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Analysis of the family environment of children with Dandy-Walker syndrome (DWS)

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Summary.

Chronic disease is a source of repetitive experiences that may permanently affect the structure and personality traits of a young patient. The whole family environment is undergoing a series of changes, which requires the support of many specialists. Dandy-Walker syndrome is such a disease as it causes many problems and often coexists with a wide range of other congenital and genetic defects.

Aim.

The aim of the study was to analyze and evaluate the relationship between health problems, parents' attitudes towards the problem of a sick child and parenting styles in the families of children with Dandy-Walker syndrome.

Methods.

30 families from all over Poland were examined. Standardized questionnaires were applied for the research. To detect statistically significant relationships were used: chi-squared test (Chi² test) with Yates correction, Shapiro-Wilk normality test, non-parametric Mann-Whitney *U* test, as well as Spearman's rank order correlation and Pearson correlation coefficient (Pearson's *r*).

Results.

In the case of analyzing the parents' approach to the problem of child's illness, the best results were obtained by the respondents in the intellectual approach, that is, this way of dealing with the child's illness dominates in their actions.

Statistically significant relationships were found between the age of the fathers and the autocratic style ($P = 0.01$) and a wide range of statistically significant relationships between the Family Systems presented in the studied group and the emotional stages of parents.

Conclusions. The results of the research on the approach to a difficult situation are as follows: emotional stages have shown that most parents are emotionally unable to cope with the child's disease, therefore parents of children born with congenital defects should be under the care of a psychological counseling center.

Keywords: Dandy-Walker syndrome, parental attitudes, psycho-social needs, health problems, Hydrocephalus, disability.

Abbreviations used in the text:

ADS - survey questionnaire Attitudes in a Difficult Situation

FS - family systems

Introduction.

Every disease in a child's life is an enormous psychological burden and in a characteristic way not only overloads the nervous system, but also affects the proper functioning of the processes occurring in it. [1] Of course, such changes depend on the duration of the disease, its clinical picture, the child's age and individual characteristics, as well as the social situation. Chronic disease is a source of repetitive experiences that may permanently affect the structure and personality traits of a young patient. This applies to both cognitive structures: self-image and perceiving the world, as well as emotional and motivational mechanisms. [2] [3] [4] [5] Dandy-Walker syndrome is such a disease as it results in many problems and often coexists with some other congenital and genetic defects. Dandy-Walker syndrome is a congenital defect of the Central Nervous System (CNS). The first case of this disease was described by two doctors: W. Dandy and K., Blackfan in 1914 [6] However, this name was used for the first time by C. E. Bend in 1952 [7]. DWS is a rare CNS defect, estimated to have occurred in 1: 25,000 - 30,000 live births, [8] although it is rather difficult to make an accurate assessment due to the fact that this defect has no statistical number assigned to it and is most often referred to as "other CNS developmental malformations". The source literature on the subject states that among the detected cases of DWS dominates the female sex [9] [10].

Parents are the first to meet the child's need for safety and emotional contact. Unfortunately, if the family is unstable and there is a hostile atmosphere or social roles are not properly fulfilled and parents make certain parenting mistakes, it becomes a source of the child's fear. This fear increases as the group of people around the child expands: doctors and nurses in the hospital, teachers and peers in kindergarten or school. How does chronic illness change the family situation? Above all, it sets new limitations and challenges that the family must face. Suddenly, parents and children are forced undergo a treatment and rehabilitation regime, which requires a complete reorganization of family life. It often happens that one of the parents must give up their work, and their whole life is centered around everything that is connected with the treatment and rehabilitation, not only physical but also social and pedagogical. The research results described in this article show how much the parents of children with DWS need support and understanding in the care and upbringing their children. This knowledge provides the opportunity to plan the right actions for a child with DWS.

Material and methods. The study involved families from all over Poland registered in the Foundation for patients with Dandy-Walker syndrome (35 families), as well as non-members reporting to consultations for specialists working at the Foundation. 42 families entered the study, but in the end 30 families were selected that correctly completed the questionnaires.

All families were informed in detail about the manner and purpose of the study. They were also in constant email and telephone contact with the person conducting the research. Two standardized questionnaires were used in the research: "Attitudes in difficult situations", "Analysis of the family environment" and also "Own family" made available by Prof Dr. habil. Maria Ryś from the Institute of Psychology UKSW in Warsaw, the Department of Psychology of Marriage and the Family. The medical records of sick children were also analyzed, in which pediatricians assigned the epicrisis to individual children, determining the needs of treatment and care for each child.

Results.

The attitudes of parents in the face of a child's illness were examined using the Attitudes in a Difficult Situation test (ADS2), which allows to determine the emotional stage of the parents of the children with DWS and how they approach the problem. To the points obtained are assigned stens that group results from very low through low, medium and high to very high. Each stage and approach is interpreted by the level of results.

Most of the respondents, both women and men (73.9% of men and 66.6% of women) obtained average results in the intellectual approach to a difficult situation, which is a child's disease. The higher the results obtained on this scale, the more a person tries to most accurately analyze the difficult situation and get to know it from different perspectives, consider all the pros and cons and understand the deeper meaning of what happened. However, low results show that parents feel hopeless or avoid thinking about a difficult situation. Instead of looking for real solutions, a person is devastated and considers the most tragic scenarios of the future, which may be the consequence of a difficult situation. These types of attitudes take away the will to act, aggravate the negative mood and can lead to depression. The results presented in the Table 1 show that 4 fathers and 4 mothers obtained low results, i.e. they have a problem finding themselves in this situation and are unable to look for solutions that could help and support the process of treatment and rehabilitation of a sick child. High results were obtained by 8 people (2 fathers and 6 mothers). These people are able to analyze well the situation they are in and understand the deeper meaning, which stimulates them to act.

Tab. 1 An intellectual approach disaggregated by gender

Level	Fathers		Mothers	
	Amount	%	Amount	%
Low 1-4 sten	4	17,3	4	13,3
Average 5-6 sten	17	73,9	20	66,6
High 7-10 sten	2	8,6	6	20

Source: author's own elaboration

In the case of emotional approach, the higher the results obtained on this scale, the more a person tries to accept the pain, deal with it with dignity, stay positive and stay calm. Such a person does not deny the pain or isolate from other people, but instead shares all the feelings and thoughts about the difficult situation with relatives and friends. If a person is a believer, he/she tries to reach for meditation, prayers or calming down the emotions.

In turn, low results indicate the emotional struggles in dealing with a difficult situation. The person is self-pitying, despairing or objecting that this difficult situation has occurred or becomes indifferent to everything.

In this case, 13 fathers and 13 mothers are emotionally unable to cope with the child's illness, half of the mothers are on the border, which means that they are not able to strictly control negative thoughts and require emotional support from other people (Tab. 2). Only 2

mothers cope emotionally, but there is no such person among the fathers of children with DWS.

Tab. 2 An emotional approach disaggregated by gender

Level	Fathers		Mothers	
	Amount	%	Amount	%
Low 1-4 st.	13	56,5	13	43,3
Average 5-6 sten	10	43,4	15	50
High 7-10 st.			2	6,6

Source: author's own elaboration

In the action approach, the higher the results obtained on this scale, the more a person tries to take all measures that can be helpful in accepting and resolving a difficult situation, actively seek support for getting help and uses his own previous experience of dealing with other problems in order to solve the current situation. Such a person makes efforts to accept and adapt to a difficult situation.

However, low results indicate a sense of helplessness, lack of strength, expectation that someone else will get involved in this situation in order to help and find a solution. The lower the results, the more a person looks for incorrect solutions - calms the pain with alcohol, sedatives or intoxicants and also reaches for food. Such a person often isolates himself/herself from people, resigns from taking any action and may even consider the possibility of suicide. Very low results obtained on this scale indicate the need for psychological or psychiatric consultation.

The results obtained in this kind of approach show that both mothers and fathers expect help from other people. It is extremely difficult for them to get help because they do not accept the situation (Table 3).

Tab. 2 An action approach disaggregated by gender

Level	Fathers		Mothers	
	Amount	%	Amount	%
Low 1-4 st.	19	82,6	26	86,6
Average 5-6 sten	4	17,3	4	13,3

Source: author's own elaboration

Emotional stages. It is very difficult to accept the fact that the long-awaited child is sick and will require a lot of effort from parents in order to function independently. Even worse is the awareness of the poor prognosis regarding the baby's life expectancy. Research results in this group of parents show that families of ill children with congenital defects should be supported by psychologists because even those who are in a healthy behavior stage have not achieved the highest possible results. It indicates that this stage is not stable enough and that parents are prone to change their attitude for other less favorable behaviors.

In the studied group, both men and women are mostly in the stage of defensive behavior. On average, fathers with 16.9 points and mothers with 16.6 points show the highest intensity of this stage. The severity of the psychological shock stage is on average 10.5 for fathers and 10.1 for mothers. The lowest severity can be observed for neurotic behaviors: on average fathers have 6 points and mothers 7.1. Tables 4 and 5 summarize the results for fathers and mothers.

Tab. 4 Emotional stages – fathers

Stage	Valid N	Ave- rage	Median	Mini- mum	Maxi- mum	Lower quartile	Upper quar- tile	Stan- dard devia- tion
Psychological shock	23	10,5	10,0	6	17	8,0	13,0	2,6
Expecting help from others	23	9,3	10,0	4	14	7,0	12,0	3,0
Sorrowing	23	6,9	7,0	4	10	6,0	8,0	1,4
Defensive behaviors, healthy behaviors	23	16,9	16,0	13	20	16,0	18,0	1,7
Neurotic behaviors	23	6,0	6,0	4	10	4,0	7,0	2,0
Acceptation	23	16,4	17,0	12	20	15,0	17,0	1,9

Source: author's own elaboration

Tab. 5 Emotional stages – mothers

Stage	Valid N	Ave- rage	Median	Mini- mum	Maxi- mum	Lower quartile	Upper quar- tile	sd
Psychological shock	30	10,1	9,5	7	15	9,0	12,0	2,3
Expecting help from others	30	10	10,0	4	18	7,0	12,0	3,7
Sorrowing	30	8,8	8,0	4	20	6,0	9,0	4,3
Defensive behaviors, Healthy behaviors	30	16,6	17,,0	11	20	16,0	19,0	2,3
Neurotic behaviors	30	7,1	7,0	4	16	5,0	8,0	2,9
Acceptation	30	15,6	16,0	7	20	15,0	18,0	3,4

Source: author's own elaboration

Analysis of the family environment. The analysis of the family environment allows to acquaint with the atmosphere of family life created by its members. The quality of impact on the psyche of children is significant and is determined by the parenting style, especially in families with a chronically ill child. By performing certain behaviors towards a sick child, we can support its development or, conversely, deepen child's deficits.

There are five types of families in family systems:

- Chaotic,
- Authoritarian,
- Normal,
- Overprotective,
- Implicated [11].

According to the research, the Normal and Overprotective families predominate in the studied group. This tendency persists among both men and women. Table 6 summarizes all results for both groups.

Tab. 6 Family systems

Family type	Intensity of traits	Fathers		Mothers	
		Amount	%	Amount	%
Chaotic	Low	23	100	30	100
Authoritarian	Low	23	100	30	100
Normal	Low	0	0	2	6,6
	Average	5	21,7	4	13,3
	High	18	78,2	21	80
Overprotective	Low	15	65,2	22	73,3
	Average	4	17,3	4	13,3
	High	4	17,3	4	13,3
Implicated	Low	23	100	30	100

Source: author's own elaboration

The description of the examining methods of the family environment structure provides information that the results falling in the range of over 30 points on the scale of a normal and overprotective family indicate an overprotective family. Scale:

- 0 -24 – indicate low intensity of a given type of traits
- 25 -36 – average
- 37 – 60 – high. [12][11]

When analysing the results presented in the table, one can notice that in the case of the studied group, we are dealing with overprotective families. To confirm, the point calculations are as follows:

- Overprotective mothers – 26 women (86.6%) obtained a score of over 30 points on the “normal” and “overprotective” family scale. The remaining 4 mothers obtained a score of 34-55 points on the “normal” family scale and 19.5-28.5 points on the “overprotective” family scale.).

Only one mother obtained a score of 34 points on the “normal” scale, whereas all the others obtained 47.5-55 points.

- Overprotective fathers – the score of more than 30 points on the “normal” scale was obtained by 21 fathers (91.3%), the remaining 2 fathers obtained the score of 41 and 44 points on the “normal” scale.

Parenting styles in the family. Each of the specific parenting styles results in some specific upbringing effects. They depend on the intensity of the behavior belonging to the style. During the style test, it was possible to obtain from 0 to 30 points, but in order to assign a person to a given style, he or she must obtain a minimum of 20 points. The democratic style is defined when a person obtains a score higher than 16 and on the scale of autocratic and liberal-unloving style below 16 points. [12]. The results are given in Table no. 40. As the results of the study show, both fathers and mothers demonstrate a democratic style of raising their children.

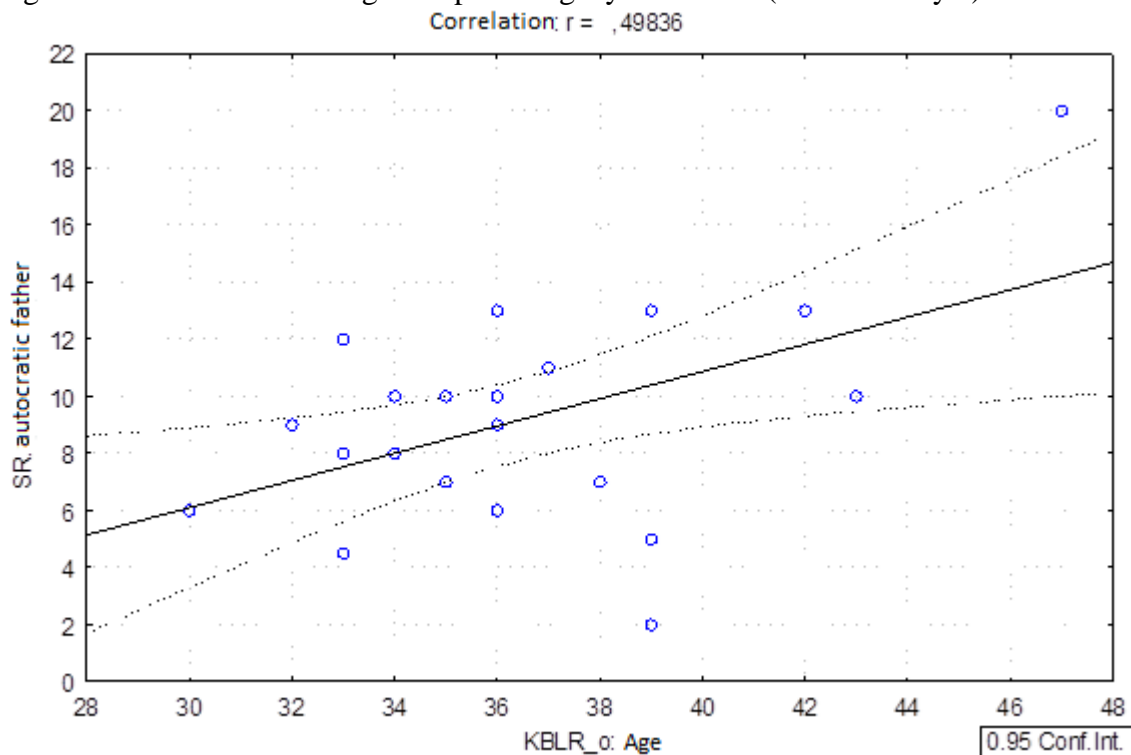
Tab. 7 Parenting styles

Parenting style	Intensity of traits	Fathers		Mothers	
		Amount	%	Amount	%
Autocratic	Very low	17	73,9	27	90
	Low	6	26	3	10
Democratic	Low	1	4,3	1	3,3
	Average	5	21,7	5	16,6
	High	17	73,9	24	80
Liberal-loving	Low	11	47,8	13	43
	Average	8	34,7	12	40
	High	4	17,3	5	16,6
Liberal-unloving	Very low	17	73,9	23	76,6
	Low	6	26	7	23,3

Source: author's own elaboration

During the analysis of research on parenting styles in the studied group, an attempt was made to check the relationship between the age of respondents and the preferred parenting style. A relationship was found showing a certain tendency, namely: the older the father is, the more he is prone to the autocratic behavior (higher intensity of the style traits). It is presented explicitly in the Figure 1.

Fig. 1 Correlation between age and parenting style - fathers (autocratic style)



Source: author's own elaboration

In the case of a group of mothers, no relationship was found between age and parenting style.

One of the variables that was taken into account during the analysis of parenting styles was the level of education of the respondents. Mothers and fathers were analyzed separately. Due to the low personal belongingness to various education groups, the division into “higher” and “lower” was adopted to examine the correlation.

The Mann-Whitney *U* test showed a statistically significant relationship for the liberal-loving style. This indicates that there is a difference in the intensity of traits in the case of this style between fathers with higher education and those with lower education (Table 8).

Tab. 8 Parenting styles and education of parents – fathers. Mann-Whitney *U* test

Parenting style variable	Rank sum Lower education	Rank sum Higher education	U	P =	Valid N. Lower education	Valid N. Higher education
Democratic	201,50	74,50	38,50	0,16	15	8
Autocratic	192,50	83,50	47,50	0,42	15	8
Liberal-loving	210,50	65,50	29,50	0,04	15	8
Liberal-unloving	177,50	98,50	57,50	0,87	15	8

Source: author's own elaboration

No statistically significant correlations between age and parenting style were found in the group of women surveyed.

For a thorough examination of the family situation, an analysis of medical records of sick children was carried out and the degree of epicrisis was determined by pediatricians. Each examined child, after analyzing the general state of health and diagnoses made, was assigned the appropriate degree of medical epicrisis. As many as seven children in the studied group were qualified to the fifth-degree epicrisis and the category of care no. 7, which means that this is a seriously ill person, unable to function independently with poor prognosis as to life expectancy. In turn, category of care no. 7 indicates that the child requires not only intensive medical and nursing care but also intensive care from other people. The second group in terms of the number of people, but with a lower degree of epicrisis, included children classified to the third-degree epicrisis and category of care no. 3. This group included 9 people. Third-degree indicates a chronically ill patient with a slightly reduced overall body efficiency and a satisfactory health prognosis, requiring periodic specialist care. This analysis allowed us to examine the relationship between the degrees of medical epicrisis, as well as the type of family systems and parenting styles. In this case, two statistically significant relationships of epicrisis degrees were noted: in the case of fathers with the severity of the “implicated family” system traits ($R = 0.661$, $p = 0.001$), and in the case of mothers with the severity of the “normal family” system traits ($R = -0.435$, $p = 0.016$). The results are presented in Table 9.

It should be added that in the case of fathers: higher degrees of epicrisis correspond to a higher severity of the implicated family system traits and when it comes to mothers: higher degrees of epicrisis correspond to a lower severity of the normal family system traits (negative correlation). On the one hand, in the case of fathers, this indicates that the more serious the child's health problems are, the more they constitute the implicated family traits. On the other hand, in the case of mothers, along with the increase in the number of health problems, we can observe a decrease in the number of the normal family traits that occur in the behavior towards the child.

Tab. 9 Family systems and the degree of medical epicrisis. Mothers and fathers.

Family systems and the degree of epicrisis	Number of people examined	Spearman's rank order correlation	P
Mothers			
Chaotic family	30	0,25	0,17
Authoritarian family	30	0,01	0,95
Normal family	30	-0,43	0,016
Overprotective family	30	0,19	0,30
Implicated family	30	0,27	0,13
Fathers			
Chaotic family	23	0,37	0,07
Authoritarian family	23	0,38	0,06
Normal family	23	-0,10	0,64
Overprotective family	23	-0,09	0,66
Implicated family	23	0,66	0,0005

Source: author's own elaboration

No statistically significant relationship was found between the degree of epicrisis and parenting styles.

Relationships between parenting style, family systems and the way of dealing with a difficult situations.

Relationship analysis was performed by division of gender in the studied group. In the group of fathers, a statistically significant negative correlation ($r = -0.4956$, $p = 0.016$) was found between the variables of the “normal family” within the family systems (FS) and the action approach in the case of Attitudes in a Difficult Situation (ADS). This indicates that higher values of the ADS variable correspond to the lower values of the FS variable. In other words, lower results, i.e. lower intensity of the “normal family” traits within FS, correspond to a higher “intensity” of action approaches.

In the case of the group of mothers, more statistically significant relationships were noted. Statistically significant correlations occurred between:

- FS the chaotic family and the emotional approach
- FS the chaotic family and the action approach
- FS the normal family and the action approach
- FS the overprotective family and the intellectual approach
- FS the implicated family and the emotional approach
- FS liberal-unloving family and the emotional approach.

Figures determining the correlation are given in Table 10. Statistically significant values are marked in red.

Tab. 10 The relationship between the Attitudes to a Difficult Situation, parenting styles and family systems. Mothers

Family systems and parenting styles	Marked correlation coefficients are significant with $p < 0,05$ N=23 – the number of people		
	ADS. Intellectual Approach	ADS. Emotional approach	ADS. Action approach
FS. chaotic family	0,11 P = 0,52	0,53 P = 0,002	0,38 P = 0,03
FS. authoritarian family	0,20 P = 0,25	0,31 P = 0,08	0,10 P = 0,57
FS. normal family	0,08 P = 0,67	-0,34 P = 0,058	-0,43 P = 0,01
FS. overprotective family	-0,44 P = 0,01	-0,04 P = 0,81	-0,21 P = 0,24
FS. implicated family	0,10 P = 0,57	0,51 P = 0,003	0,22 P = 0,23
FS. democratic style	0,16 P = 0,38	-0,20 P = 0,27	-0,23 P = 0,22
FS. autocratic style	-0,04 P = 0,81	0,19 P = 0,30	0,009 P = 0,96
FS. Liberal-loving style	-0,13 P = 0,46	-0,17 P = 0,36	-0,32 P = 0,08
FS. Liberal-unloving style	0,17 P = 0,36	0,46 P = 0,01	0,26 P = 0,15

Source: author's own elaboration

Positive correlation values indicate that higher values of variables from the ADS group correspond to higher values of variables from the FS group. In turn, negative values indicate that the higher the characteristics of the variables' values in the ADS group are, the values in the FS group lower accordingly.

Elaboration.

In the face of the difficulties experienced by parents of sick children, parenting styles presented by mothers and fathers were examined. One of the most important needs of children with DWS is the need for safety and emotional contact that parents should fulfill. Satisfying this need or intensifying the child's fears and failures depends on the parenting style. The author's own research was compared with the studies carried out by T. Lewandowska-Kidoń et al. on the styles of parenting towards children with urinary disorders [13]. In the case of both author's own research and studies conducted by T. Lewandowska-Kidoń, the identical distribution in terms of the intensity of traits of a given style was noticed. Number one was the democratic, followed by liberal-loving, autocratic and finally liberal-unloving style. T. Lewandowska-Kidoń examined at the same time the control group, that is the parents of healthy children. The results of her studies indicate that the parents of sick

children show a much lower level of democratic style, which is not beneficial for sick children. This state of affairs underlines that parents are not willing to involve the child in family matters and let them co-decide about the family life. In the case of sick children, it would be most desirable to give the child the opportunity to participate in all matters that are related to the child. Only then can the child have a chance, in a way that is not beneath child's dignity, to solve the problems together with the family. Thereby the child gains a sense of security. Furthermore, the results of the author's own research were compared with studies on the group of families with healthy children carried out by A. Zielińska and B. Ostafińska-Milik et al. [14] [15] In both studies on the groups with healthy children, the level of intensity of democratic and liberal-loving style traits as the leading ones, was almost equal in terms of the level of points.

The author's own research examines the correlations between parenting styles and attitude in a difficult situations. The results of the study were compared with the results of A. Zielińska, who also analysed such relationships among her respondents. In the group of parents of children with Dandy-Walker syndrome, one statistically significant relationship was found between the liberal-loving style and emotional approach to difficult situations. It was a positive correlation (0.46; $P = 0.01$). This underlines that higher intensity of a certain "style" traits corresponds to a higher intensity of the "approach" traits. However, the research conducted by A. Zielińska's has not shown any statistically significant relationships between this pair of variables. Nevertheless, a relationship between the liberal-unloving style and the emotional approach was discovered. This is a negative correlation (-0.30; $P < 0.05$), i.e. a greater intensity of "style" traits corresponds to a lower intensity of "approach" traits. In the author's own research, no relationship was found within the group of fathers, while A. Zielińska discovered statistically significant relationships between the liberal-loving style and the emotional and action approach. These also constitute for the negative correlations.

Raising a chronically ill child is an extremely complicated task. It is very difficult to find the perfect solution when intense feelings are involved, for instance, the mixture of love and disappointment. In such a situation, it is crucial to determine whether the parents can receive support from other people and whether they accept it. A family in which one of the parents must stay at home to look after the sick child is also experiencing financial difficulties. As it was presented in the research on families with disabled children in the lubelskie voivodeship [16], parents of children with Dandy-Walker syndrome have sufficient financial resources for life needs, however they are not able to finance the rehabilitation expenses. Precisely 40.3% of examined families with a disabled child and 73.3% of families of children with DWS in the lubelskie voivodeship experience such a situation. Both examined groups are supported by other people and institutions in their difficult situations. Families from lubelskie voivodeship declare that they are supported by their family (53.3% of respondents), by friends (24.68%), by neighbors (10.39%) and by other people and institutions (21.99%). In the case of families of children with DWS, it is respectively: family support 86.6%, friends and acquaintances support 40%, neighbors support 23.3% and other people and institutions 16.6%. Those results are satisfactory due to the fact that systemic solutions in our country are insufficient and as mentioned in the above presented research, the vast majority of the families with disabled children are alone in their struggle for a better future of their children. They are forced to rely on their own and their family's resources or to intensively request for necessary funds from various types of foundations. As a part of state social policy, such families can be granted some financial support, which in reality does not guarantee anything. Sometimes the families can receive some funds from non-governmental initiatives that support families with disabled children in early development support. One of the greatest challenges for the families with a disabled child is the inactivity of mothers who take care for a sick child up to the age of 6. This means that they do not have contact with the

labor market. They also do not have the opportunity to improve their qualifications during extended childcare leave. They lose their competences. These problems, combined with a lack of competence within the social service sector, which is often chaotic, incomplete and sporadic, as confirmed by studies carried out in the Psychology of Rehabilitation Department of the John Paul II Catholic University of Lublin, cause negative consequences of isolation of families with a disabled child. [17]

Conclusions

The results of the research on the attitude to a difficult situation are as follows: emotional stages have shown that the vast majority of parents are emotionally unable to cope with the child's disease, therefore parents of children with congenital defects should, since the very beginning, receive the support from a psychological counseling center – from the moment of diagnosis. The support given to the family should be comprehensive, ranging from receiving reliable information about the health, prognosis, treatment, nursing and rehabilitation process to the possibility of obtaining institutional help.

References:

1. A. Lewicki: *Jak powstają trudności wychowawcze*. Wiedza Powszechna, 1957.
2. I. Obuchowska i M. Krawczyński: *Chore dziecko*. Warszawa, Nasza Księgarnia, 1991.
3. I. Obuchowska: *Dynamika nerwic*. Warszawa, 1976.
4. A. Maciarz: *Psychoemocjonalne i wychowawcze problemy dzieci przewlekle chorych*. Kraków, Impuls, 1998.
5. B. Cytowska i B. Winczura: *Dziecko chore. Zagadnienia biopsychiczne i pedagogiczne*. Kraków, Wydawnictwo Impuls, 2007.
6. D. WE i B. KD: „Internal hydrocephalus: an experimental, clinical and pathological study”, *Am J Dis Child*, nr 8, s. 406–482, 1914.
7. J. Wocjan: *Wady wrodzone układu nerwowego i choroby uwarunkowane genetycznie (w): Neurochirurgia*. Warszawa, 1988.
8. O. Klein, A. Pierre-Kahn, N. Boddaert, D. Parisot i F. Brunelle: „Dandy-Walker malformation: prenatal diagnosis and prognosis”, *Child’s Nerv. Syst.*, t. 19, nr 7–8, s. 484–489, 2003.
9. I. Pascual-Castroviejo, A. Velez, S.I. Pascual-Pascual, M.C. Roche i F. Villarejo: „Dandy-Walker malformation: analysis of 38 cases.”, *Childs. Nerv. Syst.*, t. 7, nr 2, s. 88–97, 1991.
10. W. Szymański i L. Włodarczyk: „Zespół Dandy-Walkera: przegląd piśmiennictwa i opis przypadku”, *Ultrason. Pol.*, t. 5, nr 1, s. 41–46, 1995.
11. M. Ryś: *Systemy rodzinne. Metody badań struktury rodziny pochodzenia i rodziny własnej*. Warszawa, CPPP, 2001.
12. M. Ryś: *Rodzina z problemem alkoholowym*. Warszawa, Mazowieckie Centrum polityki Społecznej, 2014.
13. T. Lewandowska-Kidoń i A. Korzeniecka-Kozerska: *Style wychowania i Postawy rodzicielskie wobec dzieci z zaburzeniami oddawania moczu*. Warszawa, Dom wydawniczy Elipsa, 2015.
14. A. Zielińska: „Style wychowania w rodzinie pochodzenia, a poczucie własnej wartości w relacjach interpersonalnych i radzenie sobie w sytuacjach trudnych u młodych dorosłych”, *Ecol. HUMANA*, t. 2, nr 10, s. 102–134, 2012.
15. E. Ostafińska-Molik, B. Wysocka: „Style wychowania w rodzinie pochodzenia w percepcji młodzieży gimnazjalnej i ich znaczenie rozwojowe - próba teoretycznej i empirycznej egzemplifikacji”, *Przegląd Pedagog.*, t. 2, s. 213–234, 2014.
16. W. Otrębski, K. Konefał i M. Kulik: *Wspieranie rodziny z niepełnosprawnym dzieckiem wyzwaniem dla pracy socjalnej*. Lublin, Europerspektywa Beata Romejko, 2011.
17. W. Sekta: „Sposoby radzenia sobie rodziców z problemami wynikającymi z niepełnosprawności umysłowej ich dzieci.”, KUL, 2005.