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Parents approach towards children suffering from long term disorders

The families in which there are children with long-term disorders generally experience greater amount of stress and hardship in relation to a child upbringing than those who have healthy children.

The way the family can cope with the stress depends mainly on such factors as; the way and circumstances the family found out about the child's illness, improvement prospects, experience of the specific health problems, including symptoms manifestation and their intensity, the level and the specifics of the children functioning, the existence of their needs, adaptation problems as well as the characteristics of the family members with their system of values and approaches [Maurer 1995].

My own research [Janion 2007] along with the academic text studies allows me to specify various approaches of parents towards their ill children.

A long term disorder especially if it concerns a child and it poses a threat to his/her development and functioning consequently puts the family stability out of balance, interfering with the sense of normality, which according to Sztumskiego [1996, p. 148-149] is, for most of people, a highly valued quality. To live your life normally is to live as others do around us, as people the cultural setting we share.

The disturbance of the normality of every day life causes that a person feels the sense of threat evoking undefined existentional anxiety. As a result of the child long-term disorder his/her family undergoes a great amount of negative emotions such as; the sense of threat, despair, helplessness, resignation and hopelessness.

In the process of adaptation these negative emotions should be replaced by a constructive response to the symptoms of the illness. For most of the families the projection of the adaptation to new situation is the sense of the normality being rebuilt. According to E. Góralczyk [1996, p. 51] this normality should be expressed by the inclusion of the illness into everyday life so that the struggle with the illness would become one of the 'normal' tasks to be carried out. It should be enhanced in everyday situations and activities, which makes the routine predictable.

Parents accept their ill child trying to achieve normality. They organize everyday life adopting the methods to fulfill all the child's needs, trying to make him or her as much independent as it is possible. Thus one of the possible approach parents can take is to get involved in the process of making their child independent.

In the academic texts the independence of the child with long-term disorder is perceived as one of the most important treatment and rehabilitation processes. Parents

are aware of this and attempt to make the child deal with different situations on their own and encourage them to overcome difficulties, which of course should be adequate to the child mental and physical abilities.

For the child who suffers from a long-term disorder the aspect of self health control and self treatment is very important [Maciarz 1998, p. 31-32]. The term health self control concerns the proceedings such as; unsupervised diet control, adequate physical activities intensity, avoidance of health risk situations as well as the awareness of appearing symptoms. Self treatment, on the other hand includes the skills such as; body temperature measurement, taking medications, adequate reaction to appearing symptoms.

According to E. Wielgosz [1995, p. 114] Parents of disabled children often make mistakes by underestimating or overestimating the abilities of a child independence development, where the first situation takes place more often than the second. For the parents it is much easier to encourage the child independence in the area of self-reliance, however, it is much harder for them to let the child experience independence as far as the decision making and self – control is concerned.

The opportunity to experience the independence by the child, which is often accompanied by a great sense of achievement, facilitates the child positive self-esteem, empowering him or her both mentally and emotionally and at the same time making the socialization process easier.

The other approach taken by the parents so as to achieve normality can be observed in parents who do not fully accept the illness of their child. They tend to look after their child reasonably well, however, they do not get involved emotionally in the process. In this case it is the approach orientated on care giving without emotional involvement.

Taking care of the child who suffers from a long-term disorder is definitely more difficult than looking after a healthy child, because it involves nursing. According to A. Maciarz [1998, p. 39] the most important proceedings as far as the child care is concerned is to give the child the access to specialist medical care and to follow the medical prescriptions, treatment and therapy, as well as to ensure adequate; diet, play, rest time, and education, paying particular attention to the child physical abilities. Permanent monitoring of the child well-being and helping him or her to cope with the illness by giving a mental support when in pain results in the child mental empowerment.

Parents who are not able to accept their child illness and whose presence is painful for them often experience great difficulties in carrying out duties mentioned above. Those parents cannot establish an emotional connection with their child,thus being unable to fulfill their child emotional needs. Due to the necessity of greater care some kind of mechanical adaptation takes place. In this way parents maintain the sense of parental duty and responsibility,however, they cut themselves from the child as a person, treating him or her as an object of the rehabilitation and therapeutic treatment. By doing so those parents tend to feel a sense of normality because they actually do what they should do. In some cases looking after the child takes a form of a ritual [Formański 1998, p. 342] which enables them to decrease an emotional tension. Those

rituals are characterized by a great degree of predictability thus giving parents a sense of security

Weaker emotional ties with parents make it harder for the child to overcome difficulties. It is particularly essential for the children who have to cope with severe disorders the treatment of which requires a long-term rehabilitation and hospitalization. Those children find it hard to get over with the hardship of treatment. They are often reluctant to medical therapies Their chances for recovery are likely to be smaller.

Generally speaking, The child who is ill holds an important place in his or her family. Sometimes this position becomes a central one when the child can focus all the attention of the parents and other members of the family [Wielgosz 1995, p. 411-412]. Parents are concerned about the deterioration of their child health therefore they become over-protective. They are not able to provide the child with care within the proper limits assigned to this process. In this way the child becomes a center of the family life and the problems of the other family members are marginalized, which includes other children who also need attention and care [Hertl 1995, p. 17; Hurlock 1985, t. II, p. 407]. The fact that some parents become over-protective in relation to their ill child is caused by one of the three factors or their combination. That is; the fear concerning the child, the sense of feeling guilty for the health condition of the child or the need for not seeing the illness [Hertl 1995, p. 19-20].

Too much attention on the child can take the form of giving her or him too much help and care, thus making the child greatly dependant on others.

The child who is dependant on parents it is a child who is under their parents influence. This is because parents believe that they are the only ones to fulfill the child's needs. Being focused on the child parents try to stand by him or her as much as they can, limiting the child contacts with peers. Such parents also believe that their child is only save while with family, otherwise he or she would not be able to face presumed dangers. Those parents often over –react in relation to different situations that may be harmful to their child's health and tend to act proactively ' just in case". As the parents want to recompensed their child's suffering they make attempts at meeting all the needs and wishes even if the child does not actually want it. By doing so those parents do not give the child enough time to express what he or she really wants and longs for [Góralczyk 1996, p. 19].

One symptom of the child being dependant on parents, especially on mother, is the existence of so called symbiotic love. The psychological definition of this term describes it as the love between mother and their child that makes two persons as one unity. The stage of symbiotic love is natural and necessary in every toddler's live giving the child a sense of security and the mother a great amount of reassurance. The health condition of the child may result in disability to break from the presence of such symbiotic relation [Obuchowska 1996, p. 32-33].

In this case the mother often becomes possessive in relation to her child, disabling his or her proper development. The appearance of the child will to become independent is perceived by the mother as an emotional isolation, for which she usually can not agree [Rathus 2004, p. 189].

At times the whole attention an energy of the other members of the family is focused not on the child but on his or her illness. This approach can be classified as the concentration on the child illness and its bio-medical aspects.

All the efforts from the family side are focused on the treatment and rehabilitation when the parents primarily attempt to concentrate on medical treatment and rehabilitation looking intensively for all the information available hoping to increase their knowledge and qualifications as far as the nursing and proper care is concerned. They often ask for second opinion of the specialists,searching for new treatment methods. The time which is spent at home with the child is spent on observations and the monitoring of the child's health condition, which becomes the main subject of the family conversations.

The strong concentration on the child's illness with all the dangers it brings about puts other matters aside. This situation very often leads to the phenomena in which the child becomes an object of care, consequently a great deal of difficulties in establishing an emotional contact between the parents and the child can be observed. Such parents do not focus their attention on the person but on the ongoing tasks [Binnebesel 2000, p. 54].

All not health related issues are often marginalized, where less presumably essential matters for example; emotional problems of the child related to his or her health problem are left behind. The child in this case is exposed to non health related problems for which his or her parents are reluctant to give any help. They also tend to avoid helping the child in the socialization process which may pose certain problems due to the child health condition. It is basically the role of a friend that is often omitted. In these circumstances parents make all the efforts to provide the child with proper environment for development. They believe that when the health condition improves there will be time to catch up with other areas of emotional development [Maciarz 1998].

Both parents and children do focus their attention on "now and here",which is often overwhelming because it is difficult to think and make plans about the child's future if the diagnosis are not optimistic. The state of anxiety they are in makes it impossible for them to set any objectives for the future, which usually concerns the whole family. " Everything seems to stop and waiting follows for something that may happen" [Góralczyk 1996, p. 22].

In this situation it is hard to build hope and it seems to be impossible to prepare constructively for the child to live his or her life with the illness.

The acceptation of the other person means undisputedly positive attitude towards this person. It sometimes happens that the acceptation of the child with disability is accompanied by a passive attitude of his or her parents, which results from their hopeless situation. The hopelessness derives from the fact that those parents tend to avoid making decisions or taking any actions while facing difficult problems. The reason for this is the failure to notice the correlation between the parents own activities and the ongoing changes in the surrounding reality [Strelau 2000, p. 596-598].

Passive attitude results from the fact that parents do not believe in the sense of the efforts undertaken. The hopeless person seems to lack motivation for further actions and does very little to set free from this complicated situation.

Among the parents who have children with a long- term disorders there are those" who accept the heath condition of their child without rebellion or aggression they are usually caring, though helpless in their efforts, thus very vulnerable to stress or a family break down "

J. Formański [1997, p. 343]. This kind of behavior can be characterized as the acceptance of the child's illness with a sense of hopelessness in the situation that came about.

The hopelessness of the parents accompanying the acceptation of the child causes that, in spite of all the positive attitude towards the child,great many areas of life is not properly organized and secured. A positive emotional atmosphere and relatively satisfactory emotional family ties between the child and the family members do not change the fact that many spheres of the child emotional life remains neglected. It concerns both health needs as well as educational and social functions.

Hopeless parents are not able to provide the child with all the necessary medical care neither they are able to proceed with the adequate treatment They are also not involved enough in the child educational process. It is often down to a low educational level of such parents who are simply unable to give the child any help as far as the education is concerned. They avoid meeting the child school teachers which is usually conditioned by the fact that they do not feel confident in the education related environment. Unfortunately this kind of social withdrawal is likely to bring negative effects where the child can be deprived of the proper social functioning.

In the families who experience hopelessness despite the full acceptation it can be observed that there are some families who lack this acceptation. According to Sękowskiej [1979], there are many factors that affects the lack of acceptation but the most important is the development disorders. Therefore a long –term somatic illness and its consequences may contribute to this situation. This is often present in the families with pathological background where difficult economical situation is accompanied by emotional indifference, alcoholism and violence. Parents of such families are not interested in their children at all. Not only that they make any efforts to develop their children educationally but they give their children a negative social pattern to follow. Basically in such families,we can say. There is no control over children at all.

The level of knowledge obtained by such parents if it comes to their child disorder is extremely low. They are not familiar with the medical prescriptions and the health hazards. They do not try to search for the information as it does not interest them. Those parents ignore the medical condition of their children as they are not concerned about general development of their children.

The lack of acceptance and loneliness often leads to some destructive consequences such as neurotic reactions, aggression, socialization problems, emotional disorders, and inability to build a permanent emotional relation. In this case the child often manifests hostility to the outside world, distrust and disobedience.

The outline of different parental attitudes in relation to their children with long-term medical disorders brings up the statement that in many cases the parents show the inability of maintaining proper contact with their children and finding themselves in a new situation, which results from their child illness. It seems to be essential to sup-

port them not only in the area of information, treatment, rehabilitation but also in the field of psych-pedagogical support which should include as follows:
- Full acceptation of the child,
- Proper assessment of the child abilities and limitations,
- Building adequate relation with the child, along with the proper communication,
- Crating good education attitudes,
- Elimination of defensive strategies (avoidance, rejection, resignation and aggression) in difficult situations,
- Predefining objectives and life goals for particular members of the family as well as for the family as a whole,including the realization process evaluation,
- Assistance in solving individual family problems.

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