From Medical Prescription to Patient Compliance
A Qualitative Insight into the Neurologist–Patient Relationship in Multiple Sclerosis

Vincent Schlegel, MPH; Emmanuelle Leray, PhD

Background: Approximately 12 disease-modifying treatments are available worldwide for patients with relapsing multiple sclerosis (MS). These recent therapeutic advances have led to major changes in patient and neurologist attitudes toward drug prescription. Herein, we aimed to characterize patient choice regarding treatment for MS and identify how neurologists assess and monitor patient compliance during follow-up.

Methods: In 29 patients with MS, we observed visits to their neurologist to understand how questions related to compliance were addressed in the doctor–patient relationship. Face-to-face interviews were conducted with 15 of the 29 patients to discuss how they dealt with their drug prescription from a patient-centered perspective.

Results: Of the 15 patients with MS, nine were offered a choice of treatment. However, we found that neurologists were not always willing to consider the patients’ input. Even if physicians attempt to align treatment choice with patient preferences to ensure compliance, preferences are often assumed rather than solicited from patients. Furthermore, patients may be unwilling to make their own treatment decisions. Various ways for neurologists to assess compliance during visits were also identified. Noncompliance can be considered as a way for patients to communicate their preferences and demonstrate involvement in their drug therapy, and it can lead to a renegotiation of the current treatment course.

Conclusions: These findings suggest that the neurologist–patient relationship has a great influence on patient compliance throughout the MS disease course. Int J MS Care. 2018;20:279-286.
and doctors’ instructions regarding medical regimens, such as taking medications as indicated.\(^3\) Epidemiologic studies point out that 41% to 88% of patients with MS have trouble following their drug prescriptions,\(^4\) citing oversights, a perceived lack of efficacy, possible major adverse effects, and patients’ fear of needles as reasons why patients do not always comply with medications. As a result, new ways to enhance patient compliance have emerged, including educational programs or electronic autoinjectors to facilitate drug uptake.\(^5\)

Compliance has become a considerable focus of interest over the past few decades, not only for public health researchers but also for authorities. In terms of MS and other chronic diseases, poor compliance with medical regimens in developed countries is associated with high health risks (disease worsening, relapses, etc), and recent evaluations of the cost of noncompliance have drawn attention to this issue in public debates.\(^6\) The concept of compliance implies that patients should be passive and always follow their doctor’s instructions. In contrast, \textit{noncompliance} suggests that only patients should be blamed for not taking their medication. Thus, from a medical perspective, noncompliance is often defined as a form of deviance.\(^7,8\) However, studies have increasingly highlighted the influence of medical communication on patients’ behavior, particularly regarding compliance.\(^9\) This has brought about a semantic change wherein \textit{adherence} is intended to replace \textit{compliance} to place emphasis on the patient’s previous agreement. Furthermore, combining patients’ and health care workers’ expertise to reach a decision is more often depicted as \textit{concordance} between them,\(^10\) to insist on patients’ involvement in their care.

Although quantitative researchers are concerned with finding the best way of measuring patient compliance,\(^4\) social scientists insist on taking into account the patient experience to study personal medication practice.\(^11-13\) Adopting patients’ perspectives provides a way of avoiding a medical point of view that considers patients as exclusively passive.

In the present article, we aimed to characterize patient choice regarding treatment for MS from a patient-centered perspective and to identify how neurologists assess and monitor patient compliance during follow-up.

**Methods**

This qualitative study was conducted in Brittany, France. One of us (V.S.) made ethnographic observations during patients’ visits (n = 29; 20 women and 9 men) to their neurologist. The local MS expert center was selected because it has the largest active file of patients with MS in the region. Also, the department dedicates 1 day a week to provide multidisciplinary care to patients with MS, thus providing the opportunity to observe successive visits. In addition, we contacted neurologists’ private offices to enlarge the sample. Of the neurologists who were contacted and agreed to participate in the study, three worked in a public teaching hospital (19 visits overall) and two in the same private office (ten visits overall). No diagnosis consultations were observed. Consequently, most patients seen during visits were already taking a DMT for MS. Therefore, our assessment of patient involvement in drug choice occurred mainly when a change of medication was considered, either by the neurologist or following the patient’s request. During the visits, the observer documented observations with special attention to the discussion around treatment (how it was introduced, what suggestions the neurologist made, how the patient’s view was taken into account, what methods were used to assess drug compliance, etc) The observer did not interfere with the normal course of the doctor–patient interaction and was distinguishable from the health care providers by not wearing a white coat.

Semistructured in-depth face-to-face interviews were conducted with 15 patients (11 women and 4 men) (Table 1). These patients were recruited after being asked to participate in an interview at the end of their visit to the neurologist. Almost half of the participants agreed to participate in the second phase of the study (n = 12), and three additional patients agreed to an interview as a result of word of mouth. Informed consent was attained before conducting the interview. Participants were informed that the aim of the discussion was to understand their personal way of dealing with MS in relation to what their neurologist advised them to do and what they did on their own to manage the disease. Each participant was questioned regarding the prescription of a DMT as follows: “Have you been involved in your drug prescription? If yes, how and why did you choose this drug? How did you feel about choosing it?” All interviews were recorded and fully transcribed. Interviews were compared to create categories for analysis based on similarities and differences regarding specific topics of interest, such as the opportunity to choose the medication to be taken. These categories were then
Qualitative Study of Compliance in MS

Involving Patients or Not in Drug Prescription

When we (V.S. and E.L.) presented the study for the first time to one of the participating neurologists (man, private practice), he explained that he always “let[s] patients choose,” to encourage their adherence to the therapy and thus ensure that they would take their medication. All the patients seen in the hospital were offered the opportunity to attend a therapeutic patient education program, which in part is aimed at providing information about drugs. Of the 15 patients, nine reported that their neurologist had let them choose their treatment at least once throughout the course of the disease. Based on our interviews, this opportunity was offered at the moment of treatment initiation (n = 6), after a therapeutic pause (n = 1), and after a therapeutic failure (n = 1). The choice concerned only first-line treatments, except for one patient who had the opportunity to switch to a second-line treatment. This suggests that if neurologists consider the situation to be urgent for clinical reasons, patients are less likely to be involved in their drug prescription. For example, during one attended visit, a patient was prescribed a second-line treatment after she was found to have new brain lesions, whereas she had had the opportunity to choose her medication right after her diagnosis. In contrast, a stable clinical situation can also justify not taking patient preferences into account. An 18-year-old man who was willing to change his medication was denied that possibility by his neurologist who expressed her reluctance “to change something that works.” In other words, neurologists remain the sole judge in determining whether patient input in a given situation is possible.

Most patients were pleased to be involved in their treatment choice; however, some preferred to rely on their neurologist and did not want to play any part in the decision: “She allowed me the choice, which was really disturbing at that time, because when you know nothing, to choose between one drug or another, it’s not that obvious [...]. I told her: ‘I don’t want to choose because otherwise I’m going to choose according to personal considerations and not to treatment-related ones,’” said one 36-year-old woman. In this particular patient’s opinion, her medical condition should come before her personal preferences. A 40-year-old woman also explained that physicians have “to put their white coat on” when it comes to the prescription of a treatment. Both examples illustrate that patients would rather rely on their neurologist whom they trust to choose the “right” medication for them based on their medical expertise.

Table 1. Medical profiles of the 15 patients surveyed

<table>
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<tr>
<th>Patient</th>
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<th>Past DMT</th>
<th>Current DMT</th>
<th>Medical follow-up</th>
<th>Disease duration, y</th>
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Note: Aubagio (teriflunomide; Genzyme Corp, Cambridge, MA); Avonex (interferon beta-1a; Biogen Idec, Cambridge, MA); Beteferon (interferon beta-1b; Bayer Global Pharma AG, Berlin, Germany); Copaxone (glatiramer acetate; Teva Pharmaceutical Industries Ltd, North Wales, PA); Elsep (mitoxantrone, Mylan Medical SAS, Paris, France); Gilenya (fingolimod; Novartis, Basel, Switzerland); Reibf (interferon beta-1a; Merck Serono, Italy); Tecfidera (dimethyl fumarate; Biogen, Research Triangle Park, NC).

Abbreviation: DMT, disease-modifying therapy.
nurses: “Actually, he told me to choose which treatment I want. So I told him: ‘The least restrictive.’ Well, a weekly injection, I still had in mind to think the least possible about MS,” said a 25-year-old woman. “I didn’t want any side effects because I thought that if I had flulike symptoms during summer, people are going to say: ‘That’s weird!’” said a 33-year-old woman. Pills are mainly perceived as more convenient than injections. Indeed, for many patients, oral tablets are related to common situations such as headache. Some women even compared taking their pills for MS with taking oral contraception. However, their recent availability has led some patients not to choose oral tablets when they had the opportunity: “I excluded tablets because I considered that we lacked evidence [regarding their safety],” said one 36-year-old woman. Injections were often presented by neurologists during visits to be “safer” as they have been tested for almost 30 years, compared with pills, which have only recently become available. Neurologists play an important role in the way patients behave by delivering and framing all information concerning the medication’s characteristics (safety in particular). This could explain why some patients doubt the safety of pills.

Nonetheless, injections also created ambivalent feelings in patients’ minds. On the one hand, regular injections were more often mentally associated with the chronic disease and medical care: “I have the feeling that injections remind you that you’re sick. Injections, hospital, they remind you that you’re sick,” stated a 36-year-old woman. On the other hand, few patients considered that injections could be more effective than pills. A 45-year-old who switched from an oral medication to a thrice-weekly injection seemed to be reassured by injecting the drug directly rather than swallowing it. She assumed that an injection protected her better because it flowed through her body, and the occurrence of strong adverse effects was further proof of its efficiency: “What I inject into myself must be helping me, because I have horrible adverse effects.”

Professional Guidance

In some cases, a neurologist may choose a treatment based not only on medical considerations but also on what he or she assumed the patient’s preferences to be, without directly asking the patient. For example, a 45-year-old woman explained that her neurologist had proposed a single oral medication based on what she knew about her clinical condition, personal life, beliefs, and personality. In her opinion, her neurologist managed to “define” her personality thanks to the interview she led and the “psychological” dimension of medical practice. She interpreted her neurologist’s attempt to be as close as possible to her preferences, and she agreed with the neurologist’s reasoning that a working single mother should only have to take a pill twice a day: “She told me: ‘We won’t start with injections now, it would be too complicated with your lifestyle.’” This may lead some neurologists to create categories of patients with similar treatment profiles according to their sociodemographic characteristics based on their experience. For example, one of the five neurologists who participated in the study tended to prescribe the same treatment to patients with a particular sociological profile (ie, young, working, and/or with children). In his opinion, these characteristics meant that patients should not take a medication with a high frequency of injections to avoid affecting their private life or performance at work. Consequently, he would prefer to prescribe them an intra-muscular weekly injectable.

Nonetheless, patients’ preferences are not always what neurologists think they are. Regarding the earlier example, some patients preferred a medication with a higher frequency of injections and/or believed that was easier to take. This was the view of a 36-year-old woman who had experienced both weekly injections and daily injections and definitely preferred the latter, which was easier to take, even when her neurologist mentioned the future change of uptake frequency when switching from one injection a week to once every 2 weeks.

Management of Compliance During Visits

By management of compliance we mean the process by which a neurologist assesses the patient’s compliance during follow-up visits and makes a decision when noncompliance is identified. Patients were never directly asked about their compliance or adherence to treatment, but we identified two other ways for neurologists to assess compliance during patient visits: 1) looking for known causes of noncompliance and 2) verifying the presence of the expected effects of medication through complementary examinations.

Assessing Patient Compliance During Clinical Examination

To assess their patients’ compliance, neurologists investigated the known causes of noncompliance, such as tolerance, oversight, and tiredness with regimens.
Approximately one-third of patients were asked about how well they tolerated the drug. Neurologists also frequently asked about possible omissions and uptake consistency. A single omission is not regarded as noncompliance because it is seen as unintended. Neurologists try to identify situations in which oversights are a sign of entering into a more or less conscious process of noncompliance, at which point they are no longer classified as an oversight by the neurologist but as the patient becoming tired with the regimen. Although neurologists asked almost every patient about tolerance, there was a differentiation between the questions asked in relation to tablets and injections in terms of oversights and regimen fatigue. For example, neurologists were almost exclusively concerned about potential omissions when the patient was taking an oral medication, perhaps because it has to be taken every day and its convenience may trivialize the therapy. On the other hand, neurologists often assumed that injections created more fatigue or weariness in patients. During one visit, a neurologist asked her patient if she wanted to change her medication, switching from her daily injection to a daily tablet. The patient did not accept this change because she feared that she would forget to take her medication if it were in tablet form. Here, we can see that compliance can be used as an argument not only to modify a prescription but also to maintain it: the patient agreed that tablets might lead to more oversights, and injections were now so much a part of her daily routine that they no longer bothered her.

Although neurologists mainly focused on one of the aspects that could undermine compliance, patients mentioned interrelated factors that explained their attitudes. Two patients mentioned major adverse effects that had interfered with their daily lives. However, they both stressed not only the physical effects of taking long-term medication but also the weariness it generates. For example, after evoking the “disabling” adverse effects that occurred, a 35-year-old man explained his intermittent uptake this way: “I would say that it was psychological fatigue. It takes time; it is something constraining.”

Assessing Compliance Through Objective Criteria

Neurologists also assessed compliance by looking for the known effects of medications and considered their physiological effects using objective criteria such as magnetic resonance imaging (MRI) or blood tests. For example, “a good MRI” allows them to encourage adherence by showing patients that the disease has been brought under control by a DMT. Most DMTs also affect the immune system. A neurologist considered the decrease in white blood cells that showed up in her patient’s blood test as evidence that the drug was being taken properly. These clinical examinations brought new evidence to the attention of patients who might have doubted the usefulness of a medication or even the existence of MS. Some patients then adopted this medical discourse to explain that their drug is effective: “She told me that the MRI was rather good, since the disease is under control and that it was the expected effect of this new treatment which didn’t cure, but avoids relapses,” said a 29-year-old man.

Discussing Noncompliance with Neurologist

Patients’ decisions to discuss noncompliance with the neurologist are driven by their negative moral judgment of their own conduct and the desire to maintain a relationship of trust with the neurologist. In their mind, not asking their physician first is even worse. For example, a 46-year-old woman who had stopped taking her daily injection considered that she had misbehaved because she did not talk about it first with her neurologist: “What I did was wrong. I stopped taking my medicine on my own. I shouldn’t have. I should have asked Dr. [X] first.” The kind of judgments that patients express are dictated by what they imagine to be “good” or “bad” from a medical perspective, which undermines their own experience. This is further corroborated by a 40-year-old woman who explained that the existence of this sort of moral judgment, if it exists, would push her to take her injection as usual: “If there was nothing but that little voice inside my head saying ‘This is wrong’ [not taking her injection], I would have done it.”

In contrast, patients who reported following their prescription used terms close to submission to their neurologist: “I trust Dr. [X]. I do it. I’m obedient,” said a 25-year-old man. “I always follow exactly what they told me to do. A little sheep, as we said. I told you I fully trust doctors, this is a super important relationship,” said a 43-year-old man. On the one hand, complying with their physician’s advice seems the natural option for most patients. On the other hand, it illustrates the relationship of trust they have with their neurologist, or more generally toward modern medicine, and how it drives them to rely on their neurologist when needed. Patients have internalized the fact that they should obey physicians’ orders, even if it might negatively affect their...
quality of life, which leads them to express moral judgments on their own behavior if they do not comply.

**Dealing with Patient Noncompliance**

Depending on the result of the patient compliance assessment, a neurologist might need to intervene and make a decision if noncompliance is seen as problematic. Provided that the situation is not urgent, a physician may legitimize the patient’s behavior. In other words, he or she may authorize a noncompliant patient to stop taking the prescribed medication. This can happen when patients ask their neurologist if they can stop taking their drug for a short period. Neurologists may authorize it, particularly if the patient shows signs of fatigue with the medical regimen: “There were few times off [the medication] for the birth of my children. But every time, I asked Dr. [X] [...]. Meanwhile, I also start showing a little sign [of weariness] saying ‘I’m tired of the injections,'” said a 43-year-old man. However, requests for legitimation are not always granted by the neurologist. During a visit, a 33-year-old woman who had had trouble following her prescription in the past was refused permission by her doctor to leave the treatment at home during her forthcoming trip out of the country.

In some cases, no such request is made, and the legitimation comes after a patient has already decided not to follow his or her prescription. For example, one woman stopped taking her daily injection because she did not think it was useful in her own situation. She subsequently obtained agreement from her neurologist to definitively end her prescription.

**Discussion**

**Patients’ Involvement in Drug Prescription**

Because some DMTs have similar indications (especially among immunomodulatory first-line drugs), neurologists may allow patients to choose their own treatment within a preselected group. This practice is often described as shared decision making,14 as patients and health care providers agree on what they think the best treatment should be after expressing their personal preferences. In this article, however, rather than making comparisons with an existing model of the shared decision-making process, we identified strategies implemented by neurologists to consider or not consider patients’ preferences in their treatment decision.

Patient involvement seems to vary depending on clinical situations, the neurologists’ practice, and the patients’ social characteristics. When the choice is given by a neurologist, patients have to foresee how it will potentially affect their family life, their occupation, or their hobbies to make a decision. Patient choice is also governed by the quality and the quantity of information they receive from their neurologist, therapeutic patient education nurse, or any other health care practitioner. Being better informed about the disease and its treatment has been positively associated with patient adherence.15 Respecting patients’ preferences may also entail the neurologist not letting the patient choose their treatment if the patient does not wish to decide.

Several reasons can explain why patients are not always involved in treatment decisions. Patients may not be allowed to choose their treatment when the situation is seen as urgent or severe. Our observations showed that medical considerations still predominate over patient viewpoints regarding changes in medications (ie, if a patient wishes to make changes in their treatment course but there is no strong medical justification for this, the neurologist will not agree to this change). Involving patients in medical decisions seemed to be a major shift in medical practice and was appropriated differently according to the neurologist.

**Compliance and Patients’ Perceptions of Their Drug**

The present findings suggest that medicines are physical substances that can objectify diseases and turn them into something tangible. Thus, taking medication for MS reminds patients that they have it, especially if frequency of drug intake is high. Although tablets are commonly associated with benign situations in patients’ minds, self-injections symbolize a degree of medical expertise that patients did not require before diagnosis. Most patients were used to letting health care providers give them injections when needed. Van Der Geest et al.16 called this a metonymic association because medicines always include a degree of medical knowledge. Consequently, in patients’ minds, injections may also improve the drug’s symbolic efficiency.17 The mental association that patients make between DMTs and pills for benign situations may explain why neurologists are sometimes reluctant to replace an effective medication taken consistently with an oral one. From the neurologists’ perspective, there might also be reluctance about changing a patient’s medication for recently developed drugs because their efficacy in real life might be different from that in the clinical setting, whereas the long-term effects of other available drugs are known. The social and cul-
neurologists’ attitudes toward noncompliance. The present results show that a neurologist can allow his or her patients to cease taking their medication for a while. When a neurologist legitimizes noncompliant behavior, the initial prescription is often modified—at least verbally—so that the patient’s behavior and the neurologist’s instructions eventually converge. One could argue that once it is legitimized by a neurologist, it is no longer relevant to refer to the term noncompliance. However, with the concept of “legitimized noncompliance,” we want to stress two important things concerning the role of noncompliance in the course of a lifelong disease. First, in the case of the neurologist allowing a patient not to take their medication as previously advised, these “therapeutic pauses” are thought to prevent the advent of an undesirable event from both the patient’s and the neurologist’s perspective, especially long-term noncompliance. Second, when patients do not ask for permission, that is, when they do not comply in the first place, neurologists are constrained to change their instructions anyway. Legitimizing this kind of situation lends more importance to the patient’s experience. It reflects the fact that, through their behavior, patients can influence their neurologist’s care across the disease course.

These results also suggest the need to ask patients for their preferences throughout the disease course. In the frame of this study, giving patients an opportunity to freely express their opinions about their medication practices was a way of emphasizing the rationality of patients’ decisions, even if they may sometimes differ from that of neurologists’ decisions. This implies that patients’ noncompliance can be rational from the patient viewpoint and labeled as deviant by the neurologist.

We can assume that other strategies exist for neurologists to manage noncompliance, of which some could be very similar to those described by Luftey21 in her ethnographic study of diabetes clinics. Neurologists might try to supervise compliance by fostering patient motivation or making some adjustments (eg, prescribing tablets if patient compliance is considered to be problematic). Further studies should try to identify the various strategies neurologists are using to foster patient adherence during consultations.

Study Limitations

Several limitations to this study need to be addressed. First, in accordance with the study protocol, most patients seen during the observed visits were already taking a DMT. Therefore, patients’ views were discussed when a change of medication was considered necessary by the neurologist. Presentations of the pros and cons of each treatment were not systematic representations that patients have regarding the various modes of administration also have a considerable impact on their medication practice. Consequently, the representations that we captured in France may be different in other countries, depending on cultural, political, or social patterns.

Compliance seems to be taking on a growing importance for neurologists, and this study showed that compliance is commonly investigated indirectly during clinical visits via questions regarding the most common causes of noncompliance. The frequency of questions about tolerance during the visits shows the importance that neurologists give to adverse effects. It is, thus, the neurologist’s task to understand whether patient symptoms are just the expected effects of the drug or a sign of a safety problem. In contrast, if tolerance is good, the neurologist may try to encourage adherence that way, ie, creating or strengthening an informal agreement based on the convergence of the neurologist’s medical knowledge and the patient’s experience. From the patient’s viewpoint, adverse effects may also lead them to stop following their prescription if they feel that these effects are worsening their condition. Indeed, long-term medication use can inflict a sort of therapeutic violence on patients, but its psychological component is sometimes abandoned by neurologists who instead focus on the physical effects of the treatment. Nonetheless, patients highlight various reasons that extend beyond the occurrence of adverse effects to explain why they are not following their prescription consistently.

Neurologists’ Attitudes Toward Noncompliance

PRACTICE POINTS

- Neurologists have an important role to play in promoting drug adherence in patients with MS by considering patients’ preferences throughout the course of the disease.
- Because noncompliance is known to be the result of multiple interrelated factors, neurologists should make efforts to better understand and address these factors as opposed to assigning blame to patients.
At the patient's request, the neurologist and care manager can discuss the patient's medication practices with the patient. The reasons for this discussion include the need to improve medication adherence, to ensure that the patient understands the importance of taking medications as prescribed, and to provide the patient with the opportunity to express concerns or questions about their medication regimen.

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Conclusion
To summarize, this study observed that neurologists decide whether a patient can become involved in MS treatment decisions based not only on their appraisal of the patient’s medical condition but also on the patient’s social characteristics. However, the main interest of this study is to showcase that there are situations in which patient attitudes toward a prescription lead their neurologist to change it and that neurologists recognize patient preferences or expertise.

References

A NURSING STAR PASSES AWAY

The IOMSN is sad to announce the recent passing of Nicola “Nicki” Ward-Abel, RGN, BSc (Hons), MSCN. Nicki was a founding member of IOMSN via our UK affiliate and a founding member of the Multiple Sclerosis Nurses International Certification Board (MSNICB). She worked at Birmingham City University and Queen Elizabeth Hospital in Birmingham, UK, both as an MS clinician and as an educator and lecturer in MS. She had a special interest in the areas of sexual dysfunction, fatigue, and care of the person with progressive disease. She will be missed.