

## The Evolving Role of the Multiple Sclerosis Nurse – Implications of Future Management Directions

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### Abstract

The role of the multiple sclerosis (MS) nurse is constantly evolving, owing to the introduction of new MS therapies and new patient treatment and support strategies. The second MS nurse symposium, 'The Evolving Role of the MS Nurse: Implications of Future Management Directions' took place in Athens between 22–24 September 2011 and was attended by approximately 300 participants from 30 countries. Presentations at the symposium outlined the mechanisms of action and clinical evidence for novel therapies for MS treatment. The importance of making clinical trial data available and understandable to people with MS was addressed, followed by a summary of the latest data on established MS therapies and an update on autoinjectors and their role in improving adherence. Novel patient support strategies were outlined followed by presentations by MS nurses from different countries who discussed their roles and their opportunities to evolve against a background of very different healthcare systems. Group discussions of typical MS case examples emphasised the need for good communications and relationships between patients and MS nurses. The final session focused on communication skills, highlighting 'tips' for engaging with people with MS and examining the challenges that different patient expectations and communication media can bring.

### Keywords

Multiple sclerosis (MS) specialist nurse, MS nurse role, patient communication, MS nurse–patient relationships, MS therapies

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Multiple sclerosis (MS) specialist nurses are pivotal members of the multidisciplinary team, all having varying responsibilities such as symptom management, drug initiation and drug monitoring in people with MS. During the past two decades the role of MS nurses has evolved owing to expanding management strategies and new approaches to MS treatment. They are now involved in the development and implementation of complex patient care plans and their role continues to change as novel therapies are developed, changes to established therapies are implemented, and new concepts in patient support and compliance emerge. In the treatment of people with MS, MS specialist nurses take on a wide range of functions that go far beyond traditional nursing roles. The knowledge and skills required to effectively manage and support people with MS are considerable and demanding yet this branch of nursing is not widely recognised as a distinct speciality – there are no universal guidelines on best practice and no agreed training programmes or specific qualifications awarded. Recently, the Multiple

Sclerosis-Nurse Empowering Education (MS-NEED) European Survey operated by the European Multiple Sclerosis Platform (EMSP) gathered questionnaire data from MS nurses from six European countries to assess practices in different territories.<sup>1</sup> The findings showed that nurses regularly take a lead in many aspects of the care of people with MS including medication management and patient education, but that many thought that standards were not well maintained in their countries. The findings also showed substantial disparities in nursing practices across Europe that need to be addressed to ensure consistent and high quality care.

The MS-NEED survey results prompted the establishment of a series of annual MS nurse symposia to enable representative groups of MS specialist nurses from countries worldwide to gather and learn about new developments in MS care and, more importantly, to share their experiences and help establish a consensus on best practices in MS nursing, make recommendations on training and increase

**Table 1: Key Issue Responses Given via a Poster Surveying Symposium Attendees at the Evolving Role of the Multiple Sclerosis Nurse Meeting (Athens)**

Question	Response (%)		
	Yes	No	No view
Do you take a leadership role in coordinating multidisciplinary management of the people with MS that you care for?	84	16	0
Do you think that this leadership role should be increased?	92	5	3
Would the status of MS nurses in your country be increased if the role was a recognised speciality?	84	16	0
Would the development of a European consensus, to define MS nurse roles and responsibilities, facilitate consistency of care and improve patient outcomes?	95	5	0
Is there an MS nurse certification process in your country?	35	65	0
In the next two years will your role as an MS nurse change?	71	24	5
Will the availability of oral MS therapy significantly change your role in future patient management?	88	12	0

MS = multiple sclerosis.

recognition of the important role they play in successful treatment of a potentially devastating disease.<sup>1</sup> The first, highly successful, MS Nurse Symposium took place in Copenhagen in 2010. The second, larger and more popular MS Nurse Symposium took place in Athens in September 2011 and was attended by over 300 MS nurses from over 30 countries worldwide. This article will provide an overview of the presentations, case study group discussions and attendee feedback on MS nursing issues from the Athens meeting.

**General Attendee Feedback  
(Chrysa Chrysovitsanou, Athens, Greece)**

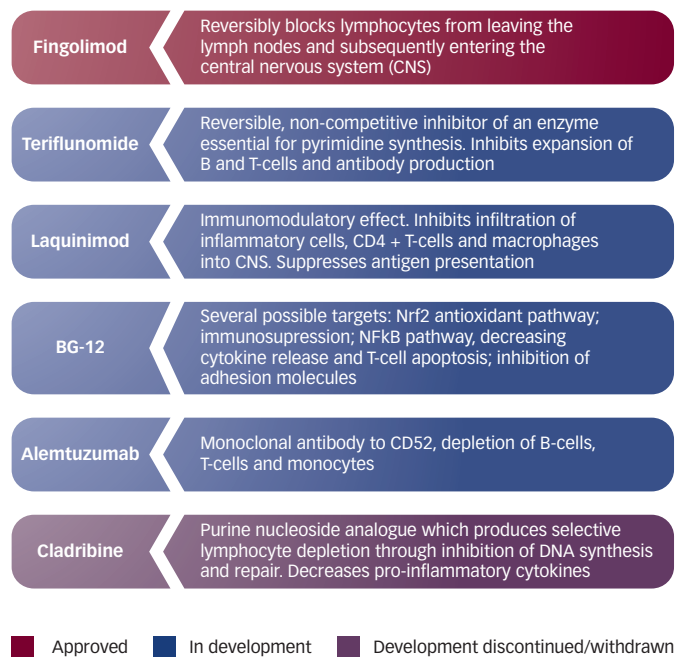
The care, support and information given by MS nurses are all of critical importance but the role of the MS nurse is changing. Nurses now often work as part of multidisciplinary teams, economic pressures affect care given and the number of different treatments available is increasing. Electronic voting by the attendees showed that most were from university (36.4 %) or community (25.6 %) hospitals. Fifty-five per cent of nurses stated that the proportion of their patients having MS was >50 % and most nurses were caring for >200 people with MS at any one time (55.4 %). The majority (59.9 %) saw themselves as MS specialists, with 54.4 % reporting that they frequently provided advice and education to people with MS and 74.4 % describing themselves as advisors/intermediaries. The most significant barrier in optimising patient care was regarded as lack of time (30.2 %) and this was followed by a lack of resources, facilities and personnel (29.3 %). Patients were thought to mostly or always have access to an MS nurse in their country by 83.6 % of nurses.

Key issue responses from attendees collected on a poster showed that a substantial majority (84 %) took a leadership role in the management of people with MS but most (92 %) thought that this should be increased. The majority of participants (84 %) thought that MS nurse status would be improved with official recognition (see Table 1). Ninety-five per cent of attendees believed that a European consensus to define roles would improve nursing practice and that the introduction of oral therapies would significantly change their role in patient care.

**Novel Therapies for Multiple Sclerosis – Theory, Trial and Clinical Practice  
Therapeutic Targets – Implications for Clinical Practice  
(Finn Sellebjerg, Copenhagen, Denmark)**

The aetiology of this complex disease is only partially understood. Various genetic factors have been identified that may contribute to the development of MS,<sup>2</sup> with the risk of acquiring the disease being up to

**Figure 1: Novel Treatments and Their Targets in Multiple Sclerosis**



20–40 fold higher in direct relatives of a person with the disease than in the general population,<sup>3</sup> suggesting that susceptibility is partially genetic, with a polygenic pattern of transmission. In addition to genetic factors, environmental factors such as vitamin D deficiency, smoking, viral infection, temperature/climate and location (latitude) have been associated with higher rates of the disease and are likely risk factors.<sup>4-7</sup>

In MS, there is a balance between central nervous system (CNS) injury (due to inflammation) and repair and the equilibrium between these two processes determines disease progression. Multiple sclerosis involves an autoimmune process in which T-cell lymphocytes recognise myelin as foreign and attack it, leading to damage, inflammation and neurodegeneration. The critical role of T cells in MS has led to these cells and associated factors providing key targets for disease-modifying therapies (DMTs). The main objective when treating MS is halting the immune attack on myelin and this can be achieved through either a general reduction of the immune response (e.g. mitoxantrone) or using a selective approach to inhibit a single effect (e.g. interferon betas [IFNβs], natalizumab or

**Table 2: Audience Responses to Questions on Management, Treatment and Communication Issues in Multiple Sclerosis**

Question	Response Categories and % Audience Response					
Which of the following best describes the level of knowledge of MS and MS therapy, for the majority of your patients?	Well informed, need little additional information 13.6 %	Informed, but with 'misinformation' common 70.5 %	Poorly informed – keen to know more 13.6 %	Poorly informed – do not wish to know more 2.3 %		
Which of the following concepts is most difficult to explain to your patients?	Annualised relapse rate 5.4 %	Risk of disability 16.2 %	Changes on MRI 10.8 %	Brain volume changes 21.6 %	Risks of adverse events 8.1 %	All of these 37.8 %
How much training in patient communication have you received?	None 11.1 %	A little at nursing school 17.2 %	A little at nursing school and more since 49.5 %	Regular communication training 22.2 %	–	
How important is the manner in which you communicate information to a patient?	Not important at all 0.9 %	Somewhat important 1.8 %	Very important 96.4 %	Not sure 0.9 %	–	
What are some of the key aspects influencing nurses' ability to provide support to patients with MS now and in the future?	Increasing patient numbers 3.8 %	Access to new technology 8.8 %	Changing patient-practitioner relationships 7.4 %	All of the above 80 %	–	–
When is your first contact with a newly diagnosed patient?	Before diagnosis (at referral) 11.8 %	At diagnosis (same day) 39.2 %	Soon after diagnosis (within 1 week) 29.4 %	Later, but within 1 month 17.6 %	Much later (>1 month) 2.0 %	–
What proportion of your patients have RRMS?	>80 % 31.9 %	75 % 33.3 %	50 % 22.9 %	<50 % 11.8 %	–	–
Which therapy is most commonly used by your patients?	Glatiramer acetate 13.9 %	IFNβ-1b EOD 19.4 %	IFNβ-1a TIW 25.0 %	IFNβ-1a weekly 19.4 %	Natalizumab 13.9 %	Fingolimod 8.7 %
What therapy is most commonly used for your patients with CIS?	IFNβ-1b 20 %	IFNβ-1a 38.2 %	Either IFNβ 12.7 %	Glatiramer acetate 5.5 %	Other 1.8 %	Most patients are not treated 21.8 %
What is the most challenging aspect of management of people with RRMS receiving DMTs?	Compliance/adherence 36.4 %	Adverse event management 15.2 %	Follow-up/monitoring requirement 9.1 %	Other 1.5 %	All of these 37.9 %	–
With the interferon your patients use, which of the following potential adverse events associated with treatment do you find most challenging?	Flu-like symptoms 40.2 %	Injection-site reactions 40.2 %	Depression 10.3 %	Liver function changes 4.6 %	Nabs 4.6 %	–

CIS = clinically isolated syndrome; DMT = disease-modifying therapies; EOD = every other day; IFNβ = interferon beta; MRI = magnetic resonance imaging; MS = multiple sclerosis; Nabs = neutralising antibodies; RRMS = relapsing-remitting MS; TIW = three times weekly.

fingolimod). However, it is also important that this effect on the immune system is reversible. Novel oral agents currently available or in late-stage development for the treatment of MS are shown in *Figure 1* and although all have been shown to act on lymphocytes, they do so in a variety of different ways. Fingolimod, for example modulates S1P receptors, reducing inflammation.<sup>8</sup> Activated lymphocytes are 'locked up' in lymph nodes and kept out of the bloodstream, reducing their ability to infiltrate the CNS. After stopping fingolimod treatment, lymphocyte levels return to normal in one to two months. BG-12, teriflunomide, laquinimod and alemtuzumab are all novel MS agents currently in development and have varying mechanisms of action (summarised in *Figure 1*). Teriflunomide reversibly blocks DNA synthesis; laquinimod suppresses antigen presentation although its molecular target is unknown; BG-12 has several possible modes of action on cytokines and apoptosis; and alemtuzumab is a CD52-specific monoclonal antibody leading to depletion of B cells, T cells and monocytes.

## Assessing the Clinical Evidence (Martin Duddy, Newcastle upon Tyne, UK)

In MS treatment there are three overall goals – preventing/shortening relapses, preventing or delaying disability accumulation and addressing existing disabilities. As mentioned above, there are several potential oral therapies (see *Figure 2*) in different stages of development for the treatment of MS and three of these drugs are currently undergoing Phase III trials. Teriflunomide, a DNA synthesis inhibitor, is currently undergoing trials versus placebo, versus IFNβ and is also being assessed for use in clinically isolated syndrome (CIS). In the Phase III TEMSO trial, teriflunomide reduced annualised relapse rate (ARR) in MS by 31 % versus placebo.<sup>9</sup> Laquinimod, an oral immunomodulator, was compared with placebo in the Phase III ALLEGRO trial where it reduced ARR by 23 % and disability progression by 36 %.<sup>10</sup> BG-12, an oral formulation of dimethyl fumarate, has achieved its primary outcome measures in the Phase III DEFINE study.<sup>11</sup> Development of another potential therapy, oral

cladribine, has recently been discontinued owing to adverse event concerns and it has been withdrawn from the market in countries where it was already approved.<sup>12</sup>

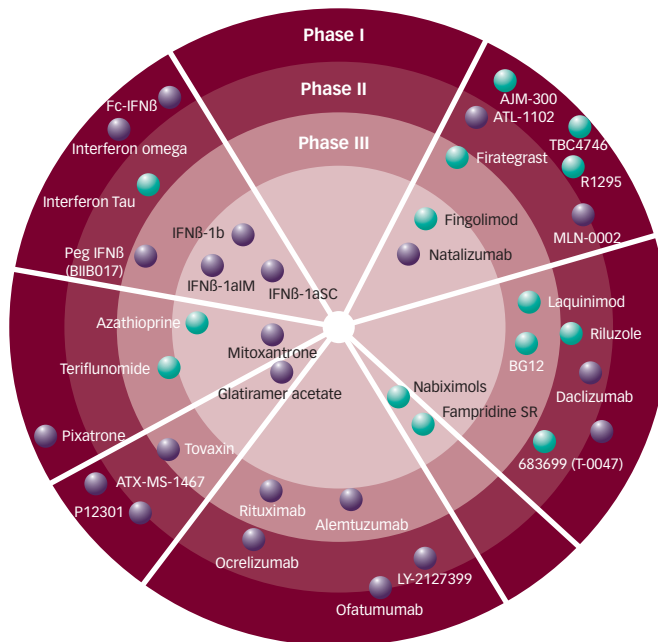
Fingolimod is the first of these novel agents to have gained approval in the EU and US and is now approved in more than 40 countries although licensed indications vary by country (e.g. ‘relapsing forms’ of MS in US, relapsing-remitting MS [RRMS] in Canada and either highly active RRMS despite IFN $\beta$  treatment or rapidly evolving severe MS in the EU). For fingolimod, data from the Phase III FREEDOMS (versus placebo)<sup>13</sup> and TRANSFORMS (versus IFN $\beta$ ) studies<sup>14</sup> support its use in RRMS. In the FREEDOMS trial,<sup>13</sup> ARR was reduced by 54 % (p<0.001), time to disability progression confirmed after six months was reduced by 37 % and Gd-enhancing lesions were reduced by 82 % compared with placebo at two years. In the TRANSFORMS trial, ARR was reduced by 52 % (p<0.001), there was a 40 % reduction in brain volume loss (p <0.001) and Gd-enhancing lesions were reduced by 55 % compared with IFN $\beta$  at 12 months.<sup>14</sup> Some very common AEs (occurring in >1 in 10 patients) were observed including: increased gamma-glutamyl transferase and liver enzymes; viral infections; headache; diarrhoea; and cough. With the exception of disturbed liver function tests, all these AEs were reported with similar frequency in the placebo arm. Bradycardia, hypertension, macular oedema, disturbed liver function, teratogenicity and infections are all safety/risk areas of special interest with fingolimod and it should not be used in patients with active malignancy, immunocompromised with HIV or those with, or at risk of, severe infections. Assessment including full blood count, liver enzymes, ophthalmologic or cardiovascular examination (in some circumstances), varicella zoster virus (VZV) immune status and pregnancy testing should be completed before initiating therapy and monitoring should occur during treatment. A pre-treatment ECG is recommended by some centres. A risk-management programme is in place for fingolimod use in MS and Phase IV trials are in progress to assess treatment satisfaction, safety and tolerability, effects of the treatment on activities of daily living, and on depression and coping in people with MS.<sup>15</sup>

### Making Trial Data Meaningful to My Patients (Del Thomas, Hereford, UK)

The trial data in MS are complex and need to be interpreted and given clearly to people with MS. Delivering the data this way provides answers to questions and addresses anxieties.

Patients have a variety of issues and questions on MS therapies, including: why should I take it?; what if I don't take it?; does it work?; how does it work?; will it make me better?; how do I take it and how often?; what are the side effects?; what tests do I need? A survey of nurses attending the symposium found that most people with MS are reasonably well informed but 70.5 % of patients are thought to have received misinformation and need to be corrected (see Table 2). Alternatively, some patients (13.6 %) are poorly informed and need good quality guidance on the management of their condition. Certain parameters such as ARR, risk of disability progression, MRI changes and adverse side effects, can be challenging to explain to people with MS (see Table 2). After treatment has been decided, there are a variety of factors that can affect patient adherence and these include: economics; healthcare organisation issues (such as access to MS nurses); condition-related factors; patient-related factors (injection fear, etc.); and therapy-related factors. Multiple sclerosis nurses need to listen, communicate, keep their knowledge current, understand, explore treatments, decide on best strategies and monitor patient progress.

**Figure 2: Intravenous and Oral Treatments for Multiple Sclerosis Currently Marketed or in Phase I–III Development**



*Intravenous agents are shown in purple, and oral agents are indicated in green. IFN $\beta$  = interferon beta; IM = intramuscular; Peg = pegylated; SC = subcutaneous; SR = slow release.*

### What's New in Established Interventions? Evidence for Established Therapies (Tjalf Ziemssen, Dresden, Germany)

Although various potential new treatments are in development for the treatment of MS (see Figure 2), the IFN $\beta$ s and glatiramer acetate (GA) continue to be the mainstay of MS treatment. The audience vote showed the people with MS cared for by the attendees most commonly receive IFN $\beta$ -1a three times weekly (TIW), IFN $\beta$ -1a weekly or IFN $\beta$ -1b every other day (see Table 2). In CIS, patients most commonly receive IFN $\beta$ -1a TIW but a sizeable proportion (21.8 %) of attendees said their patients receive no treatment at all at this stage. It is important to stress the rationale for starting disease modifying treatment early, as illustrated by the BENEFIT trial in which there was a 42.4 versus 53.4 % conversion to clinically definite MS for patients receiving early versus delayed treatment.<sup>16</sup> When treating RRMS, the traditional first-line therapies (IFN $\beta$ s and GA) provide similar efficacy (29–34 % reduction in relapses, similar time to first relapse 228–331 days) although GA has less clear evidence on prevention of disability (12 versus 23–37%).<sup>17</sup>

There is a large body of evidence showing efficacy of DMTs when used over long periods of time for the treatment of MS. In one observational cohort study IFN $\beta$ -1b use was associated with a reduction in relapse rates of 40 % over 17 years and disease progression to secondary progressive MS (SPMS) was delayed by 6.6 years compared with placebo or other treatments.<sup>18</sup> Owing to the long-term treatment programmes involved in MS and because patients live for 30–40 years with the disease, maintaining follow-up of people with MS is extremely important but can prove difficult. For more severe and refractory MS, escalating therapy is needed. Natalizumab is a highly effective DMT for use in highly active RRMS, and has been demonstrated to reduce the relapse rate from 0.78/year to 0.26/year in one study.<sup>19</sup> A major safety issue with this therapy

**Table 3: Communication Skills for the Clinic – Tips and Hints**

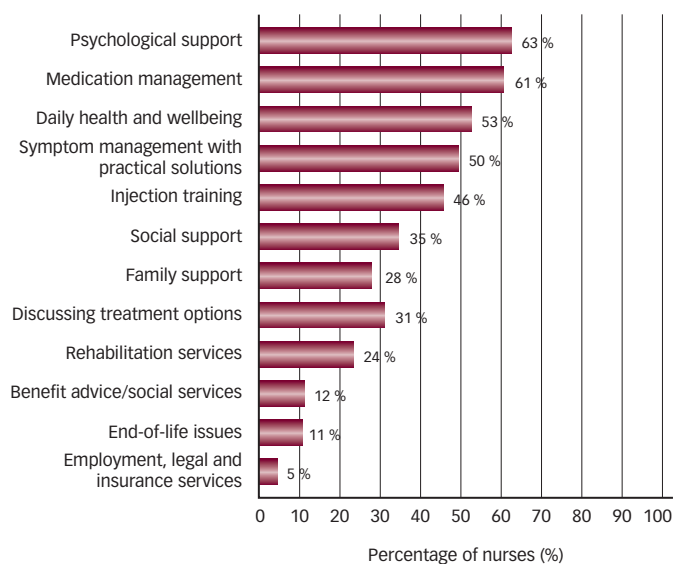
- The conference participant survey indicated only 22.2 % of attendees had received regular communication training, however 96.4 % agreed that the manner in which information is given is very important
- 70 % of complaints in healthcare are due to inadequate communication
- There are unique communication challenges in multiple sclerosis. The disease is complex and variable, there is a need for long-term medication and compliance, and encouraging necessary lifestyle changes can be difficult
- Studies show that satisfaction and compliance are reduced if doctors do not show warmth, ignore concerns, use jargon or fail to explain issues clearly<sup>28</sup>
- Doctors frequently ignore patient concerns: in consultations with patients with chronic illnesses a study showed that 54 % of patient complaints and 45 % of their concerns were not elicited
- Physicians who are poor communicators tend to have patients with poorer adherence<sup>29</sup>
- Good communication requires good questions, active listening, picking up non-verbal cues and providing emotional support
- Consultations should be patient-centred,<sup>40</sup> the first two minutes of a consultation are key to establishing a rapport
- Giving information is difficult. It has been shown that only 50 % is retained and therefore information should be given in small amounts
- Telephone consultations are more difficult requiring the doctor/nurse to check patient understanding frequently and to speak clearly
- The doctor/nurse should establish what the patient knows at the outset. Most patient concerns are associated with symptom treatment, diagnostic procedures and prognosis
- Decision-making should be shared with the patient
- Encouraging lifestyle change is challenging and requires a motivational approach from nurses and doctors

is progressive multifocal leukoencephalopathy, shown to occur in <1.0/1,000 patients treated for 1–24 months with no prior immunosuppressant use, 2/1,000 with prior immunosuppressant use and in 4/1,000 and 11/1,000 in these groups treated over 25–48 months.<sup>20</sup> Mitoxantrone can be used in the late stages of MS but is approved for use in MS in only a limited number of countries and is used much less now owing to safety issues. There is no standard treatment for MS as it is an individual disease that varies according to the patient.<sup>21</sup> As treatment options increase, treatment decisions will get more and more complex, although the concept of individualised therapies in MS remains a pipe dream. Due to the complex nature of MS, multidisciplinary teams are needed to implement appropriate treatment plans.

### Autoinjector Update (Mathias Bruns, Berlin, Germany)

Both IFN $\beta$  and GA therapy require parenteral self-administration by either subcutaneous or intramuscular injection and, because of this, patient compliance can be an issue. In addition, adverse effects can occur and in patients undergoing IFN $\beta$  and GA therapy, injection site reactions (ISRs) were considered by the participants to be as challenging as flu-like symptoms (see *Table 2*). To increase patient compliance, the patient experience must be improved and there are several ways in which this can be achieved. First, it has been demonstrated that using smaller (narrower) needles and autoinjectors improves patient experiences and improves adherence.<sup>22–24</sup> Second, rotation of the injection site can reduce ISRs, pain and trauma and may improve compliance.<sup>25</sup> In addition, autoinjectors can be helpful for patients with limited mobility or dexterity and provide the ability to administer injections at body sites that were previously inaccessible.

**Figure 3: Percentage of Multiple Sclerosis Nurses who Often Provide Advice and Education on Patient Issues**



Source: Hartung et al., 2011.<sup>1</sup>

Many autoinjectors are now available and include: Extaviject 30G (a multiple use autoinjector with a 30G hidden needle, simple to operate); RebiSmart™ (an automated system which is good for younger patients but often too complex for older patients); RebiDose™ (a single use autoinjector); and the Avonex Pen (a single use autoinjector with a 27G needle, that is simple to operate). A survey of people with MS published in 2009, showed that 51 % of 798 patients were non-adherent to IFN $\beta$  during the month prior to the survey, largely as a result of their dislike of injections and/or ISRs.<sup>26</sup> Furthermore, there are distinct patient preferences for different autoinjectors, with a survey of 200 people with MS shown videos about two devices demonstrating that 70 % would prefer to use Extaviject 30G over the Betaject® Comfort device.<sup>27</sup> To improve patient compliance, patients should be given information for different autoinjectors and be able to opt for the most appropriate one for them. Not all of the manufactured types of autoinjectors are currently available in every country throughout Europe.

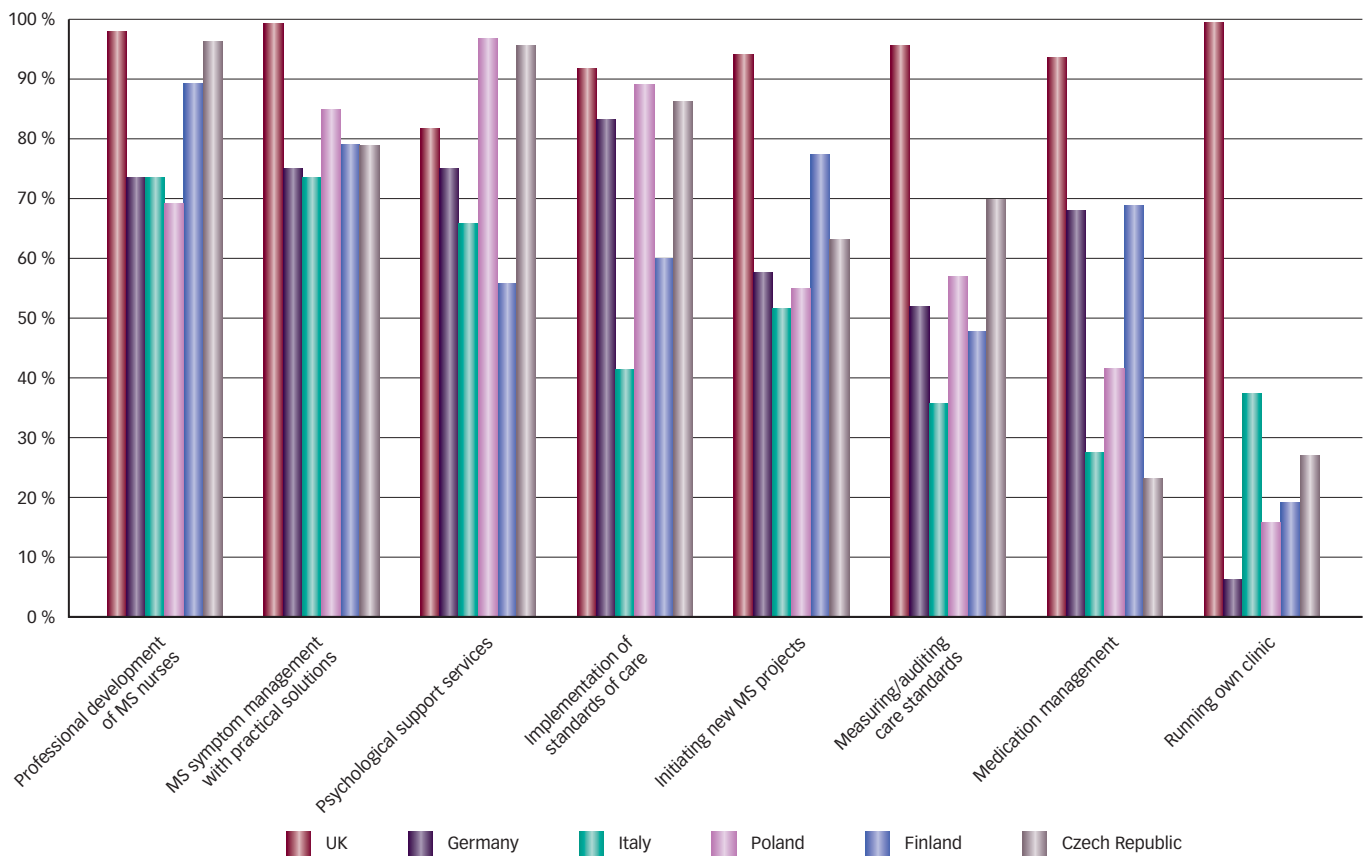
### Evolving Paradigms for Support of People with Multiple Sclerosis

#### New/Evolving Concepts in Support of People with Multiple Sclerosis

(Diane Lowden, Montreal, Canada)

The key aspects influencing a nurse's ability to provide support to people with MS are increasing patient numbers, access to new technology and changes in patient-practitioner relationships (see *Table 2*). In Canada there are an estimated 75,000 people with MS, which is an increase on previous estimations but prevalence has been shown to vary between regions of the country.<sup>28–30</sup> The incidence of MS in Canada is also rising, resulting in increased pressure on healthcare systems.<sup>31,32</sup> In addition to rising patient numbers, complexity is growing in terms of choice of treatments and how to use them (whether and when to start, etc). MS nurses are valuable in managing people with MS because many primary care practitioners feel ill-equipped to deal with MS and there is inconsistent access to family physicians. The advent of new treatments, including oral therapies, can increase the need for

**Figure 4: Multiple Sclerosis Nurses who Believe that Specialist MS Nurses in their Country have the Opportunity to Take a Lead in Key Areas**



MS = multiple sclerosis. Source: Hartung et al., 2011.<sup>1</sup>

**Table 4: Feedback from Multiple Sclerosis Nurse Discussion Groups on Multiple Sclerosis Case Examples**

Case Example	MS Nurse Discussion Group Responses and Issues Raised
<p>1. 38-year old male with MS for 10 years; busy with job and sport/social life. Has RRMS with mild disease activity. Always says everything is “fine” and rarely attends MS clinic. Takes IFNβ-1a IM weekly. Recently had a bad relapse but not told anyone (nurse alerted by patient’s wife). Patient then admitted to having a relapse 18 months earlier. Patient is in denial, does not want to admit he is doing badly and is trying to protect himself and his family</p>	<ul style="list-style-type: none"> <li>Relationship with MS nurse or neurologist is not functioning properly</li> <li>Start patient at clinic again, improve communication, decide if a neurological exam is needed</li> <li>Improve relapse management and determine whether patient is not adhering to treatment and why. Patients at high risk of non-adherence should attend MS clinic and share issues</li> <li>In some countries (e.g., Poland) patients must attend an MS clinic monthly but treatment programme space is limited</li> <li>Establish contact with patient’s partner/spouse to aid treatment adherence</li> <li>Involve a psychologist (may be limited by cost). Nurses can provide some psychological support</li> <li>If patient has a relapse, treatment may be escalated or changed but this requires neurologist authorisation – MS nurses do not have direct contact with neurologists in all countries</li> </ul>
<p>2. 47-year old female diagnosed with RRMS 15 years ago. Had two relapses in previous 10 years but otherwise healthy and active. More recently has had a bad relapse and failed to recover fully – now has mobility problems after two months of treatment</p>	<ul style="list-style-type: none"> <li>Patient likely to have SPMS. At this stage, what is the objective of treatment? Other than DMDs, what assistance can be offered? What do you tell the patient?</li> <li>What is the role of work in individuals with SPMS?</li> <li>MS nurses need to improve their skills to manage patients with SPMS; should be part of a network and should be able to deal with problems, e.g., incontinence</li> <li>Patients with SPMS and carers need financial advice on coping if unable to work. In France, nurses help with employment issues and advise on workplace conditions</li> <li>All patients are different and need individual support. Honesty is important to gain trust – disabled patients often get lost in the healthcare system. Patients need advice on issues such as wheelchairs and end-of-life issues</li> </ul>

DMD = disease-modifying drug; IFNβ-1a = interferon beta-1a; IM = intramuscular; MS = multiple sclerosis; RRMS = relapsing-remitting MS; SPMS = secondary progressive MS.

**Table 5: Overview of Poster Presentations at the Evolving Role of Multiple Sclerosis Nurse Meeting (Athens)**

Author/Study Title/Institution or Location	Objectives	Methods	Findings	Conclusions/Recommendations
<b>Telephone Surveys and Questionnaires</b> Hartung et al., MS-NEED Study Hartung HP, Ross AP and MS-NEED Study Group led by the European MS Platform (EMSP)	Understand role of MS nurses in Europe, raise awareness of roles, identify best practice, promote need for services to people with MS, identify areas where nurse roles can be expanded	Telephone survey of 280 specialist MS nurses in six countries: Czech Republic, Finland, Germany, Italy, Poland, UK	MS nurses have wide-ranging roles. >50 % advise on psychiatric support, medication health and wellbeing, 50 % advise on symptom management, but only 5 % advise on employment, legal or insurance matters. 59 % help patients gain access to new treatments. Many MS nurses' roles go beyond traditional responsibilities	MS nurses regularly take a lead in medication management but think standards of care are not always maintained. There are disparities in nursing practice between countries. MS nursing should be recognised as a speciality. To avoid inconsistent care, knowledge should be shared and best practice established. There is a need for a European consensus framework to define roles and responsibilities
Lavier et al., University Hospital Centre Besancon, France <sup>41</sup>	Integrate TE in MS and evaluate impact	Neurologists and nurses took TE training. Methods applied during clinical trial visits. Evaluated by anonymous patient survey	in MS care throughout Europe 80 % responded to survey, 100 % satisfied appreciated warm reception and listening by nurses. Integrating an educational process to clinical trial visits is necessary	Patients benefit from regular follow-up that includes good listening and discussion
Moberg et al., Danish MS Treatment Centre, Copenhagen, Denmark <sup>42</sup>	Brochure assessment of response to a relapse given to patients. Questionnaire given to patients to assess if information is relevant and helpful	Brochure given to c. 400 patients in MS clinic. Brochures/questionnaires ask basic questions around the relapse and methods to treat it	Received 30 questionnaires – next step: write the brochure and prepare new questionnaire and revise brochure (due to finish 2013)	Full results and conclusions will be available soon
<b>Drug Administration</b> Liban et al., Lorraine MS Treatment Network (LORSEP) Nancy University Regional Hospital, Nancy, France <sup>43</sup>	Standardise methylprednisolone bolus administration in home settings	Patient monitored for AEs and other issues for 18 months, 374 patients received 894 bolus doses	No difficulty in 80 % of cases, technical problems reported in 20 % cases. 94 % satisfaction level with management, equipment etc. Side effects in 181/374 patients included red spots, tiredness, headaches, nausea, insomnia, agitation	Coordinated management of bolus administration in the home ensures safety and protection. Nurses appreciate monitoring structure and recognition of professional status
<b>Measures to Increase Treatment Adherence</b> Assand, St George Hospital, Achrafieh, Lebanon <sup>44</sup>	Ensure adherence to treatment without compromising QoL. Provide individualised patient support and education	Primary role: to make patients take injections, secondary role: educate and support patients and carers to live well with MS	10 guidelines: think positively, eat well, move body, keep brain sharp, relax, maintain healthy weight, participate in social life, control MS, ask for help, focus on sleep	When supported/educated, many patients regained normal life, many gained independence, motivation to follow sleep treatment, and exercise and became more involved in social activity
<b>Informing the Patient of a Multiple Sclerosis Diagnosis</b> Debouverie et al., Lorraine MS Treatment Network (LORSEP) Nancy University Regional Hospital, Nancy, France <sup>45</sup>	Document manner in which patients are informed of their MS diagnosis in the Lorraine MS Management Network	Patients told of diagnosis over 24-year period. Conducted semi-directive interviews on aspects of learning about MS diagnosis involving 10 neurologists, 8 nurses and 41 patients (83 % female)	Participants unanimous that the time of diagnosis marked the starting point of relationship with doctor. Progress of treatment acceptance, disease and adherence to treatment are dependent on way information is conveyed	Strong points: early diagnosis, two consultations, documentary information, patients enabled to make note of questions, patients can repeat questions with nurses. Points for improvement: more time needed, more information at regular intervals, continuity of treatment, explanations of tests and exams, regular meetings with a nurse and/or psychologist

**Table 5 Continued: Overview of Poster Presentations at the Evolving Role of Multiple Sclerosis Nurse Meeting (Athens)**

Author/Study Title/Institution or Location	Objectives	Methods	Findings	Conclusions/Recommendations
<b>Patient Meetings and Telephone Support</b> Bocwinska, Cracow University Hospital, Cracow, Poland <sup>46</sup>	To better support MS patients and provide activities by arranging patient meetings	Local patient meetings assess needs and encourage contact with peers	Neurologists, ophthalmologists, psychologists and dieticians attend. Yoga and other activities offered and involved one-to-one meetings with various HCPS	Patients rated meetings as 9–10 (on a scale of 1–10). Patients enjoy and look forward to meetings and are diligent about attending
Berfein and Zolotaryov, Barzilai Medical Center, Askelon, Israel <sup>47</sup>	Achieve 100% compliance by providing telephone support to improve quality of treatment. Twelve patients interviewed, mean period of 6.13 years within the clinic from a population of 250–300 patients with MS	Provided a schedule of planned telephone calls to support and aid understanding of doctor's explanations and inform on new treatments, support groups and activities	Of 12 patients, the importance of telephone support was graded high by eight and moderate by four. As a factor in encouraging patients to stay with the clinic, 12/12 patients rated it as high	Supporting patients with regular telephone calls is likely to aid adherence to treatment
<b>Case Report-based Studies</b> Iakob et al., Emergency County & University Hospitals Bucharest, Romania <sup>48</sup>	Assess the support received by a patient receiving DMDs in MS – case report	Patient had symptoms for nine years, experienced relapses (gait instability while receiving IFNβ-1b)	AEs included arthralgias, and flu-like symptoms (treated with standard pain relief). Also had ISRs which resolved. Patient said he "didn't feel better" with IFNβ-1b but told that goal was to decrease relapse rates and severity	Patient functional with little change in status and able to work but has occasional headaches and gait instability
Toufexis, Cyprus Institute of Neurology, Nicosia, Cyprus <sup>49</sup>	Ensure safe swallowing (decrease choking risk/aspiration pneumonia) improve spasticity and pressure on sacral sores	Patient was assessed using a holistic approach and nursing plan for individualised care formulated	21-year old patient with RRMS for seven years with ataxia, spasticity, decreased vision, tremor and unable to expectorate with associated choking episodes. Nasogastric tube, enteral feeding, oxygen, nebuliser therapy provided and suction performed	Patient improved and was discharged. Patient and carers given instruction on safe swallowing pressure area care and limb positioning. Good rapport between HCPS, patient and family, and good support improved confidence of patient and family, improved QoL and outcome
Harris, University of Calgary, Alberta, Canada. OPTIMUS programme <sup>50</sup>	Provide tips for success in MS patient care when working in a multidisciplinary team	Rehabilitation team to maximise patient functional ability, control, improve QoL, improve disease knowledge and management	Example of a 28-year old MS patient who wanted to start a family – programme provided guidance on issues such as spasticity, bladder/bowel control, exercises and medications during pregnancy	Nurses should: understand their MS nursing role, consider perspectives of other HCPS, accept input from and respect all other team members, recognise that MS is complex – needing multidisciplinary approach. Effective teams should be unified and and communicate effectively

AEs = adverse events; DMD = disease modifying drug; HCPS = healthcare providers; IFNβ = interferon beta; ISR = injection site reaction; MS = multiple sclerosis; QoL = quality of life; RRMS = relapsing-remitting MS; TE = therapeutic education.



changes to patient management because ensuring compliance with oral therapy requires a different approach to that for injectable therapies. Greater numbers of patients, financial constraints and restricted access to medical expertise in remote areas increases the need for new types of support. In addition, changing care practices, technology and increased patient autonomy drive the need for a new paradigm in MS care. In Canada, face-to-face meetings can be difficult to arrange, owing to factors such as the distance to travel. Communication patterns are changing due to increased patient autonomy, expectations, access to information, shared decision making and differing outcome goals. Multiple sclerosis treatment centres are at the forefront of this change in healthcare communication trends and can almost be seen as victims of their own success. Owing to their specialised knowledge, multidisciplinary teams and access to trials and treatments, they have become too busy and therefore a new paradigm is needed for enhanced patient support. To provide increased patient support it has been shown that telephone support programmes for people with MS can be highly effective, especially for remote locations.<sup>33</sup> In addition to this, algorithms have been developed that help to identify patients at risk of early discontinuation of therapy and needing support.<sup>34</sup> The introduction of online resources has been shown to be valuable for people with MS helping with reassurance and coping with MS therapy.<sup>35</sup> Web-based portals for self-monitoring symptoms, ordering medications and receiving updates and disease information are popular with people with MS<sup>36</sup> and use of self-care tools such as 'My Toolbox' (a chronic disease self-management programme) are also valuable for patient support.<sup>37</sup>

## What are the Opportunities for the Role of the Multiple Sclerosis Nurse to Evolve?

### Expanding Clinical and Compliance Aspects (Kaye Hooper, Brisbane, Australia)

The example of an MS clinic within a tertiary university hospital in Queensland, Australia was presented, with more than 1,000 people with MS attending the clinic. MS nurses' activities within the clinic include clinical management, patient care and mentoring, referrals and professional development. Multiple sclerosis nurses operate an 'Easy Call' phone service for patient enquiries and raising concerns, and are responsible for knowing how to handle and interpret problems from patients often very remote from the clinic. They also provide expert advice, deal with triaging problems and discuss patient problems with neurologists. In summary, MS nurses need to be involved in patient education, clinical practice, patient support and advocacy. They are required to work in partnership and collaborate with other healthcare professionals and they must have current knowledge, expertise in MS symptom management and new MS treatments. Lastly, MS nurses need to establish successful networks with MS support organisations and societies, and be able to provide support materials and contribute to advisory boards.

### Increasing the Role of Patient Support and Psychosocial Care

#### (Emanuela Chiarini, Montichiari, Brescia, Italy)

The role of the MS nurse in Italy needs to evolve and is in a phase of substantial change. The MS nurses' role has several domains including: symptoms manager, patient and family advocate, MS team collaborator, counsellor and educator. Examples of their diverse roles include training in bladder control, self-catheterisation for symptom control and self-injection for patient therapy. In MS, the disease

evolves and the patient also needs to evolve as the illness progresses. Multiple sclerosis care lasts throughout the course of the disease and not just when relapses occur and therefore MS requires a system of comprehensive care that empowers the patient at all stages. Comprehensive care in MS is designed to address the medical, social, vocational, emotional and educational needs of patients and their families. The team approach facilitates co-ordination of services and continuity of care. Within this team, MS nurses are in a position to take a holistic view of the patient and their families and optimise their quality of life. This type of comprehensive care, however, is limited by cost cutting, poor appreciation by healthcare organisations and the separation/non-co-ordination of care facilities.

### Communication Skills for the Clinic – Tips and Hints (Catherine Hood, London, UK)

The ability to communicate effectively with patients is a key skill required by MS nurses. Good communication requires asking the patient questions to ascertain their level of understanding and to recognise patients' concerns and needs. When treating people with MS it is important to find out what the patient wants and accommodate that – the doctor/nurse-patient relationship is a lengthy one and should be a continued partnership. Decision making about MS treatment options should be shared with the patient and, because of this, it is essential to effectively communicate the differences, advantages and disadvantages of each therapy. Furthermore, it is important to remember that people with MS are all different and thus require different treatment and different levels and types of support. Because MS is a complex and variable disease, with the need for patients to make lifestyle changes and comply with long-term medication regimes, there are unique communication challenges. To overcome some of these challenges, a summary of helpful tips and hints for communicating in the clinic were presented and are summarised in *Table 3*.

### Feedback from Discussions of Two Multiple Sclerosis Case Examples

Two case studies discussed at the symposium emphasised the importance of good communication skills when treating people with MS. The first illustrated the challenge of dealing with a patient who reports that he is fine but, in reality, is in denial and doing badly. In this instance, it was agreed that communication is a key step in understanding the patient, determining their true disease status and addressing their problems, possibly with altered therapy. Another case example was of a patient who had been living with MS for a long time and who now has mobility problems after a bad relapse. In this case, it was agreed that the patient was likely to have SPMS and would need help with various matters including work problems, finances, wheelchairs, incontinence and end-of-life issues. Effective communication with the patient is essential to help maintain quality of life and support carers at this stage of the disease. An overview of these cases and consensus responses is given in *Table 4*.

### Summary of Conference Posters

A series of studies, conducted by participating nurse groups from various clinical centres, were presented as posters, mostly focusing on the substantial improvements that could be gained from greater communication with patients and providing enhanced support leading to better treatment adherence (see *Table 5*). The MS-NEED study was a large-scale telephone survey of 280 nurses from the Czech Republic, Finland, Germany, Italy, Poland and the UK that determined

the wide range of roles and responsibilities adopted by MS nurses and their importance in patient management (see *Figures 3 and 4*). Although this study highlighted the leading role that MS nurses take in patient management, some respondents felt that standards of care in MS are not well maintained at all treatment centres and that marked differences in practice exist between the countries included. The study also indicated the need for a consensus framework to define roles and responsibilities, to establish best practice and to ensure improved outcomes in MS across Europe.

## Conclusions

As novel MS therapies are introduced and new patient treatment strategies emerge, the role of the MS nurse is constantly evolving. They must be knowledgeable about advances in MS treatments and have expertise in the newest therapies for symptom management. Coupled with this, the role of the MS nurse now involves patient education, clinical practice, research and patient support, and advocacy. Multiple sclerosis nurses need to adopt a holistic approach and treat the entire

patient, not just one aspect of MS. In addition, it must be remembered that people with MS are all different and thus require different treatments and different levels and types of support. Advances such as the introduction of oral DMTs call for new patient management strategies to ensure patient compliance and, as the pivotal members of the team responsible for the treatment management of people with MS, nurses are often responsible for designing and/or managing these new strategies. Another key role of the MS nurse is that of educator. This role is rapidly evolving as the use of tools such as telephone support lines and online education programmes are introduced as part of support networks for people with MS. A key component of patient education and support is effective communication and it was recognised that MS nurses need to be skilled communicators, however, in general, there is limited training given for this important aspect of the job. Finally, an international consensus is required in MS nursing practice to provide a universally accepted definition of the role of the MS nurse, recognition of their skills and to provide better outcomes for people with MS receiving long-term care. ■

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