

European Life Sciences Circle Event: Patient Empowerment – a New Paradigm in Disease Management?

Tuesday 2 March 2010

European Parliament

EFA speaker, Lina Buzermaniene

The event was hosted by MEP Jorgo Chatzimarkakis from the Alliance for Liberals and Democrats for Europe (ALDE), founder of the ELSC and member of the European Parliament Committee on Industry, Research and Energy (ITRE).

The purpose of the event was to highlight how empowering patients with chronic diseases can lead to a better medical outcomes, while decreasing the costs of health care.

Psychologist Ad Kaptein talked about **patient empowerment in healthcare management**. He took the examples of studies on self management of patients with cancer, asthma and COPD and came into the conclusion that it leads to better outcome. He also insisted on the importance of nursing care. He spoke of the necessity to understand that patients go through different stages, and of the importance to take those stages into account to help them in managing their disease. He concluded that empowered patients are the ideal patients for physicians as they ask questions and their treatments tend to work better.

Next speakers were health professionals who presented **forms of self-management**. Professor C. Klonoff and Dr Stephan Martin presented the example of diabetes. They spoke about the self monitoring blood glucose method as an example on empowerment through monitoring, vital information and control on your disease. Nowadays patients with diabetes tend to suffer from less complications than in the 1980s, thanks to better information on their diseases.

It was followed by a discussion on the practical and economic aspects of patient empowerment.

Diabetes patient Mike Meyhoff talked about his **own experience as a patient**. After being diagnosed with diabetes in 2004, he participated to a German practical implementation study which encouraged persons with type 2 diabetes to become more active in 2008. This programme provided him with guidance, and support through telephone calls as well as self monitoring, and encouraged him to change his lifestyle for example by practising sport. As a result his quality of life was greatly improved.

Dr Stephanie Stock, health economist, presented the result of a study by AOK which showed that German self management programmes, which work through evidence-based guidelines and medical education, lead to lower mortality rates. She noted that patient have to a central role to play in the management of their disease.

Jim Furniss, Director of Global Market Access Strategy, presented the ROSSO study which comes to the same conclusion on a positive effect on the **costs-benefit of patient empowerment**.

The last round of discussion was about “the effect of patient empowerment on the therapy outcomes in kidney disease and chronic respiratory disease anagement chaired by MEP Miroslav Mikolasik.

EFA Board Member and President of the Lithuanian Council of Asthma Clubs Lina Buzermaniene spoke about **learning to live with chronic respiratory diseases**. She presented EFA, and then showed some patients perspectives about living with these diseases. She demonstrated the need for a continuous education of the patients, through peer groups, and a partnership relationship between patients and doctors or nurses and presented EFA’s project “Learn to live with asthma“ as a possible model of educational tool for all chronic diseases. She concluded that patients have a right to understandable information and continuous support, to adhere to their therapy and have a better quality of life.

Psychologist Ad. A Kaptein spoke a second time, now about **patient empowerment in the treatment of asthma and kidney disease**. He presented medical psychology, the psychology of being correctly healed. He said that psychological state of a patient as consequence on lengthy and frequent hospitalizations, and heavy medication is important to take into consideration. He noted that self-management is mostly about the way patients “cope” with their disease, as they have their own perception of their disease. He advocated for a culture of listening to patients and insisted on the importance of taking into account patient stories.

Final speaker was Dr Per Ake Zillen, who spoke about his **experience as a kidney disease patient**. He first talked about the relationship between patients and doctors. Indeed doctors have the power of medical expertise, their professional integrity and a decision making capacity, but patients come with their own expertise and integrity. So through exchange, the relationship should be that of mutual empowerment. He noted that patients shouldn’t expect everything to come from the carers. He took his own example, as he was suffering from kidney cancer and lost an important percentage of his kidney functions. He asked for alternatives to waiting for dialyses, and through a treatment with medication and a special diet, he managed to keep the minimal function necessary for a transplant. He said that patient need to be provided with educational programmes that help them to learn about their diseases as well as motivate them and teach them about healthy behavior.

The Speakers handed **recommendations on patient empowerment** to MEP J. Chatzimarkakis. They recommended to:

- Establish patient empowerment and self-management of chronic diseases as a priority of the new Commission in its work program and all new EU health policy activities,
- Ensure EU-wide structured care models for chronic diseases that include educational programs to enable patients to take responsibility and manage their condition,
- Ensure that core models and recommendations for Health Technology Assessments currently developed at EU level follow predictable, common criteria and methodologies which take into account the actual patient-self-management activity in the investigated treatment procedure.

Sources:

ELSC conference: European life science circle: Patient Empowerment – a New Paradigm in Disease Management? On Tuesday 2 March 2010.

Program of the event:

http://www.gowebdesign.be/elsc2/images/programme_ELSC.pdf

And booklet of the event.