



Parents' attitudes towards a difficult situation resulting from the chronic disease of their child

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Abstract

Introduction and objective. The family is a reliable and permanent source of support for every human being. It is the key link in the welfare system. The aim of the study is to assess parents' attitudes towards the occurrence of a difficult situation resulting from a child's chronic illness.

Material and methods. The study involved randomly selected parents of children with chronic diseases (N=107). The study was carried out at the Dental Clinic of the 'Little Prince' Children's Hospice in Lublin

Results. The study revealed that for parents a difficult life situation is mainly associated with the disability of a family member or a friend, whereas the action approach is the most frequently chosen attitude towards a child's chronic disease. In the examined group of parents, a significant correlation was observed between the age of the parents and the choice of a specific parental attitude towards the child's chronic disease (in terms of intellectual approach). However, no significant correlations were found between the parents' place of residence and the choice of a specific parental attitude towards the chronic disease of a child.

Conclusions. During the diagnosis of chronically ill children, parents should also be educated in this regard. Therapy and psychological help, as well as directing parents to relevant support groups, organizations or associations, will prove immensely valuable while coping with a difficult life situation.

Key words

children, parental attitudes, parents, chronic disease, paediatric patient, difficult situation

INTRODUCTION

The family is a reliable and permanent source of support for every human being. It is the key link in the welfare system [1]. The occurrence of a child's chronic disease or disability is one of the most serious problems that the family can encounter [2]. We can observe the different behaviors and attitudes of family members in such a situation towards a sick child whose physical and psychological pain, sometimes social isolation and loneliness or emotional discomfort, allow us to perceive a sick person as the main subject of care [3]. Diagnosis of a chronic disease causes family reorganization [4]. In order for a given disease to be classified as a chronic disease, it must meet the following criteria: it must have biological, psychological or cognitive base, and last at least one year. In addition, it must be the direct cause of one or more of the following consequences: limitation of daily functioning, including being active and fulfilling social roles in relation to the cognitive, physical, emotional or social development sphere; the need for medical, psychological and educational care, that is completely different from that addressed to healthy children [5]. Attention should be also drawn to the

periods of treatment that are the cause of the need to stay at home for a long period of time, and the occurrence of dependence on one of the restrictions arising from a given disease, such as: taking medications, using life or health support machines, a specialized diet or the need for constant care provided by other people [6].

T. Burish and L. Bradley compared acute diseases and chronic diseases, indicating four basic criteria that distinguish chronic disease from acute disease [7]. These criteria include:

- 1) Cause(s) of the disease.
- 2) Course of the disease. In the case of an acute disease, the symptoms and causes are easy to recognize and the condition is short-term with a predictable end; whereas a chronic disease develops slowly and it is difficult to predict how long it will last, and is characterized by a so-called 'silent phase of the disease' [8]. It is not possible to achieve full recovery from a chronic disease, and a rapid recurrence phase of the disease can often be observed immediately after the dormant phase [9]. Any therapeutic activities are aimed primarily at enabling the patient to function in the best possible way in everyday life, although it is worth stressing that it will never result in the full recovery of the individual.
- 3) The nature of the disease. In acute diseases, the patient is unable to recognize the symptoms and associate them with the cause; in chronic diseases, it is difficult to associate the cause with the symptoms until their full development.

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4) Consequences. In acute diseases, it is possible for the patient to recover fully after undergoing appropriate treatment [10]. Often, acute disease do not cause permanent changes in the patient's life. However, in the case of a chronic disease, dependence on medical procedures and treatment tends to continue until the end of a sick person's life, which affects the somatic, mental and social functioning of a person.

Chronic disease is recognized as a large stressor that affects the current situation of the child and the child's family. There are often also specific requirements and restrictions that must meet [5]. In this difficult situation, the family must go through a process of learning how to cope with this situation, referred to as adaptation. It is worth underlining that this process is not a passive adjustment to the existing requirements by changing behaviour, but is a creative reaction to the difficulties and threats that can be encountered [11]. These actions should result in a favourable assessment of the profits and losses incurred, which are associated with being affected by a chronic disease. The occurrence of chronic disease contributes to a number of changes in the life of each child [12]. Thus, the adaptation process is long and complex [13]. The specific requirements and experiences of a person has to significantly influence the subjective perception of the current situation. The patient, including a child, thus creates a vision of the new life situation, as well as the surrounding reality and problems that he or she experience in the perspective of his or her own health, and which have to be dealt with in everyday life [5, 14].

The knowledge that a child acquires is accumulated as an image, and then as a concept of him- or herself, the surrounding world and his or her own disease. A difficult situation occurs when there is an imbalance between the needs and tasks, as well as the methods and conditions for their implementation [15, 16]. The imbalance affects a normal situation in which the regular course of activities is disturbed and the probability of completing the task at a normal level is reduced. Disturbances in the matter of predictability of a given situation, which increase the likelihood of failure, describe the situation as difficult, and the entity needs to use additional resources to cope with it. Depending on the type and genesis of those disturbances, the following difficult situations are distinguished: deprivation, overload, impediment, and emergency situation.

In the family in which a child has a long-term health problem, there are certain behaviours that hinder the normal functioning of family relationships [17]. Referring to the concept that treats the family as a system, it should be mentioned that the family is not only the sum of its individual members [18]. First of all, relationships and interactions between family members are significant. The problems encountered by one family member can negatively affect not only that particular person, but also the whole family system, namely, other family members. It is therefore assumed that the child's illness affects the whole family. Many Polish studies have described problems of this type. One of them is the demanding attitude of children with chronic diseases, which is further strengthened by the behaviour of the parents [1].

For fear of a sick child, the parent requires "society" to adapt to the needs of the chronically ill child. When parents are misunderstood by society, they react with anger. Such

situations occur, for instance, in a school environment where a parent tries to influence the teacher in order to reduce educational requirements [4]. An overprotective attitude of parents is an important factor in the functioning of a family with a chronically ill child [19].

Although mothers bear the main burden of care for sick children, there are also cases in which only fathers look after the children. However, the experience of researchers indicates that a child's illness often leads to the divorce of the parents, and the fathers of sick children are often the initiators of such decisions.

Research conducted by W. Pilecka shows that the sense of self-efficacy among children with chronic diseases may develop more slowly. This is due to the parents' overprotective attitude that results in doing everything for the child, even those tasks which the child can perform on his or her own. Thus, the child is unable to prove him- or herself [13].

OBJECTIVE

The aim of the study was to analyze parental attitudes towards a difficult situation resulting from a child's chronic disease depending on such variables.

MATERIALS AND METHOD

The study was conducted at the Dental Clinic of the 'Little Prince' Children's Hospice in Lublin, during which only chronically treated patients were examined. Data was collected between December 2018 – March 2019. The scale Difficult Situations (PST2) by Maria Ryś et al. was used which consists of two subscales and contains 48 theorems. A database was created and statistical analyses were carried out on Statistica 9.1 computer software. (StatSoft, Poland). A random selection of parents (N = 107) with children with chronic diseases – allergy, asthma, backache, headache, chronic bronchitis, thyroid disease, neck pain, high blood pressure, gastric or duodenal ulcer, inflammation of the areas and bones, rheumatoid arthritis, diabetes mellitus, malignant neoplasm – who reported to the clinic during the surveyed period. All parents who came to the clinic and agreed to the examination within the months were examined. The research group was the group that reflected the number of chronically ill children admitted to the dental clinic over a given period of time, and were the basis for determining the needs of this group. In addition, the test results may indicate the direction of further research in the case of problems of families of chronically ill children.

Parents' participation in the study was anonymous, either the mother or father completed the questionnaire, and the person coordinating the study explained anything not fully understood in the instructions or questionnaire. Return of completed questionnaires was taken as confirmation of consent to participate in the study. The time to complete the survey was about 10–15 minutes. The study was carried out in two stages: Stage I – aimed at developing the concept of methodical work and preparation of research tools. The next step was obtaining the consent of the facility management to conduct tests. Stage II – consisted in conducting appropriate tests.

Statistical analysis. The study characteristics and research sample were developed based on the analysis of percentage distribution, frequencies of qualitative variables for quantitative variables, as well as descriptive statistics – the average, standard deviation, minimum and maximum values. Statistical correlations between the child's age and the selected stage were performed using the Pearson correlation coefficient (Pearson's *r*). Statistical analysis was performed using SPSS v. 21 software.

RESULTS

107 surveyed families took part in the study. The child's age in the study was 12.46 ± 7.91 years and the parent's age 39.69 ± 8.18 years. The results are presented in the Table 1.

Table 1. Age characteristics of the study group (N = 107)

Variable	Descriptive statistics					
	N	Average	Median	Minimum	Maximum	SD
Child's age	107	12.46	10.00	3.00	3.50	7.91
Parent's age	107	39.69	38.00	29.00	60.00	8.18

N – number of respondents/number of parents in the study group; SD – standard deviation

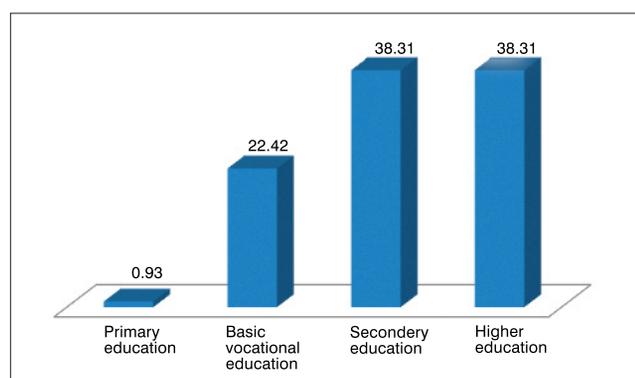


Figure 1. Difficult life situation in the opinion of respondents

Shaping parental attitudes is a long process that lasts for many years while raising a child. There are many significant factors in literature that influence their formation, including: the personality of the parents (value system, emotional sphere or self-image, life experiences, i.e. parental attitudes in their own families), level of education, type of work performed (as a potential source of stress or satisfaction), parent's gender, quality of marriage and mutual relations of the spouses, parents' attitude to their own parental role, the emotional character of the family and the type of the motives for having children or the lack of such motives, the course of pregnancy and childbirth, state of health of the child, parents' expectations regarding the child's characteristics, gender of the child, social network of support provided to the family (emotional, instrumental and information support), the presence of a person who is the authority for parents, the order of births of children in the family. Figure 1 presents the level of education of parents participating in the study. The level of parents' education and selected stage of the child's illness are presented in Table 2.

In the present study, the examined group of parents clearly defined what for them constitutes a difficult situation. According to respondents, a difficult life situation is definitely

Table 2. Parents' education and the selected stage of disease

Variable	Marked effects are significant at $p < 0.05$							
	SS Effect	df Effect	MS Effect	SS Error	df Error	MS Error	F	p
Shock stage	56.80	3	18.93	993.42	103	9.64	1.96	0.12
Waiting stage	41.58	3	13.86	1,193.17	103	11.58	1.19	0.31
Mourning stage	21.42	3	7.14	1,417.21	103	13.75	0.51	0.67
Proper def. beh. stage	9.10	3	3.03	410.89	103	3.98	0.76	0.51
Neurotic def. beh. stage	9.95	3	3.31	624.69	103	6.06	0.54	0.65
Adaptation stage	6.63	3	2.21	326.84	103	3.17	0.69	0.55
Intellectual approach	34.51	3	11.50	1078.68	103	10.47	1.09	0.35
Emotional Approach	23.60	3	7.86	1746.69	103	16.95	0.46	0.70
Action approach	18.16	3	6.05	1,298.74	103	12.60	0.48	0.69

the death of a family member or a friend – 9.34% of all respondents. Another situation causing a state of stress is someone else's illness – 0.93% of the total, followed by the illness of a family member or a friend – 1.86% of all respondents. Another difficult family situation indicated by the respondents was the disability of a family member or friend. This answer was given by all respondents, i.e. 107 people – 100% of the entire surveyed group. The respondents did not indicate their own disability as a difficult life situation.

The study group was asked to provide information on the difficult life situation in their family. For this purpose, six difficult family situations were identified. The results are presented in Table 3.

Table 3. Event categories perceived by the respondents as a difficult life situation

Type of event	Answers given	
	N	Percentage
Accident	1	0.93
Death of a family member or a friend	10	9.34
Someone else's illness	1	0.93
Illness of a family member or a friend	2	1.86
Disability of a family member or a friend	107	100

N – number of respondents/number of parents in the study group

The present study analyzed which type of actions was most often taken by the respondents. Out of 107 respondents, the action approach was the most common choice 34.02 ± 3.52 and the least was the neurotic defensive behavior stage 8.11 ± 2.44 . The results are presented in the Table 4.

The study also analyzed the relationship between the child's age and a given disease stage. The obtained results did not show significant statistical correlations between the child's age and the selected stage (Pearson's *r*). (Table 5.)

The results obtained in the current study did not show significant statistical correlations between the child's age and the approach (stage) acquired by the parent. However, a statistical difference was obtained between the parents' attitude in a difficult situation and the age of the parent in the intellectual approach, where a statistical difference of $p = 0.02$ was observed.

Table 4. Stage types and the chosen approach towards a chronic disease

	Stage type					
	N	Average	Median	Minimum	Maximum	SD
Shock stage	107	9.57	9.00	4.00	17.00	3.14
Waiting stage	107	11.04	11.00	5.00	18.00	3.41
Mourning stage	107	10.46	10.00	4.00	17.00	3.68
Defensive behaviour stage (proper behaviours)	107	18.00	18.00	10.00	20.00	1.99
Defensive behaviour stage (neurotic behaviours)	107	8.11	8.00	4.00	16.00	2.44
Adaptation stage	107	17.79	18.00	11.00	20.00	1.77
Intellectual approach	107	28.31	28.00	18.00	40.00	3.24
Emotional approach	107	29.15	29.00	16.00	40.00	4.08

N – number of respondents/number of parents in the study group; SD – standard deviation

Table 5. Relationship between the child's age and disease stage

	Average	SD
Child's age	12.46	7.91
Shock stage	9.57	3.14
Waiting stage	11.04	3.41
Mourning stage	10.46	3.68
Defensive behaviour stage (proper behaviours)	18.00	1.99
Defensive behaviour stage (neurotic behaviours)	8.11	2.44
Adaptation stage	17.79	1.77

SD – standard deviation

DISCUSSION

Parental attitudes constitute a long-term process in the aspect of raising a child, determines the attitude towards the child, determines the style of upbringing, and the selection and effectiveness of the educational methods. In order for the parent's behaviour towards a child to be defined as an attitude, one more condition must be met: the tendency towards such behaviour must be established and remain constant over a period of time. Family members attribute important educational elements to their life situation [8]. One of the most significant elements in terms of raising a child is the age of both the child and the parents. The average age of parents who took part in the study was 39.69, while the average age of the child was 12.46. Parental attitudes, as shown by the authors' own research, are also influenced by the level of the parents' education. The largest group was represented by parents with secondary education (38.31) and higher education (38.31).

The perception of a difficult situation is fundamental to family management due to the fact that parents believe the child's abilities are closely related to their understanding of the child's medical condition, as well as the requirements and restrictions associated with it [8].

107 surveyed families took part in the study, of which 85 were conjugal families, representing 79.43% of the total, and 22 of whom were single-parent families, i.e. 20.56% of all those surveyed. 63.55% of respondents were urban inhabitants and 36.44% were rural inhabitants. In the entire study population, 46.72% of children with chronic disease did not have siblings, while 33.64% of respondents declared that the sick child did have siblings, and a group of 14 people indicated that they had siblings with disabilities – 13.08% of respondents. However, a group of 7 respondents answered that they have both healthy and disabled siblings – 6.54% of all respondents. The mean age of the children in the study was 12.46 ± 7.91 years and the parent's age 39.69 ± 8.18 years.

The results of this study confirm that chronic illness of a child meant a difficult situation for the whole family. Information about a serious illness threatening the child's life often came as a shock and a source of stress for all the family members. In the current study, all parents surveyed clearly defined what constituted a difficult situation for them. Accordingly, a difficult life situation was first of all the death of a family member or a friend – 9.34% of all respondents. Another situation causing stress is someone's own illness – 0.93% of the total, then the illness of a family member or a friend – 1.86% of all respondents. As another difficult family situation, the study group indicated disability of a family member or a friend. This answer was given by all respondents, i.e. 107 people – 100% of the study group. The results obtained in this study did not show significant statistical correlations between the child's age and the attitude (stage) presented by the parent. On the one hand, a statistical difference was observed between the parents' attitude in a difficult situation, and the parent's age in the intellectual approach, where a statistical difference of $p=0.02$ was observed; therefore, the parent's age correlated with the parent's intellectual attitude to the chronic illness of the child. Very valuable research results were obtained by Pilecka who indicated that a sense of self-efficacy of children with chronic diseases may develop more slowly due to the fact that it enhanced the over-protectiveness of their parents, in the form of helping the child with all tasks, even if the child was capable of performing them by themselves. Consequently, the child has no chance to prove him- or herself [13]. On the other hand, research carried out on determining parental attitudes among parents of children who had undergone a bone marrow transplant, showed that parents acquired attitudes that can be classified on an adverse upbringing scale of concentration [1]. As in the present study, the authors demonstrate that the duration of child's illness did not affect parental attitudes. Kózka conducted research among parents of children with a diagnosed heart defect – the obtained results showed the existence of adverse attitudes in terms of upbringing in the scales of dominance, helplessness and concentration.

The current state of health of the child, the material situation of the family, course of the disease and prognosis, as well as the received social support or relations prevailing in the family during the treatment of the child's disease, affect how the family will adapt to the highly aggravating situation and whether they will be able to cope. In their study, Ledwoń and Wróbel focused on the performance of certain tasks which are connected with a stronger tendency to improve the mood, and weaker tendency to affect negatively on the mood [21]. In contrast, emotion-focused style no longer

affects negatively not on the mood, but on the expression of emotions associated with chronic illness, e.g. a child's cancer. This is a predictor of mood elevation. In turn, studies carried out by Pawelczak-Szastok et al. indicated that parents experienced the highest intensity of anxiety which definitely exceeded the norms for age [19]. However, they noted that the results in the category of anxiety as a state were higher than in the category of anxiety as a trait. Lepiarz analyzed the mental health problems of parents of children with cancer [21]. She showed that 43% of parents of sick children had depressive symptoms (depression, guilt, problems with concentration, other anxieties), and 60% of them developed other functional disorders. According to research by Khymko and Micylkowska-Nowak, 11% of mothers who raise a chronically ill child can be characterized as alienated, which is caused by believing that only in this way they can they cope with the pain and stress [5]. Khymko and Micylkowska-Nowak proved that parents who are involved in raising a child with a chronic disease are in a state of constant tension due to two factors: the child's illness and rejection by society.

The reorganization family life due to the child's disease mainly depends on the seriousness of the disease is and whether the parents raise the child alone, whether the child is able to attend classes in kindergarten or integration school, or whether the parents can receive support from other people. A disease that threatens the child's life or an incurable disease, affects and changes the image and functioning of the whole family and each of its members separately. Such families often feel guilty and it is not dependent on the fact that objectively it is not their fault. Finding people in such a situation brings temporary relief as it allows the showing of a way to explain the inexplicable – the threat to the health and life of the child [5].

Health policy aimed at chronically ill people usually focuses on adults. As a result, the important aspects of child care are underestimated and not taken into account. Key differences between chronic diseases of adults and children include morbidity rate, etiology and course of the disease, as well as natural differences between children and the type of care they need.

CONCLUSIONS

The conducted research found that the attitude presented by parents has a great impact on the formation of the child's personality. It does not determine it, because the child's individual characteristics, as well as environmental impact, are also important, but the impact is so large that it cannot be underestimated.

Parental attitudes exert a great influence on children's emotional development. Children who reject parents are characterized by high affection, low emotional life control, emotional instability, aggressiveness, arguments and rebellious attitudes towards the environment, while children who have democratic attitudes, have a sense of security, and have a mild and cheerful disposition.

The disability of a family member or a friend constitutes a difficult situation for respondents who are not always able to handle it properly. Although only a small number

of respondents exhibited neurotic behaviours, the ratio of healthy behaviours to other behaviours is still a matter of concern (only 18% of respondents were at the stage of defensive, healthy behaviour, which indicates the urgent need for more detailed research aimed at identifying specific problems with adaptation to difficult situations.

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