

Psychological aspects of living with rare disease: development of psychological skills of rare disease patients. how to improve patients` quality of life by developing psychological skills necessary to cope with the disease.



Authors: Jolanta Wierzba^{1,4}, Joanna Jaglowska¹, Emilia Galosz-Suszk², Ewa Witalis³

1. Medical University of Gdansk, Department of Hematology, Oncology and Endocrinology Poland

2. Psychotherapy, coaching – Emilia Galosz- Suszka

3. Nutricia Poland

4. Medical University of Gdansk, Department of General Nursing

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Abstract:

Basing on the example of psycho-education project for phenylketonuria patients (PKU) and caretakers in Pomerania region (Poland), general conclusion can be drawn, that for the improvement of patients well-being not only medical care, but also psychological knowledge and skills are very important. Some psychological skills are crucial to cope efficiently with the disease and they should be trained to patients and caretakers.

The project of psycho-education for PKU patients and caretakers in Pomerania includes workshops designed specially for 3 target groups:

1. Parents of small children with PKU (age 0-3)
2. Teenagers with PKU (age 14-18)
3. Young women with PKU (age 18-25)

Each of these groups has specific needs concerning psychological skills, which depend on the group`s age and stage of life:

Parents of small children: building psychical strength and developing new attitudes.

Teenagers: getting ready for independent life.

Young women: preparing to be a mother.

To cope efficiently with the disease all patients and caretakers need both:

- a) basic medical information about the disease and its treatment
- b) basic psychological information about the mechanisms connected with the disease and psychological skills necessary to cope with it.



Most of the support projects usually concentrate on medical aspects of PKU, the treatment and the diet. But for the improvement of patients well-being the psychological aspects are also very important. That is why the workshops include both: short medical education module psycho-education workshop, aiming to deliver basic knowledge and training skills, such as: self-motivation, self-discipline, self-reliance, resistance to stress, optimism, communication skills etc. Although there are some psychological skills specific for different groups of patients and caretakers, the above mentioned skills are quite universal and can be helpful for many rare disease patients and caretakers.

Summary:

For the improvement of patients well-being, psychological knowledge and skills are very important. The project of psycho-education for PKU patients and caretakers in Pomerania region is an example of an effective psychological support. It includes both: basic medical education and psycho-education workshops. Different groups of patients have different psychological needs, but some of the skills, such as: self-motivation, self-discipline, self-reliance, resistance to stress or communication skills, are helpful for all rare disease patients or caretakers. It is very important to give patients and caretakers the opportunity to learn these skills.

