Journal of the Neurological Sciences 335 (2013) 1–4

Contents lists available at ScienceDirect

Journal of the Neurological Sciences

journal homepage: www.elsevier.com/locate/jns

A patient's perspective of partnership in the treatment of multiple sclerosis: MS regimes—An orchestrated approach

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ARTICLE INFO

Article history:
Received 7 April 2012
Received in revised form 23 July 2013
Accepted 20 August 2013
Available online 30 August 2013

Keywords:
Multiple sclerosis
Partnership
Doctor–patient relationship
Guidelines
Education
Disease-modifying drugs
Adherence
MS-Society

ABSTRACT

Having been an MS patient for over 15 years, I will give you a short picture of what I expect from my doctors with regard to an equilibrated doctor–patient-relationship. Though such partnership also involves soft components like “My doctor's understanding of my personal situation” as well as “His understanding of my personality”, this speech is limited to the hard components “Consideration of my individual course of disease” as well as “Provision of information and thereby educating me comprehensively”. Also, I will point to some important legal aspects of such partnership and finally will give you some thoughts about some kind of “public partnership” in the internet.

Consideration of individual course of disease: The doctor's choice of an appropriate treatment based on a careful and sound analysis and evaluation of the patient's personal individual course of disease may be impaired by strict compliance with guidelines. While guidelines may be helpful to ensure a broad high-level patient-centered care, they bear the risk that patients are treated according to standard programs just for the doctor to be on the safe side.

Education of the patient: I will explain how I would like to be educated by my doctor in a perfect world. I will then elaborate that a comprehensive patient education may prevent loss of confidence as well as allegations like biased attitude of doctors, and may also positively influence cost pressure and adherence to treatments.

Legal aspects of partnership: It is a physician's legal duty to educate his patients comprehensively. The right of the patients to be educated derives from their right of self-determination, which in turn arises directly from the patients' human dignity and personal rights.

Forums and Medical Councils of MS-Societies: Internet communities do not seem to be too happy with their MS-Societies and experts. Statements of MS-Societies or their Medical Councils on hot topics have sometimes been slow. Via the forums, MS-Societies may get an idea of the questions and problems MS patients have. They could inform the Medical Council accordingly, so that reactions regarding new developments or surprising trial results do not take too long.

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0022-510X/$ – see front matter
http://dx.doi.org/10.1016/j.jns.2013.08.025

1. Introduction and overview

1.1. Introduction

I must say that it is quite impressive to see the concerted worldwide MS knowledge here in front of me, so, to be honest, I think this is one of the few occasions where I am quite happy that I am already seated.

Let me first introduce myself: my name is Antoinette von Pückler, I am 42 years old, I am a lawyer and I live in Frankfurt/Germany. I was diagnosed with MS in 1995. During the first years, I had some not so severe relapses, while at the latest around the year 2000, my MS turned to be progressive.

1.2. Overview

When I was first thinking about a partnership between doctor and patient, I was thinking about my relationship with my two favorite doctors and what makes the difference between them and my relationship with other doctors. There are in fact several factors. The ones on the “soft side” are:

- an understanding of my personal situation,
- an understanding of my personality,

while, on the “hard side”, there are

- consideration of my individual course of disease,
- provision of information and thereby educating me comprehensively.

All these components are integral parts of a partnership between doctor and patient, so this is quite a huge field. I will first give you a quick example of an experience regarding the “soft components”, but will then rather limit this speech to the “hard components”.

Afterwards, I will give you some thoughts about the legal aspects of such partnership as well as some kind of “public partnership” regarding the forums in the internet and the Medical Councils of MS-Societies.

2. Consideration of personal situation

I will now start with an example where the personal situation of the patient was completely disregarded. You will imagine that a consideration of the patient's individual circumstances is somewhat crucial for any confidence building for a partnership.

A friend of mine had her first MS-event at the age of 41. She couldn't see clearly anymore and had a numb lip and cheek. She was divorced from her husband and had two children at the age of 9 and 12 years. Knowing from me how a first MS-event may look like, she organized for an MRI on a certain Wednesday afternoon, where lesions were found. She was then directly kept in the clinic and the doctors started an in-patient cortisone treatment the same evening, the first infusion taking place at 10 pm. Without any consideration that she had to organize for her children, where they could sleep, who could bring them to school, whether the father was free etc. etc. I think that it is obvious that it would have made no difference if the cortisone treatment had started the next morning, which, as you know, is even better for the body.

I could certainly tell you some more funny stories here (like the one that I was once nearly kicked out of a trial because I planned a trip to India), however, the soft components are very individual and I only have 20 min, so I will turn straight to the hard facts.

3. Consideration of individual course of disease

3.1. Key issue: the guidelines

First of all, what I really expect from my doctor is that he reviews and analyzes my personal individual course of disease in detail. Based on such careful review, we can sort out which treatment may be appropriate for me.

However, there is one thing that makes such individual review and a decision-making based on it quite difficult, which is: Compliance with Guidelines.

Of course, with so much research worldwide and several drugs available, it is certainly helpful for a general neurologist somewhere in the field to have some guidance. Therefore, Guidelines are certainly needed to ensure a broad high-level patient-centered care.

But they also bear the huge risk that doctors treat their patients according to standard programs just to be on the safe side, without any fantasy and courage for the individual condition. This may leave little room for personalized medicine and partnership.

3.2. Future guidelines

What I would add to future Guidelines are therefore two additional issues:

Firstly, they should clearly address the general limitations of Guidelines: They do not release the physician from his duty of careful evaluation of each single case, and it may be required to deviate from Guidelines.

Secondly, the physician could receive some guidance on how to educate the patient, as well as a framework for some reading material for the patients.

4. Education of the patient

Let me now turn to the key-point of the partnership between physician and patient which is the education of the patient. Only an educated patient is able to really discuss and jointly take decisions with you, including bearing the responsibility for such decisions.

I will limit this issue to the education with regard to treatments, even though Christoph Heesen and his group have impressively shown that education and decision-sharing starts at a far earlier point in time: When doing the diagnostic tests [1].

Unfortunately, I never felt sufficiently educated by my doctors.