

Treatment Adherence and Satisfaction in Multiple Sclerosis Patients from Upper Egypt

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Abstract: Multiple sclerosis (MS) is one of the most common disabling autoimmune disorders of the central nervous system. It affects up to 2.22 million young and middle-aged adults worldwide, leading to disability and loss of productivity. Although there is no cure for MS, marked evolution has been made in the disease modifying treatments (DMTs) that can alter the disease course. With increased number of available DMTs of different mechanisms of action, the aim of treatment was shifted from just reducing relapse rates and slowing the progression to preventing any symptoms of new disease activity. However, non-adherence to DMTs is a major problem as in other chronic disorders, adding more to the morbidity, mortality, and health care costs related to multiple sclerosis. Therefore, particularly for populations with limited resources, early identification and management of factors leading to non-adherence to DMTs is a wise strategy that will be reflected on patients, their families and society.

Keywords: Multiple Sclerosis, disease modifying treatment, treatment adherence, treatment satisfaction

1. Introduction

Although Egypt was considered to be located in a low- to moderate-risk zone for MS based on the 2013 MS Atlas (1), the prevalence of MS in Egypt was estimated to be 25/100.000 population and continues to rise steeply (2). Patients can typically live with MS for 30 or 40 years (3,4) and in such developing country like Egypt particularly the South of it, MS would significantly affect the quality of life of patients and their families with marked economic consequences on the society (5). Despite the increasing landscape of available DMTs, non-adherence to the prescribed DMTs is a major obstacle that hinders the effect of the drug on the disease with consequent increased burden on individuals, caregivers, and society (6). This definitely creates an urge for interventions that early address and manage causes of non-adherence (7).

1) Increasing landscape of DMT utilization in Egypt:

After domination of the injectable DMTs such as interferon beta preparations and glatiramer acetate for over 15 years, with the introduction of oral immunomodulators fingolimod, teriflunomide, and dimethyl fumarate, and infusion DMTs like Ocrelizumab, patients with multiple sclerosis (PwMS) did not only benefit from a more convenient route of administration, but those treatments also introduced more potent therapy and novel modes of action (8, 9).

Globally, over the past ten years, prescriptions for highly effective DMTs may have increased in Europe, Australia, and North America. In the Middle East, a similar movement was seen, though it was less in size. This has varied greatly between the various nations, with Egypt, for example, seeing a slower rate of change than nations with higher income per capita (10).

2) Treatment adherence

Adherence to treatment has been defined by the World Health Organization as “the extent to which a person’s behavior—taking medication, following a diet, and/or executing lifestyle changes—corresponds with agreed recommendations from a healthcare provider” (11,12). Also, according to WHO, adherence to long-term therapy for chronic illnesses is only around 50%. Consequently, non-adherence will result in poor treatment outcomes, greater long-term disease sequelae, and increased health care costs (11).

Despite the proved benefits of DMTs use among MS patients, the rates of adherence to DMT among MS patients are often variable and in some cases are quite low. Special issues regarding non-adherence in PwMS are associated with consequences on person, caregivers, and society (13–15). Patients with MS require long-term treatment, without possible treatment holidays to prevent MS relapses or disease progression. When patients do not adhere to their prescribed treatment, relapse rates, rates of hospitalization, disability with risk of disease progression will increase putting more load on the healthcare resources with higher costs of DMTs for progressive course (13–15).

Non-adherence can be either Intentional or unintentional. Intentional non-adherence is an active process as it involves the patients making a decision to stop taking their prescribed therapy. It is driven by patients’ subjective perceptions concerning their treatment, disease and prognosis, as well as their objective experiences with their medications, perceived efficacy concerns. Unintentional non-adherence is a passive process – patients fail to adhere to prescribing instructions through forgetfulness, carelessness or circumstances out of their control. As such, both intentional and unintentional non-adherence may potentially be addressed by patient education and better communication between patients and their healthcare workers (16).

On the other hand, adherence can be difficult to assess, as health care providers tend to overestimate the levels of patient adherence, and patients often self-report their adherence inaccurately—either because of poor understanding of their treatment requirements or to conceal their conscious non-adherence. So, it is very important to assess adherence with objective measures (16).

3) Treatment satisfaction:

Although Medications' efficacy and safety are the main focus of the physician when choosing the proper DMT in this era of increasing DMT options, other patient-related factors such as patients' satisfaction and experience with received treatment may affect adherence and the treatment outcomes. WHO categorized the barriers to adherence into five broad domains: social and economic factors, health care team and system-related factors, disease-related factors, therapy-related factors, and patient-related factors. Given that patient-related factors (e.g., concepts) are often the most amenable to change, this should be targeted through educational programs and during the follow-up visits (16).

The low rate of medication adherence among MS patients has been closely linked to the treatment satisfaction that is best described by the Treatment satisfaction questionnaire for medications (TSQM)(17). This is an established generic instrument where four blocks of questions describe the individual's perceptions of the treatment's effectiveness, tolerance, convenience, and overall satisfaction. The effectiveness of the drug's treatment was evaluated in terms of the patient's impression of the drug's overall effectiveness. The drug's tolerability was evaluated based on its negative side effects and convenience was evaluated by the ease of use, storage, and transferability of the medication (for example, for use during trips). The general level of treatment satisfaction was evaluated in terms of the good and bad aspects of one's quality of life since beginning to get that particular DMT. Several studies have shown that adherent patients usually report greater satisfaction scores with their received medications compared to the non-adherent group (17–20).

Patient's expectations, such as an apparent lack of efficacy, is a frequently cited obstacle to adherence that could result in dangerous choices that prioritize short-term benefit above long-term effects (21). In order to create realistic goals for relapse prevention or handicap reduction rather than a cure, it is crucial to understand what patients expect from a particular treatment and the risks of not taking DMTs. Additionally, it is crucial to use complementary therapies to target troublesome symptoms including exhaustion, stiffness, pain, and bowel/bladder malfunction and to provide activities to enhance cognitive performance (21).

On the other hand, convenience and side effect profile are important aspects where inconvenient modes, needle phobia, schedules of administration, long periods of therapy, and significant side effects are important causes for dissatisfaction with a certain treatment(22).A significant association was found between non-adherence and using an injectable DMT in several studies (23–27). A study by Turner et al., specifically examined the injection anxiety as a

predictor of non-adherence, finding that the only determinant non-adherence at any follow-up was the injection anxiety even among sustained users of DMT (23).

In contrast, those patients on oral drugs have the highest adherence (22). Better adherence to oral drugs could be explained by the easier administration and the absence of injection-related issues (25). Becker et al. (28) noted that most MS patients would choose oral over injectable treatments. Also, the requirement for injections may reduce patient adherence (29). Besides the side effect profile associated with injectable DMTs, they are typically used as first-line therapies for MS, and fingolimod as a second-line therapy was associated with improved clinical and radiographic outcomes therefore greater patient satisfaction (29).

A study by Calkwood et al., investigated the switch from injectable DMTs to fingolimod, although no absolute TSQM values were reported, however, patients switched to oral therapy improved on the effectiveness scale depending on the original injectable DMT by 12–18 points, on the side effects scale by 9–31 points and on the convenience scale by 38–44 points. Therefore, it is recommended to use TSQM as a tool to screen for patients who may become non-adherent due to unsatisfactory components of their medication (30).

4) Measures to improve treatment satisfaction and adherence:

Given the finite resources of the health system, and the substantial cost burden imposed by MS, on patients, caregivers and the health care system, improved treatment adherence may be one of the best strategies for managing MS (31). Currently over 15 DMTs are approved for MS with different efficacy and safety profiles. Deciding which DMT to use in a specific patient requires a careful analysis of a patient's disease course for high-risk factors for early progression, consideration of the efficacy and safety profile for potential therapy, as well as understanding of a patient's lifestyle and expectations. The integration of these factors is necessary for the treatment optimization of patients with MS which is by far more important than any improvement in specific medical treatments (32).

More importantly, since the current therapies are disease-modifying, not curative, shared treatment decision is crucial to maintain adherence required to optimize the clinical outcomes. To participate in the DMT decision-making process, patients need to have adequate understanding of both their disease and the benefits/risks of treatments. Consequently, will encourage treatment adherence and improve patient satisfaction (33).

2. Conclusion

Without improving patient adherence, the evolution that took place in diagnostic and therapeutic strategies will go without value. Therefore, a good specialist and patient communications with informed shared decision on the DMT of choice that fits both efficacy and safety as well as convenience will definitely make the patient more willing to adhere to the prescribed DMT. Regular follow-up of patients to objectively screen for non-adherence and non-

satisfaction well help early catch and management of suboptimal treatment responses

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