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89 – Making Sense of Chronic Disease

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The number of people with chronic disease is increasing due to longer lifespan under better conditions and improved capacity for prevention and treatment of many life-threatening diseases. A chronic disease always induces changes in a person's life and might result in negative effects on quality of life and well-being. From a socio-economic point of view and from the doctor's perspective, there is a lot of knowledge about chronic diseases. But how do patients perceive life with a chronic disease? Patients do not always perceive themselves as ill when diagnosed (1). Patients have various ways of coping with a chronic disease. Can we as family doctors (FDs) contribute to a more successful coping process?

We performed a qualitative study based on analysis of audiotaped consultations initiated by two key questions. The patients had a variety of chronic diseases. Twenty women and seven men seeing their FD (the first author, their FD) in family practice were included. The key questions dealt with the feeling of mastering life with a chronic disease (2).

To have a feeling of control was important for our patients (3). Developing a personal explanatory illness model appeared necessary to gain control. Our patients created inner images of their illnesses by combining the perception of symptoms with the information provided by their doctor.

If the explanation from the doctor did not coincide with the perceived symptoms, it caused a lot of anxiety and distress. Emotions played an important part in the coping process (4).

Visualizing the disease could be helpful in improving understanding. A patient with chronic lower back pain was for example, shown a plastic spine and then said that she understood the anatomy and cause of the pain. Another patient saw the inside of her knee during arthroscopy and then fully understood her symptoms.

The future and issues related to treatment were of the utmost importance to our participants. We usually emphasize that the prognosis is important. Giving the condition a name was equally important, because how can the doctors treat a disease that they cannot even name? Naming the disease was also important for the participants when talking to friends and family about the disease.

For two of our patients the disease was an advantage in their new life. A younger father with a heart problem could be at home and take care of his son when he returned from school. An elderly woman with post-polio syndrome was glad that she could stay at home and read a lot of books, her favourite occupation. Her sons tried to persuade her to go for a daily walk.

The participants explained why it is important that the doctor listens to the patient. A young man with epilepsy wanted to tell the doctor his experiences about the associations between stress and attacks, but the doctor was more interested in the

concentration of anti-epileptic drugs in the blood tests. The young man was disappointed, and the doctor might thereby have missed some important information.

Cultural differences in illness perception were also observed. A young Turkish woman with pain in her joints and muscles did not understand that the word “rheumatism” as the term used by Turkish doctors did not have the same meaning in our country (5).

The key question design, triggering off the responses we have systematized in our project, is implemented in the context of clinical practice. It can be used as a clinical strategy for prompting a new dialogue, or - as in this study - as a research tool providing access to knowledge from patients on specific issues. The theoretical and methodological foundation of this design has previously been presented and discussed (6).

The key question procedure does give access to the full truth, but provides a partial and temporary insight into a specific domain – in this case about what could make a difference for patients with chronic diseases. We wanted to describe how patients experienced life with a chronic disease. Compared to a traditional interview study, the key question design holds a special potential for clinical validity, since the study context is similar to the situation where the findings are to be applied.

What this study adds to previous knowledge

As FDs we can explore patients’ resources by focusing on what the disease means to the patient. According to Antonovsky, people hold different levels of General Resistance Resources (7). As doctors we can explore these. Our findings demonstrate how making sense of a chronic disease is a complex process, not just a matter of talent.

Kleinman and Aujoulat emphasized the therapeutic effect of illness narratives (8). To appreciate the patient’s experience and be able to help, the doctor must witness a life story to validate its interpretation and to affirm its value for the patient.

Take-home messages

- Behind every patient with a chronic disease we find an unique person.
- To clarify the patients' explanatory illness model is important.

Original abstract

<http://www.woncaeurope.org/content/bf103-making-sense-chronic-illness>

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