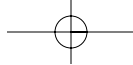
WE WOULD APPRECIATE YOUR COMMENTS AND SUGGESTIONS ON HOW WE CAN IMPROVE FUTURE ISSUES OF *COUNSELING POINTS™*.

What future topics would you like to see addressed in *Counseling Points™*?

Are there any other comments, suggestions, thoughts about *Counseling Points™* that you would like to share?

MSCP-2005-01





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