

RARE DISEASES IN THE SLOVAK REPUBLIC
EUROPLAN NATIONAL CONFERENCE

PSYCHOLOGICAL ASPECTS OF PATIENTS AND THEIR FAMILIES
SUFFERING FROM A RARE DISEASE*Prevendárová J.*Comenius University in Bratislava, Faculty of education,
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Severe chronic disease always negatively impacts the psyche of the patient, regardless what organs or organ systems are affected. There are several factors contributing to mental health and serenity, e.g.: quality of health care, social and economic support, personality predisposition of the patient, their partnership, family and wider society relations. Shedding of friendly relations and leisure activities, as well as problems in the partnership are the most serious factors that produce frustration, anger, low self-esteem or even a sense of futility. These emotions, along with pain and fear of disease and fear from the future in many cases eventually lead to depression. Therefore we consider it necessary to pay attention not only to the physical condition of the patient with a rare disease, but also to their psyche; in the broader context of partnership and parenthood. In case of a pediatric patient comfort and serenity of parents has a strongly harmonizing effect on the physical and mental condition of the child. The article deals in detail with the symptoms of distress of the patient and his family, and finally defines the goals of psychological counseling and therapy, including family therapy as a whole.

Keywords: *rare disease – patient's psyche – adaptation difficulties – family problems – psychological counselling*

It is known that rare diseases (hereafter only RD) comprise a very heterogenic group of diseases. In connection with the title of the lecture, it is only natural to ask, what these diseases have in common at the psychological level. The psychological impact of a disease is much bigger if the problems in the health, social and economic sphere further complicate the personal and relationship problems in partnership and family. Six key areas connected with patient's mental state were identified.

These are:

1. Health care problems

Correct diagnosis and commencement of adequate treatment are in case of an RD often preceded by several years' period during which patients demand attention of the medical staff. Often they are treated for a completely different disease or ignored – considered malingers. Of course, this is connected with the state of current scientific knowledge as well as with the general state of health care system. Patients and their families are stressed by the uncertainty which is connected with the hesitation, procrastination, and experts' mistakes, not mentioning the fact that in the case of rare diseases, it is extremely difficult to find the right specialist.

2. Social and economic support problems

What is meant by this are the problems caused by employers, social services and overall state support. Economic handicap of patients stems from their reduced working ability and sometimes total inability to work.

In the context of the lack of health care and insufficient social and economic support, patients must deal with negative emotions of fear, anger, mental fatigue, frustration, blame and self-blame, low self-esteem and often with feelings of futility.

3. Impaired family conditions

Mental discomfort is to a great extent connected with relationship and family problems and follows from the insufficient support from patient's relatives. It is most marked if the disease is unrecognized (undiagnosed) for a long period of time. It has almost become a rule that after some time family members stop to believe patients' complaints and they stigmatize them as hypochondriacs.

Burdening of family members is a reciprocal problem – the longer they are burdened with the care, the longer more unpleasantly the patient feels.

In the context of insufficient support from parents and other relatives, the above-mentioned emotions of fear, anger, and frustration are further accompanied by sorrow, feeling of guilt, helplessness, and hopelessness.

4. Problem with dwindling friendships and leisure activities

Disappointment, feeling of social isolation and uselessness which can result in depression are characteristic of patient's predicament.

5. Impairment in partnership and sexuality

Long-term health impairment in an adult patient often brings problems in the area of partnership and sexuality. Some of these diseases directly affect the sexual functions and fertility; in other cases, the sexual malfunction will appear secondarily as a consequence of the feelings of guilt and shame – especially if the disease affects patient's outer appearance (skin lesions, etc.). Pain, insomnia and chronic fatigue leading to apathy surely do not contribute to a happy partnership. Therefore, in many aggravated conditions only few partnerships will hold up.

6. Elevated mental vulnerability

Mental problems do not concern only patients with psychiatric diagnosis. The circumstances accompanying an RD always bring mental vulnerability and stress also in premorbidly strong, stable and composed people. The more significant and long-term the physical problems are (particularly if not properly treated), the more

the mental discomfort leading to severe states of depression with potential suicidal tendencies deepens.

Physical and mental states of a patient are interconnected. Mental discomfort is mainly connected with fatigue and pain, which are some of many RD symptoms. Furthermore, there are many limitations, and rules concerning the regime (adherence to dietary measures and a specified, limiting and monotonous daily regime). As regards RDs with phasic course, although short-term relief, joy, and hope occur in the remission phase, the following attack of the disease brings despair, hopelessness, and aggravation not only of person's physical, but also mental condition.

Factors contributing to mental coping with a disease

1. **Accessible and quality health care** leading to alleviation or elimination of the symptoms of an RD secondarily influences the psyche and provides hope and relief.
2. **Symptoms, development, and prognosis of a disease:** Relatively mild course of the disease, but mainly good prognosis are usually decisive factors which influence mental composure of the patient and his family.
3. **Personal predispositions:** In this connection, it is possible to consider resilience as a patient's ability to withstand or regenerate after a severe disease, adapt to constantly changing conditions, and prosper despite impeding circumstances (Slaninová, 2008). The ability to constructively react to challenges is very individual and it is connected for example with patients' value-orientation, their interests, attitude to themselves and to other people, and with the type of their nature. The sanguine type of a person characterized by power, composure, and higher nervous activity processes (as opposed to the choleric or melancholic type) has probably better precondition to cope with the pressure brought by the disease.
4. **Family factor:** If the family is compact, flexible (reacting to changes and challenges flexibly), open to outsiders, and capable of accepting help to alleviate the burden of responsibility, it contributes to the composure and support of the patient. The effort to maintain certain family customs regarding holidays, leisure time, etc. is also important. Positive factors also include allocation of tasks among individual members of the family with regard to their personal abilities, but in such way that none of them would be extremely overburdened (this concerns mainly mothers taking care of a sick child).
5. **Spirituality:** Patients confronted with the predicament brought by a rare, chronic and often also life-threatening disease often search for consolation in spirituality. It is known that people finding refuge in God, religion or some other form of spirituality complain less and take suffering as a part of life. They try not to see the disease as a burden and focus more on searching for its meaning and understanding where all its limitations lead (Frankl, 2012). To see the disease as a challenge means to find positive aspects in these limitations in form of healthier lifestyle, stronger feeling of joy from little successes, with hardening of the psyche due to surmounting of impediments etc.

Symptoms of mental discomfort in a sick child

- Children can suffer from isolation and the lack of social contacts, as well as from being ridiculed by their peers, as a result of which the self-perception in terms of underestimation or overestimation of one's abilities is changed. They can have problems with communication with the world as well as with the lack of social skills.
- In regular school, they lag behind and their performance is unstable. In case of missing school repeatedly, they may be considered lazy, bad or inattentive.
- They might come across as insecure and self-insufficient and they might require constant presence of an adult. Sometime these children start to behave as if much younger and let them be nursed, fed; they cuddle in arms, and require protection.... They also have fear reactions(to dark, new situations, doctors, e.g.)
- Frequent sight, hearing, movement, mental, and speaking skills impairments have far-reaching consequences on their perception, learning, social relationships, and social inclusion.

Symptoms of mental discomfort in parents of children with RD

- Parents experience mostly fear that the disease gets worse; naturally, they are concerned about medical intervention and pain felt by their child, and in case of a negative prognosis, they are afraid of lethal conclusion.
- Gradually, they are forced to adjust their expectations, visions, and hopes (for example regarding possibility of education, work, etc.); and to change their routine regime and family stereotypes.
- Parents (mainly mothers) often suffer from chronic fatigue and stress connected with daylong care; sometimes they suffer also from sleep deprivation, or sleep disorders.
- This can also disrupt their intimate married life and cause mutual estrangement.
- As long as parents have also another healthy child, they can suffer from feelings of guilt that they cannot devote themselves to it as much as to the sick one.
- Child's disease tests the mental immunity of parents, their organization skills, the strength of mutual family bonds, help from the social environment, as well as the ability to cope with extra expenses on treatment and rehabilitation.

Goals of psychopathological counselling, individual and family therapy

A) In adult patients

- Patients need psychological help when they experience the stages of inner chaos, fear, suffering, sorrow, hopelessness, etc. The goal is to relieve these states as much as possible, by means of either traditional psychotherapy or effective methods, so called energy psychology. In our therapeutic centre for emotional unloading, we use a method called EFT – Emotional Freedom Techniques.

B) In parents of sick children

- The primary goal is to enable parents to understand the new life situation, to deal with the tasks connected with child's disease effectively and to help them with adaptation to a particular situation.
- In case they are interested, it is appropriate to provide parents with a contact to self-help groups, and inform them about the right to particular social services and benefits.
- To provide family with the opportunity to overcome feelings of insecurity, fear, anger, despair, or hopelessness is another important goal; if necessary, also to handle disrupted family relationships and communication and to help clarify unsaid expectations, hidden blaming, unclear roles, etc.
- If necessary, to teach them to relax and make use of leisure activities, which are not many.
- To focus on the support of positive attitude where rejection of one's lot in life occurs. To search with parents for permanent values which can be fallen back on in the time of need. To support positive intentions, life goals, and perspectives of each family member.
- To analyze parental expectations and children's demands, and to help them to adapt education to each child's need, be it sick or healthy; and to support educational competence of parents.

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PSYCHOLOGICKÉ ASPEKTY PACIENTOV A ICH RODÍN POSTIHNUTÝCH ZRIEDKAVOU CHOROBOU

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Závažné chronické ochorenie má vždy negatívny dopad na psychiku pacienta, bez ohľadu na to, ktoré orgány alebo orgánové systémy postihuje. Činitele prispievajúce k psychickému zdraviu a vyrovnanosti sú viaceré: súvisia napríklad s kvalitou zdravotníckej starostlivosti, sociálnou a ekonomickou podporou, s osobnostnými predispozíciami pacienta, jeho vzťahmi v partnerstve, rodine a širšej societe. Ubúdanie priateľských vzťahov a záujmových aktivít, ako aj problémy v partnerstve sú najzávažnejšími faktormi vyvolávajúcimi frustráciu, hnev, pocit nízkej sebahodnoty až zbytočnosti. Tieto emócie spolu s bolesťou a strachom z ochorenia i z budúcnosti v nejednom prípade vedú napokon k depresii. Považujeme preto za nevyhnutné venovať pozornosť nielen fyzickému stavu pacienta so zriedkavou chorobou, ale aj jeho psychike a to v širšom kontexte partnerstva a rodičovstva. V prípade detského pacienta má pohoda a vyrovnanosť rodičov výrazne harmonizujúci vplyv na fyzickú aj duševnú kondíciu dieťaťa. V článku sa podrobne zaoberáme symptómami psychickej nepohody u pacienta a jeho rodiny a v závere definujeme ciele psychologického poradenstva a terapie, vrátane terapie rodiny ako celku.

Acta Fac. Pharm. Univ. Comen. 2013, Suppl VIII:55-60.