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# Optimizing treatment initiation: Effects of a patient education program about fingolimod treatment on knowledge, self-efficacy and patient satisfaction

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ABSTRACT

*Background:* Satisfaction with information on medication is linked to adherence, but patients are often dissatisfied with information about medication. Information about treatment with fingolimod is important for MS patients since an active role in managing treatment is required from them. To facilitate optimal treatment initiation, a nurse-led patient education program on fingolimod was implemented in a Swiss MS center.
*Objective:* To evaluate the impact of the evidence-based comprehensive patient education program on knowledge, self-efficacy and patient satisfaction.
*Methods:* Knowledge gain, subjective perception of being informed about the new treatment, self-efficacy in handling it and satisfaction with the program were evaluated in a pretest–posttest design. Patient reported outcomes were collected before and after an educational session on the first-dose day at the MS Center in a consecutive sample of 98 people with MS. Data was analyzed descriptively, score comparisons were done by Wilcoxon tests, and associations were estimated with Spearman's correlation coefficient.
*Results:* Knowledge increased significantly from pre- to posttest. Similarly, perception of being informed and self-efficacy increased significantly. Satisfaction with the program was high. Pretest-differences in knowledge concerning gender and marital status were balanced after the educational session. Results did not differ between patients with fingolimod as first treatment and those switching from other MS treatments. At posttest perception of being informed and self-efficacy were significantly related to satisfaction.
*Conclusions:* An evidence-based comprehensive treatment education program is suitable to satisfy MS patients' information needs at treatment initiation. It enhances short-term treatment knowledge and self-efficacy in handling a new treatment in daily life. MS Nurses can thus contribute to effective treatment education and potentially to medication safety and adherence.

## 1. Introduction

Providing knowledge on medication is one of the cornerstones of patient education and self-management programs for patients with chronic conditions (Holman and Lorig, 2004; Lorig, 2001). However, information on medication is often considered insufficient by patients, whether provided in a hospital setting, by the family physician, the specialist, or the pharmacist (Barber et al., 2004; Borgsteede et al., 2011; Dickinson and Raynor, 2003; Luethi, 2012; van Geffen et al., 2011). Patients are particularly dissatisfied with information on potential medication-related problems (Auyeung et al., 2011; Mahler et al., 2012). In a qualitative study by Modig et al. (2012), frail elderly were comfortable with information when they trusted the physician or the information they received. They felt comfortable with information when they were satisfied with the information about their medicines and felt in control of them. Trust and confidence made them feel safe with their medication. In contrast, they felt insecure with

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information when they distrusted the health care system or drugs in general. Insecurity was also felt when information was poor and when healthcare professionals demonstrated little availability. In general, medication safety is increased when patients are well-informed about their treatments (Coulter, 2011). Satisfaction with information about medication and better physician-communication are linked to better adherence (Horne et al., 2001; Zolnierek and Dimatteo, 2009). In two systematic reviews some evidence was found that educational activities combined with behavioral support or counseling can enhance medication adherence (Ryan et al., 2014; Viswanathan et al., 2012).

In MS, treatment knowledge has played an important role since more than 20 years, when injectable beta-interferons (IFN) and Glatirameracetat (GA) were introduced. In a life-long chronic and potentially debilitating disease, treatments that can reduce the burden of disease or slow the disease to any extent seem highly valuable. A survey of needs among Swiss people with MS showed that information about treatments and the results of latest research ranked among the top five needs (Egger et al., 2012).

During more than a decade, specially trained MS nurses have instructed people with MS how to apply injectable treatments and how to cope with side-effects. They became an important source of information for treatment-related issues. In 2010 fingolimod, the first oral MS treatment was registered (Kappos et al., 2010). Fingolimod and other new MS treatments have highly specific modes of action and are complex in management. They have multiple facets like concerns about efficacy, safety, tolerability, monitoring etc. With the new oral drugs, patients are more independent from health care professionals on the one hand; on the other hand they have to take a more active role in treatment management, especially with regard to monitoring safety-issues. Given this development, providing treatment knowledge becomes a prominent feature in MS patient education.

To satisfy patients' need for information at treatment initiation, a nurse-led evidence-based patient education program on fingolimod treatment was developed at the MS Center of University Hospital Basel, Switzerland, and was provided to all patients starting on fingolimod. Aims are to provide basic knowledge about fingolimod treatment that is applicable in daily life, combined with sufficient self-efficacy in handling all treatment aspects. Optimal treatment initiation is intended, fostering trust into the new medication and a feeling of safety with it. At the same time vigilant attention to potential side-effects and limitations in effectiveness are to be conveyed. Clarification of misconceptions, often resulting from internet searches and discussions with other people, is a further objective.

### *1.1. The patient education program*

The education program is based on an "information talk" delivered by a nurse on the day of the first dose during the six hours cardiac safety monitoring.

The information talk comprises six main topics about fingolimod, titled in every-day language:

- How it works (efficacy and mode of action)
- How to take it (all aspects of administration, pauses and non-adherence)
- How to store it and how to travel with it
- How to get it (pharmacy, costs and insurance)
- Potential side-effects and how to understand the patient information leaflet
- Safety issues, risks and their prevention, monitoring over time

The content is written on text cards which are complemented by picture cards. Pictures and cartoons underline the spoken words to make those easier to understand and memorize. At the end of the talk, four pocket "memory cards" are handed over to the patient, showing the essential key points that should be kept in mind, reinforced by a manufacturer's booklet.

The session takes approximately 60 min for treatment-experienced patients, or 90 min for newly-diagnosed patients. Significant others are welcome. Though much information is delivered, the nurse aims at creating a dialog, in which the patient has a significant part of the talking time and expresses his/her considerations, questions and concerns about the new treatment. Emotions or coping themes coming up during the talk are given first priority, as factual information can hardly be absorbed then. The talk is tailored to the patients' needs. For example, discussion of side-effects is reduced if patients do not want to know about it to avoid negative influence on their attitude towards treatment. The information talk is at the same time a standardized and an individualized program.

The program was developed by a master-prepared nurse (first author), and was delivered by her and two other MS Nurses. To ensure know-how and consistency of information-giving, regular educational training had extended over a period of about six months. Intervention fidelity was assured by half-yearly mutual observations during an information talk according to a quality-standard.

### *1.2. Study objectives*

Using a one-group pretest–posttest design, we aimed to evaluate the effects of the information talk on knowledge gain, the patients' perception of being informed about their new treatment, their current certainty and future confidence in being able to handle all treatment aspects and their satisfaction with the information talk.

## 2. Materials and methods

### *2.1. Subjects and setting*

The day starting on fingolimod at the MS center, patients gave written consent for the study. Eligible participants had to start fingolimod at the center, had to be at least 18 years old and to speak sufficient German for understanding the patient information. Patients with moderate to severe cognitive deficits were excluded.

### *2.2. Data collection*

The informed consent process, as well as distribution and collection of questionnaires, was done by a nurse investigator, whereas an MS-Nurse performed the information talk. The roles were separated to reduce response bias resulting from dependency.

### *2.3. Outcome measures*

Outcomes to be tested were knowledge gain on fingolimod treatment, three self-assessment ratings and satisfaction with the information talk. The three self-assessment ratings were participants' subjective perception of being informed about the new treatment ("information") and two self-efficacy ratings: their current certainty of being able to handle all treatment aspects ("certainty") and their confidence in being able to handle all treatment aspects in future ("confidence"). Self-efficacy is defined as "people's judgments of their capabilities to organize and execute courses of action to attain designated types of performances"