

POSTER PRESENTATION

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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

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Based on the example of psycho-education project for PKU (Phenylketonuria), patients and carers in Pomerania region (Poland), could draw general conclusion: 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 patients and carers should be trained.

The project of psycho-education for PKU patients and carers in Pomerania includes workshops designed especially 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:

1. Parents of small children: building psychical strength and developing new attitudes.
2. Teenagers: getting ready for independent life.
3. Young women: preparing to be a mother.

To cope efficiently with the disease all patients and carers 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, psychological aspects are also very important. That is why the workshops include both:

- short medical education module
- psycho-education workshop, aiming at delivering 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 carers, the above mentioned skills are quite universal and can be helpful for many rare disease patients and carers.

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