ADAPTING THE PATIENT PARTNER PROGRAM TO AXIAL SPONDYLOARTHRITIS: THE JOURNEY OF BELGIAN PATIENTS TO BECOME EXPERT TEACHERS IN RHEUMATOLOGY.

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Background:

Patients with axial spondyloarthritis (axSpA) were trained to deliver experience-based workshops to medical students, general practitioners, physiotherapists and other healthcare providers concerning axSpA. The most important aims of these workshops are to improve the early diagnosis and to increase awareness of axSpA in the medical sector. Taking an expert role as a patient however requires an extensive training.

Objectives:

To describe the training program in detail and to illustrate both the less successful and the optimal implementation steps taken thus far

Methods:

In its first iteration, the training program was developed as a resource book including a curriculum, significant amounts of homework, without enough time for practical exercises. This resulted in a drop-out of a large portion of trainees. Thereafter, the training method has been adapted by copying successful parts of the approach of The Patient Partner ® Program for Rheumatoid Arthritis (launched in 1999). Also, more concrete training opportunities via a DVD demonstrating the complete course and training materials, as well as offering hands-on trainings during a three day overnight stay were added. Besides creating opportunities for intensive practicing with each other, there was also more time for informal contacts and it allowed for proper group dynamics. So there is a lot of time for sharing among patients with a similar health background. A comfortable environment was created for the candidates, enabling them to go through a complete process and giving them sufficient time to train all the components of the program

Results:

On February 22nd 2018, five fresh SpA-patients started the training, all five of them successfully completed the training on June 2nd 2018. On a first evening of familiarization, trainers tried to know more about the motivation of the trainees, while in an individual interview a rheumatologist reassured that the candidates have the correct diagnosis, as their story should be consistent. The selected candidates received part 1 of the training manual by mail and they were invited to profoundly study the terminology and the anatomy, related to their disease.
During the first full day of the training, the trainers took time to explain this terminology and anatomy. Later on this constituted the building blocks of the course. The trainers closed this first day demonstrating the history taking and they asked the trainees to study at home their personal medical file.
On day 2, the homework of the previous day was first discussed, followed by related exercises. Day 2 finished with the demonstration of the clinical examination.
The training program was completed with three days with overnight stay. During these days a lot of practical exercises of the clinical examination were organized, followed by a discussion of the impact of the disease and

the importance of active participation. The program ended with a general rehearsal and a written as well as an oral test to evaluate how each trainee had assimilated all this

Conclusion:

In the training program PPP SpA, the trainees learn to tell a uniform and academically correct story. This contains an accurate history taking and a correct clinical examination reinforced by the personal history of the Patient Partner. Moreover the whole process helps each Patient Partner to have a better insight in their own illness, a better capacity to cope and to develop more skills in the dialogue with medical practitioners. The experienced positive feedback of the trainees after every course is the best motivation to continue with this approach