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COMMUNICATION IN THE FAMILY AND THE SENSE OF COHERENCE IN MOTHERS OF CHILDREN AND YOUNG PEOPLE WITH DISABILITY

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SUMMARY

Background:

The aim of the research is an analysis of the functioning of mothers of mentally-handicapped children and adolescents. Given the absence or inconsistencies in the results of hitherto research emphasis was placed on the sense of coherence and communication in the family as factors conditioning the organisation of intra- and interpersonal functioning.

Material/ Methods:

Tested were 58 mothers with handicapped children. The sense of coherence was measured using the Life Orientation Questionnaire devised by A. Antonovsky (SOC-29). To measure the quality of family communication as well as the balance within the family system employed was the Family Evaluation Scale in its Polish adaptation FACES IV (D.H. Olson). A unique questionnaire devised by the authors was employed to evaluate the child's disability and for assembling socio-demographic data.

Results:

The results of those tested for their general sense of coherence and of the components: feelings of intelligibility and reasonableness are noticeably lower than those obtained in the population as a whole. The child's age as well as the concurrent occurrence of mental disability is significant for the mothers' sense of coherence, though it is of no significance in the evaluation of the quality of family communication. In addition in balanced family systems, mothers perceive their life situation as a calling and not as a threat.

Conclusions:

Comprehensive family support covers supporting the development of a child with a handicap as well as individual help for the family especially in the initial phase – before and after diagnoses as it is difficult to foresee a child's future development. Such activity helps to create a stable base to work with a handicapped member of the family.

Key words: family system, disability, sense of coherence, communication

² The 'Good Education' Association

INTRODUCTION

The appearance of disability in a child affects family life, changing the hitherto organisation and communication patterns amongst family members, as well as bestowing on each of them new roles. Child disability is a stressor leading to changes in the functioning of marriage, equally as a parenting pair, it absorbs their personal reserves as well as being connected with time, energy and finances (Skórczyńska, 2007; Stelter 2013; Furgał, 2012). The difficulties with which the parents of those with development disturbances and disabilities grapple are similar to those experienced by the parents of chronically ill children (McDaniel et al., 1992 from: Furgał, 2010). They experience a feeling of guilt and go through mourning at the loss of a 'normal' childhood and the joint plans for the family's and child's common future. In the initial phase after the diagnosis of the child's disability the factors conditioning the proper development of the family, such as subjectivity, plasticity, positive emotional bonds, bilateral communication, plasticity, a correct perception of reality may be subject to disturbances. For the functioning of the family system, following the shock phase and getting over the loss, it is important that there is an inner-personal development and system reorganisation covering all the mentioned dimensions (Liberska, Matuszewska, 2011). From an evaluation of the difficulties of the task facing the parents of a disabled child there needs to be a process of advising, into which each of the carers puts behavioural and cognitive effort in order to cope with the challenge deemed burdensome or exceeding resources. Then when the personal and family resources are insufficient for a problem to be resolved, or an individual has a negative experience coupled with their utilisation/use a defensive attitude may be adopted and a withdrawal from task realisation. (Lazarus, 1986; Hobfoll, 2006).

COMMUNICATION IN A FAMILY WITH A DISABLED CHILD

According to Walsh (1998), one of the processes having a significant influence on the elasticity of the family is the set of parental communicative processes, with the help of which trust is aroused in the family and which forms an open form of expression amongst family members. Communication is the measure of a family's functioning with disease, and has by many authors been underscored as a significant source of stress, but also when it is correctly shaped and directed it may constitute a potential and source in coping with the challenges and the specific problems caused by the child's disturbance or disability (Chin, Win, Walters, 1978; Świętochowski, 2010; Liberska, Matuszewska, 2011). Disturbances in the process of communication may result from the carer being overburdened, tensions resulting from limitations for other members of the family than the handicapped person themselves, conflicts resulting from psychological problems experienced by the sick individual (Pecyna, 1993). Problems with communicating may result from the illness being treated as a taboo subject, the avoidance of

conversations on the subject of health or passing over in these of the person who is ill. (Kozieł et al, 2003). Open communication according to Seligman (1989) becomes the 'first victim' of disease in the family. It results from Radochoński's research (1987) that in families with a sick person there often occur internally contrary announcements, the partners of conversations do not mutually listen to each other and do not show empathy to each other. In accordance with the principles of the system approach, flawed communication processes are conducive to a secondary intensification of disease symptoms or cause the appearance of somatic and psychosomatic ailments in other family members (de Barbaro, 1999; Zubrzycka, 2001). Simultaneously open communication, an acquiescence over talking about a disease and all its consequences for all family members, the disclosing of emotions connected with a difficult situation enables one to move on to finding solutions and establishing a plan for those changes that have to be implemented (Radochoński, 1987, Malina, 2011). In the case of a handicapped child two-way communication in relations with a parent is not always possible as a result of their dysfunctions (intellectual, connected with the organ of speech or resulting from difficulties in forging contact). A dysfunctional change caused by a child's intellectual disability results in the exclusion of the child from the communication process or a reduction in its effectiveness, which causes a trivialisation in relations within the system as well as limiting contacts with the outside world. In turn a pro-developmental change in the area of two-way communication is the development of alternative and new means of comprehension with the child, which is conducive to adaptation and in the construction of emotional bonds, and also optimises the conditions for family development as a whole and for its individual members. One-way communication, however, is restrictive for the carer and results in a sense of frustration as well as preventing one from coping with tasks and stress inducing situations (Liberska, Matuszewska 2011).

For a family with a disabled child the specific needs of the patient and the problems with which all the members of the system grapple constitutes the source of stress. A handicapped child requires greater care and help in everyday and also activities done by themselves (Kazak, Marvin, 1984). Children with autism, as a result of communication problems both in the verbal and non-verbal field, cause the manifestation of frustration resulting from the difficulty in reading the needs even in the most patient and understanding of carers. (Schilling, Gilchrist, Schinke, 1984). There can be observed in autism both deficits in empathy as in communication manifesting themselves in, among other things, a lack of speech, a reversal of pronouns, the appearance of echolalia as well as disturbances in nonverbal communication. (Pisula, 2000). The mothers of children with autism when compared to a group of mothers with Down syndrome children and a group of normally developing children more often talk of a sense of desiring more of a manifestation of feelings from their own child. However, despite the limited classic signals pointing to devotion/attachment on the part of the child, the mothers of those with autism equally to the mothers of children developing normally, engage in care and an affectionate bond with the child (Pisula, 1993; Pisula, 2003). Children with a moderate degree of disability require greater control, monitoring of their behaviour and encouragement to do tasks than is the case with able-bodied children. Besides, the disabled are more susceptible to somatic ailments, emotional lability, and also display a tendency to withdraw from relations or to display aggressive behaviour in them directed towards the carer (Koller, Richardson, Katz, McLaren, 1983). Children with a disability or with development disturbances often require therapy or rehabilitation, which come with financial outlay, and also with the need to fulfil many formalities, organise transport for the child, ensure conditions at home conducive for exercising motor abilities, cognitive and communicative competences, and also those connected with doing activities on one's own.

THE SENSE OF COHERENCE

Within the aspect of coping, Antonovsky places first the sense of coherence as an element of the adaptive mechanism right next to the generalized resistance resources (GRRs). As he claims (Antonovsky, 1995, p. 34), 'a sense of coherence is man's global orientation, expressing a degree in which that man has an intense, lasting, at least dynamic sense of certainty that (1) satimuli emanating over the course of life from the external and internal world are structutalised in character, predictable and explainable; (2) available are resources that allow one to cope with the demands placed by these stimuli; (3) these demands are a challenge worthy of effort and involvement.'

The components of a sense of coherence are: comprehensibility, manageability, equally resourcefulness-controllability (Heszen, Sek, 2008) as well as meaningfullness. The first of these factors constitutes a cognitive component of coherence and represents the degree to which a person obtains stimuli from the external and internal environment as well as evaluates them whether they are clear, structuralised, coherent and ordered. Someone with a strong sense of comprehensibility expects the stimuli with which they come into contact in future will be predictable in character, and in a situation of surprise they will be able to explain and order the said. Here, it is not important whether a given stimulus is desired by the individual or not – for they will be able to see sense in it anyway. A sense of resourcefulness is a cognitive-intrumental variable signifying the level of awareness on the part of an individual of the external and internal resources available to them as sufficient in order to cope with the inflowing stimuli. A person with a low sense of resourcefulness often considers 'life to be unfair' or feels themselves a 'victim of fate,' while in the case of a high resource level an individual is able to cope with even difficult situations, not despairing over these. A feeling of sensibleness constitutes a motivational-emotional factor and is the most important component to a sense of coherence. Someone with a high level of sensibleness treats at least a part of problems as a calling and as situations worthy of effort and not merely as burdens (Antonovsky, 1995). The sense of coherence develops during the course of socialisation, and an effect on its shape is exerted by the historical context in a man's life, the interaction of society and the sociocultural context, including up-bringing patterns and role systems as well as incidental events. (Antonovsky, 1979, from: Sęk, Pasikowski, 2001). According to research a sense of coherence positively and both directly and indirectly impacts on health, conditions the initial evaluation of stressors and the effectiveness of coping with difficulties (Sęk, Pasikowski, 2001). Although a sense of coherence is a realively stable trait of personality, a diagnosis for a child of disability may significantly affect its modification.

It results from the research available that the level of the sense of coherence amongst parents with handicapped children is lower than is the case for the parents of children whose development has been normal. (Margalit, Leysner, Avraham, Lewy-Osin, 1988, Margalit, Raviv, Ankonina, 1992). According to Olsson and Hwang (2003) the parents of children with intellectual disabilities characterised by a high level of a sense of coherence prior to diagnosis may treat their life situation as a calling, while parents with a low level of this trait perceive the child's problem as a threat to the stability and personal and family composure. The chronic stress that one may note in caring for a disabled child, starting from the difficult moment connected with diagnosis through the struggle with the various challenges resulting from the child's age, right up to fears accompanying the parents throughout as to the future for their offspring, can result in a lowering in the carers' sense of coherence. From Olsson and Hwang's research (2003) it results that the parents of children with intellectual disability are characterised by a low level in their sense of coherence than is the case with the parents of healthy children. The age of the disabled child did not, however, result in any differentiation in this level amongst the carers.

THE CHILD'S AGE AND INTELLECTUAL DISABILITY AS PREDICTORS OF A PARENT'S FUNCTIONING

The parents of children with development difficulties experience stress from an array of sources, while the means of dealing with them depend, among other things, on what is the intensification of problems connected with the crisis brought about by disturbance or disability in their perspective. Carers taking care of those intellectually handicapped experience a sense of helplessness, anger, irritation and fatigue. This situation is brought about by, among other things, the fact that individuals intellectually handicapped display a reduced ability to adapt to changes and do not behave in the way expected of them by their surroundings. They often speak unclearly, move too slowly, their thought process is disturbed, and what they experience is often difficult for others to understand (Kościelska, 2010). In especially difficult situations are to be found the parents of children with deep-rooted intellectual handicaps, for these involve daily nursing, care, and upbringing for the child, in whom other symptoms and somatic disturbances may

appear (Baran, Chojecka, 2009). Those with deep-rooted disability note disturbances in communication, manifesting itself in incomprehensible speech for those around. As a result of disturbances to the cognitive processes there is a reduction in the ability to read facial expressions essential for maintaining interpersonal relations. It does not disappear entirely though even in those with deep-rooted intellectual disability (Janiszewska – Nieścioruk, 2001 from: Baczała, Krasoń, Stasiarowska, 2013). The testing of adult parents with intellectual disability has shown that their well being was additionally connected with the level of the child's adaptive abilities, and negatively with the intensification in difficulties in bringing up their son or daughter. (White, Hastings, 2004 from: Pisula, 2010).

Having a child with development disturbances often make it difficult for parents to adapt to subsequent phases in the cycle of family life and to the individual development of every member of the system. However, the results concerning changes in the intensity of parental stress together with the child's age are not uniform. On the one hand, it is noted that the experiencing of parental stress has a negative effect on the well being of the family as a whole and on its individual members (Phetrasuvan and Sandor-Miles, 2009 from: Pisula, 2010). The parents of older children with autism experience greater difficulties than those with younger autistic children (Holroyd et al., 1975; Bristol and Schopler, 1983, Marcus 1977 from: Pisula, 1993). The parents of children with disabilities admit that they have been condemned to endless, exhausting care over their child and they are frightened as to whether they will be able to look after it and worry about the material situation (DeMyer, 1979 from: Pisula, 1993; Pisula, 1993). The parents of older children whose development has been impaired do not look forward with optimism. This results in some of them more realistically approaching the possibility of changing the situation they find themselves in, while for others this is connected with an increasing sense of resignation (Pisula, 2007, 2010). However, there are reports on the results of which one may conclude that family life in families with children with deep-rooted development disturbances is enhanced thanks to the child (Yau and Li – Tsang, 1999 from: Pisula, 2010). The majority of families with the passing of time also express a greater awareness of the positive influence of a handicapped child on their lives (Pisula, 2010). The parents of older children with autism 'declare greater positive experiences connected with their own parenthood and evaluate more the impact of the child on their life and that of the family.' (Pisula, 2010, p. 84). The greater amount of stress in the case of parents with younger children is explained by the shock experienced following the diagnosis of disability in the child, as well as their sense of a lack of knowledge and ability to bring up a child with special needs (Pisula, 1998). They waste a lot of energy searching for a final diagnosis, and also appropriate methods of caring for the child and for institutions where they can find support. In this regard parents with older children have greater experience at their disposal, which they often share with novice carers in support groups or with the framework of associations set up by the parents of children with disabilities.

THE AIM OF THE RESEARCH

The aim of the research was to analyse the functioning of mothers with children and adolescents with disabilities coupled to mental handicaps. Given the lack in inconsistency of hitherto results, emphasis was placed on the sense of coherence and communication in the family as factors conditioning the organisation of intra- and interpersonal functioning.

In the salutogenetic design/model it is assumed that health constitutes the possibility for a counterbalancing of requirements and resources, and with the same the effective coping with stress. According to Anthonovsky (1995) the level of health is demarcated by, among other things, the sense of coherence – an internal central factor which is conducive for undertaking challenges and perceiving one's possibilities as sufficient for the solving of the problems. The system model for family functioning points to communication as one of the most important elements in interpersonal relations, enabling parents to adapt their functioning to the situational requirements or those connected with the life cycle (Margasiński, 2010). The aim of our research is an analysis of the functioning of the mothers of children with a disability in relation to their sense of coherence and communication within the family as they evaluate matters – when compared to the population (as a whole) as well as within the context of diversity in the family system. A mother, as the parent who more often, directly and on a daily basis, takes care of a child than is the case with fathers, is to a greater degree exposed to burn out in a way similar to that experienced as a result of work (Siemiński, Nitka-Siemińska, Nyka, 2007). The sense of coherence on the individual level, while communication on the interpersonal constitute superior dimensions organising man's functioning. The child's age and the coupling of mental disability with other handicaps may be an additionally factor burdening work with the child, conditioning the sense of coherence and communication within the family. In the face of a lack of reports into the significance of the hitherto joint presence of two or more impairments hampering mothers' development for family communication and sense of coherence or also the incoherence in test results on the functioning of a parent, depending on the child's age, the following research aim was formulated:

The following research questions were asked:

- 1. Do there exist differences in results on a sense of coherence and the quality of communication in the family of mothers of children with disability and average attainments in the general population?
- 2. Does the child's age and the appearance of intellectual disability coupled with another developmental disturbance constitute a significant predictor of the sense of coherence in mothers and their evaluation of the quality of communication in the family?
- 3. Do mothers from balanced and unbalanced family systems with a disabled child differ in their sense of coherence and evaluation of the quality of communication in the family?

Table 1. The types of developmental disturbances and the occurrence of intellectual disability in the children of the tested mothers

			Type of disorders		
		Global developmental disorders ¹	Other developmental disorders ²	Other ³	Total
Mental	Mental No		4	5	20
retardation Yes		6	17	14	37
Total		17	21	19	57

¹ autism and Asperger Syndrome

INDIVIDUALS TESTED

The research encompassed 70 women – the mothers of children and teenagers with disabilities. Questionnaires were completed by 58 individuals, while 12 persons refused to participate in the research giving no reason or as a result of a misunderstanding of the content of the tests (these were chiefly individuals with only a primary-school level of education). The age of those tested was in tha range of 30 to 63 years (Mean=41.5; SD=8), the majority of those had a completed secondary school (29 persons), tertiary (15 persons) as well as with a secondary vocational education (10 persons); educational level was not given by 4 individuals. The women tested were chiefly inhabitants of large towns (over 100,000 inhabitants; 26 persons) and the countryside (21 persons), small towns (7 persons) and towns (2 persons); 2 persons gave no information on place of abode. The vast majority of those tested were married (50 persons) or in a partnership (4 persons), with only three of those tested not being in a relationship. The age of the mothers' children ranged from 3 to 24 years old (Mean = 12; SD = 6), with 31 of them being aged 3 to 11 (early and middle childhood) while the remaining group of 27 had adolescents (12-24 years). In the mothers' evaluation their children had mild disability (15 persons), moderate (16 persons) or severe (27 persons). Intellectual disability was diagnosed in 37 of the 58 children; one mother gave no information on the subject. Differentiation in the children's group also applied to the type of disability (see Table 1).

RESEARCH INSTRUMENTS

Two normalised questionnaires as well as our own questionnaires were employed. The **Family Evaluation Scales** (Margasiński, 2013) in its Polish adaptation FACES IV (D.H. Olson) contains 52 statements relating to seven scales (Scales of balance: *Balanced coherence*, *Balanced flexibility* as well as Scales of imbalance: *Untied, Entangled, Rigidity, Confusion*). The person tested responded to each statement on a scale from 1-I completely disagree to 5-I completely agree. In the present report a general gauge showing the entirety of the family's functioning and allowing the evaluation of the level of balance within

² chiefly: cerebral palsy

³ Down syndrome, faults in the sense organs, other developmental disorders

the system was employed, arrived at by dividing the average of the sten results obtained on the Balance scales by the mean of the sten results from the Imbalance scales. An indicator generally higher than 1 means that the system has maintained balance (a 'healthy' family system), while a result lower than 1 represents an absence of balance in the family ('problematic' family system). The current research also employed the Family Communication Scale, which may be used independently of the other questionnaire scales. The reliability of the various other scales is pleasing (Margasiński, 2013), while the questionnaire itself is the instrument applied in diagnostic practice.

The Life Orientation Questionnaire SOC-29 devised by Antonovsky in the 1980s in its Polish adaptation by the Warsaw Institute of Psychiatry and Neurology's Unit of Clinical Psychology, the Poznan UAM Institute's Department of Psychoprophylaxis and the Department of Labour Psychology at the Institute of Labour Medicine in Łódź in 1994 (Antonovsky, 1995) measures the sense of intelligibility, reasonableness and resourcefulness. The instrument encompasses 29 test positions, to which the testee gives their answer on a scale of 1 to 7, selecting the preferred answer located below the figure. On the basis of a summing up of results a general indicator can be achieved showing the sense of coherence as well as three results covering every component (sense of intelligibility, resourcefulness, sensibleness). Those who stipulated a strong sense of coherence were characterised by increased results in the three scales while those who displayed a low sense of coherence had lowered results in all the factors. The correlations between the SOC components are strong. The SOC-29 instrument is universally available, the reliability of the scales is pleasing (Pasikowski, 2001).

Our own questionnaires, beside providing sociodemographic data of those tested, allowed one to define the child's traits of disability as well as the mothers' subjective view of the specifics of the difficulties they experience.

TEST RESULTS

Mothers' sense of coherence and communication in a family with a handicapped child

In order to assess the differences in the sense of coherence amongst the average results obtained in the general population (cf. Pasikowski, 2001) and the results of mothers bringing up a handicapped child the t-Student test was used for one attempt. To determine the differences in communication evaluation in the family between the results of the women tested and the general population sten scores were used and again with the t-Student test for a single attempt.

It results from Table 2 that the mothers of handicapped children differ in the level of their sense of coherence when related to the general population. Analysis of the average differences obtained by the tested women when compared to those from the comparative group (M = 132.36; SD = 20.39) shows that mothers

Table 2. The sense of coherence of mothers with handicapped children

Sense of coherence	М	SD	t	df	р
Sense of comprehensibility	39.33	8.95	-3.500	54	0.001
Sense of resourcefulness	46.69	10.33	-0,918	54	ns
Sense of sensibleness	40.31	8.42	-6,748	54	< 0.001
General result	126.33	24.51	-1.825	54	0.07

Table 3. Communication in the family. The perception of mothers with handicapped children

	М	SD	t	df	р
Communication in the family	5.56	2.29	0.179	53	ns

with handicapped children are characterised by a low sense of the predictability and rationalism of the world as well as of their own life situation. A statistically significant difference appeared in the sense of comprehensibility and reasonableness. Taking into consideration the mean obtained within the population (the sense of comprehensibility: M = 43.55, SD = 8.49; the sense of sensibleness: M = 40.83, SD = 7.09) one may acknowledge that the mothers of children with disabilities have to a lesser degree than is the mean a sense of the predictability of events as well as their coherence allowing for cognitive structuralisation, while appearing difficulties they rather view as a calling and are to a lesser degree motivated to their undertaking and the solving of problems. There were not noted differences in the perception of their personal resources as equally external ones as being sufficient to cope with difficult situations. The results obtained justify the conducting of deep analyses which will allow one to determine whether the sense of coherence differentiates mothers from balanced and unbalanced family systems. Within communication in the family a result was obtained that displayed the absence of statistically significant differences in the perception of quality within the aspect of the functioning of the system between the mothers of children with disability and average persons within the population.

The age and appearance of intellectual disability in a child as a predictor of mothers' sense of coherence and communication in the family

There was conducted, with the aim of obtaining answers to the third of the research questions, a two-factor analysis in 2 x 2 system, where the dependent variable was the sense of coherence as well as each of its components (the sense of comprehensibility, the sense of resourcefulness, the sense of sensibleness), as equally the quality of communication in the family. The independent variables were the child's age (children vs. adolescents) as well as the diagnosis of intellectual disability (children with a disability of a different type coupled with intellectual disability vs. children with a disability yet without a diagnosis of intellectual disability). An analysis of the subject literature has shown that the results of hitherto research into the significance of age and the fact of intellectual disability for the sense of coherence and the quality of functioning within the

family system are not consistent. In addition, in the reports available there has been analysed only the general sense of coherence.

In the case of a general sense of coherence a statistically significant effect was obtained by age (F = 4.088, p < 0.049, df = 1,50) – the mothers of children with disabilities obtained lower results than the mothers of adolescents whose development was not entirely correct. To a lesser degree in relation to the predictability of the world are the convictions of mothers with intellectually disabled children coupled with another difficulty than were those of mothers who have development disorders but who do not have diagnoses of intellectual disability (the group effect depending on the diagnosis of intellectual disability: F = 4.184, p < 0.046, df = 1.50). The effect of the child's age and intellectual disability interaction were not obtained as predictors of the mothers' sense of coherence.

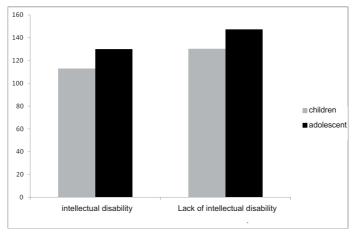


Figure 1. The sense of coherence in the mothers of children and adolescents as dependent on the diagnosis of intellectual disability

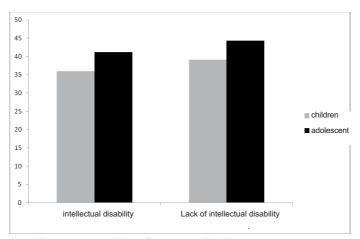


Figure 2. The sense of comprehensibility of mothers of children and adolescents as a dependence on the diagnosis of intellectual disability

Within the scope of a sense of comprehensiveness there was not noted any main statistically significant effects (child's age: F = 2.637, df = 1.50, p = 0.108; diagnosis of intellectual disability: F = 0.975, df = 1.50, p = 0.328) or the effect of interaction.

Within the scope of resourcefulness two main effects were obtained. On this level the tendency is for mothers with handicapped children to view their external and internal resourses as less sufficient to cope with challenges than is the case with the mothers of adolescents with disabilities (the main effect of age: F = 3.334, df = 1.50, p = 0.074). The mothers of disabled children also do not see themselves to be as wronged by fate when their children are not intellectually handicapped (the main effect of the diagnosis of intellectual disability: F = 2.942, df = 1.50, p = 0.093). Equally in the case of this component the sense of coherence did not obtain a statistically significant effect in the interaction of age and intellectual disability in the anticipation of mothers' sense of resourcefulness.

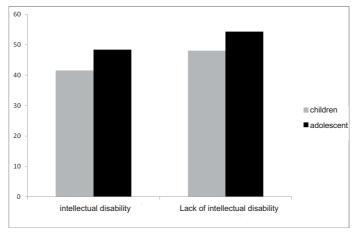


Figure 3. The sense of resourcefulness in mothers of children and adolescents as a dependence on the diagnosis of intellectual disability

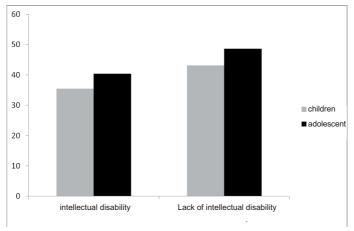


Figure 4. Sense of sensibleness in mothers of children and adolescents in relation to diagnoses of intellectual disability

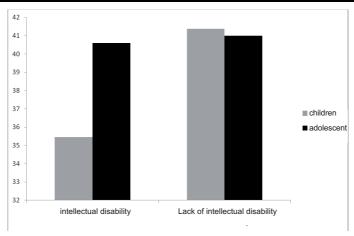


Figure 5. Communication in the family in the evaluation of mothers of children and adolescents as a dependence on the diagnosis of intellectual disability

Inclusion within the child age group is a variable which at the level of tendency is significant in the development of mothers' sense of sensibleness (F = 3.443, df = 1, p = 0.069), wherein those of them who bring up a child with a disability to a lesser degree treat the problems as situations worthy of effort than is the case of the mothers of adolescents with developmental difficulties. Analysis of the variants for the sense of sensibleness as components of the sense of coherence present in the mothers of children with disability also showed the main effect of intellectual disability coupled with another type of handicap (F = 7.832, df = 1, 50, p = 0.007). The mothers of children not additionally encumbered with intellectual disability less often felt burdened by problems, and also to a greater degree had a concept of sense in life than the mothers of children from the second group. Within the scope of a sense of sensibleness there was also not noted the effect of interaction among the independent variables.

Within the area of family communication quality evaluation as perceived by the mothers of children with disability, statistically significant main effects were not noted (child age: F = 1.088, df = 1, 50, p = 0.302; diagnosis of intellectual disability: F = 1.911, df = 1, p = 0.173) as equally an interaction effect.

The sense of coherence and communication and the 'health' of the family system with a disabled child.

On the basis of the results obtained on the various scales (*Balanced cohesion*, *Balanced elasticity*, *Non-connection Entanglement*, *Rigidity*, *Confusion*) the general index was calculated which defines the entirety in the functioning of a family (Margasiński, 2013). A general index higher than 1 represents a balanced family order – such a set of results was obtained by 43% of mothers. While the lower the index, lower than 1, which was obtained by 57% of those tested, the more problematic the family system becomes.

Table 4. The sense of coherence in mothers with disability from 'balanced' and 'imbalanced' family systems as well as communication in the family in their perception.

	imbalanced family system		balanced family system					
	М	SD	М	SD	t	df	р	d
Sense of comprehensi bility	38.16	7.55	40.83	10.46	-1.100	53	ns	0.30
Sense of resourcefulne ss	43.32	10.47	51.04	8.50	-2.937	53	0.005	0.81
Sense of sensibleness	37.03	8.32	44.54	6.56	-3.632	53	0.001	1.00
Sense of coherence – general result	118.52	24.18	136.42	21.44	-2.858	53	0.006	0.79
Communicati on in the family	36.30	6.69	44.76	3.78	-5.286	52	< 0.001	1.47

In Table 4 there is presented a comparison of the results of balanced and imbalanced families with regard to variables connected with a sense of coherence as well as communication quality within the family. A higher general sense of coherence was displayed by mothers from balanced than imbalanced families. Statistically significant differences, to the benefit of the mothers from 'healthy' families was also obtained within cognitive-intrumental components (the sense of resourcefulness) and motivational-emotional (the sense of sensibleness). Only the sense of comprehensibility did not differentiate the women from both types of family system. Communication in balanced families with a disabled child is evaluated as significantly more effective by mothers than is the case in imbalanced systems.

DISCUSSION

To the first of the test questions: Do there exist differences in the results on the sense of coherence and quality of communication in the family of mothers of children with disabilities and those obtained as an average amongst the general population? an affirmative answer was given in relation to the general sense of coherence as well as its components: the sense of comprehensibility and the sense of sensibleness. In relation to the comparative group the mothers of children with handicaps presented a low level of a general sense of the predictability and rationality of the world, something borne out by the results of hitherto research (Cf. Margalit, Leysner, Avraham, Lewy-Osin, 1988; Margalit, Raviv, Ankonina, 1992; Olsson, Hwang, 2003). The parents of children with a disability are to a lesser degree than the parents of healthy children convinced as to the possibility of understanding and controlling reality, and also perceive sense in the solving of the difficulties they experience. For the results obtained indicate the area that should constitute the centre of attention for persons helping the parents of children whose development has not taken the totally correct

course. However, the mothers of children with disabilities are characterized by a similar level of resourcefulness to the average in the general population. For in the case of the tested women we are dealing with average results in relation to the sense of resourcefulness, while the result for the sense of comprehensibility and sensibleness were noticeably low in relation to those obtained for the population as a whole.

The results obtained for the second of the research questions showed the significance of the child's age and the accompanying mental disability in conjunction with another type of disability for mothers' sense of coherence. The higher general index of coherence as well as the higher result in the area of two of its components: the sense of resourcefulness and the sense of sensibleness in the case of the mothers of adolescents with disabilities as well as in the mothers who bring up children with developmental difficulties which are not connected with mental handicaps. The result on age is in accordance with hitherto reports, on the basis of the results of which it turned out that the parents of the youngest disabled children experience the greatest intensified stress and disorganisation within family life and individual functioning as a result of diagnosis (cf, for example, Beckman, 1991; Baxter et al., 2000). For there is connected with this positively proceeding adaptation the utilisation of a strategy involving the reformulation of difficulties experienced – changes in understanding them as merely problems to treating them as a challenge, the coping with which has sense. Reformulation is connected with the mothers' evaluation of the child's impact/influence on their life as an important factor conducive to personal development which, similarly, to social support may avert depression and fears for the future (cf. Gray and Holden, 1992). Equally it results from the research of King and colleagues (2006 from: Pisula, 2010) that the parents of children with disability after the period of shock and disorientation start to declare an increasing sense of control over events. Their value system and designated life goals undergo change and become a starting point for planning and the search for problem solutions. Therefore why does the intellectual disability of a child accompanying another handicap additionally lower mothers' sense of coherence? It is certainly more difficult to predict the development dynamic of a child with multiple forms of disability (cf. Basiłowa, 2009) and to provide this child with care than is the case with a child only suffering from a single type of difficulty. It is more difficult for specialists to convey coherent information to the child's parents on the course of development as well as the actions needed for the child's stimulation. Then the parent's sense of resourcefulness becomes threatened, in particular when in relation to the demands connected with looking after a child with several disabilities the parent is balancing on the limits of endurance. (cf. Sharpley, Bitsika, 1997). Care of a child with several disabilities is a task that makes the realisation of a parent's individual aims difficult, goals formulated and established before the birth of the child or before the diagnosis of developmental disturbances. Threatened is the sense in life and the reasonableness of one's own actions, which adversely affects role fulfilment in the family, and in the case

of mothers means that they view motherhood as frustrating and full of fears (cf. Wallander, Venters, 1995).

Further analyses in which there was a search for answers to the question: Do mothers from balanced and imbalanced family systems with a disabled child differ in terms of their sense of coherence and communication quality evaluation in the family? revealed that the source for mothers in 'healthy' families is to view their life situation as a calling and not as a threat, which allows them to mobilise the strengths needed to overcome everyday tasks (rehabilitation, therapy for the child, constant care and nursing). The women tested from the two types of system did not differ however on their approach to the present as something coherent, with the future as being predictable, which may be connected with the specifics of a child's disabilities and the difficulties in determining the dynamics of a child's development. Antonovsky (1995) in analysing the possible combinations of componants and their influence on the functioning of man claims that a situation comes about rarely when a low level of comprehensibility is accompanied by a strong sense of resourcefulness; for an individual for whom the world around is not very predictable and is generally disorderly will not be able to cope with it. The author considers such a combination to be unstable. In turn an individual with a high level of resourcefulness and a high sense of comprehensibility, with a low sense of sensibleness, may quickly lose control over his own resources/reserves for they are deprived of the appropriate motivation. One may conclude therefore that the mothers of children with disability attempt to cope with difficult situations, mobilising their reserves, however a deficit in the range of the two other components in the sense of coherence, and particularly in the scope of a sense of comprehensibility, confirms that they find themselves in an unstable individual situation and are within the risk group of burnout.

Communication within the family can be a factor easing the conveyance of meaning and sense to the array of difficulties encountered by a mother of a child with disability. It was stated in the face of the results obtained that the women tested evaluated the quality of this aspect of the family system's functioning as being merely average. Deeper analysis in which mothers from the balanced and imbalanced systems were compared showed, however, that communication in the family may be one of the strong sides of the 'healthy' families in which a child with disability is brought up. This result has confirmed the hitherto theoretical analyses on family's system functioning with disease (de Barbaro, 1999, Liberska, Matuszewska, 2011) as well as the results of research (Radochoński, 1987, Margasiński, 2013) which show the absence of open communication with regard to difficulties experienced by all family members as a factor enhancing an illness's symptoms as well as derivatively disorganising family life. Also Szulman-Wardal and Mański (2014) have pointed out the importance of the process of communication in a disabled child's development. A good communicating and supportive parent is an enormous asset and resource to draw on and undoubtedly leads to activity progress on the part of the child. In psychoeducational or therapeutic work with the parents of children with disabilities it therefore follows to emphasise the significance of open communication with oneself and particularly in the case of mothers the ability to speak openly about the problems connected with everyday care enables an outlet for emotions and enables the family to establish common tasks and goals as well as to search for solutions to their problems.

It follows to agree with other authors that parenthood when the matter concerns a disabled child to a greater degree changes the personal situation of the mother than is the case with the father. (Beckman, 1991; Gray, Holden, 1992; Veisson, 1999). Mothers more than fathers experience the stress connected with a child's disability (Goldberg et. al, 1986 from: Baran, Chojecka, 2009; Shonkoff et al., 1992), they have diagnosed with more depression symptoms (Bristol et al., 1988), they have a low level of coherence and satisfaction from life (including marital relations) than is the case for fathers (Olson, Hwang, 2003; Bidzan et. al, 2013), and also more often seek the help of professionals and more pessimistically think about the child's future (Little, 2002 from: Żmijewska, 2010). Although recently researchers have attempted to equally examine the fathers' situation in relation to children with disability it is still true that deeper forms of analysis lie with studies of the mothers' functioning in such life situations.

CONCLUSIONS

Comprehensive support for a family should encompass both the support for the disabled child's development as well as individual help for the family especially during the initial phase – before and after the diagnosis is made when it is difficult to predict the child's development. Such action helps to create a stable base for working with the family's disabled member.

REFERENCES

- Antonovsky, A. (1995), Rozwikłanie tajemnicy zdrowia. Jak radzić sobie ze stresem i nie zachorować. Warszawa: Fundacja IPN
- Baczała, D., Krasoń M., Stasiorowska V. (2013). Niepełnosprawność intelektualna kompetencje komunikacyjne rozwiązania praktyczne. W: D. Baczała, J. J. Błeszyński (red.). Rozwój społeczny osób z niepełnosprawnością intelektualną. Ograniczenia i możliwości w zakresie kompetencji społecznych (s. 123-138). Toruń: Wydawnictwo Adam Marszałek.
- Baran P., Chojecka E. (2009). Rodzice i rodzeństwo w obliczu zaburzeń rozwoju występujących u jednego z dzieci. W: Brejnak W. Zabłocki K. (red.), Wczesna diagnoza i wspomaganie rozwoju dziecka z dysfunkcjami (s. 136-147) Warszawa: Stowarzyszenie Dobra Wola OPP.
- Barbaro de, B. (1999). Ogólna teoria systemów. W: B. de Barbaro (red.) Wprowadzenie do systemowego rozumienia rodziny (s. 9–17). Kraków: Wydawnictwo Uniwersytetu Jagiellońskiego
- Basiłowa T. A. (2009). Złożone i sprzężone zaburzenia rozwojowe u dziecka: dyskurs teoretyczno praktyczny. W: Baczała D., Błeszyński J. J., Zaorska M. (red.) *Osoba z niepełnosprawnością. Opieka. Terapia. Wsparcie.* (str. 45-54) Toruń: Wydawnictwo UMK
- Baxter, C., Cummins, R., Yiolitis, L. (2000). Parental stress attributed to family members with and without disability: a longitudinal study. *Journal of Intellectual and Developmental Disability*, 25(2), 105-118.
- Beckman, P. (1991). Comparison of mothers' and fathers/ percpetion of the effect of young children with and without disabilities. *American Journal on Mental Retardation*, 95, 585-595.
- Bidzan, M., Koszewska, A., Bieleninik, Ł. (2013). The quality of life of the parents of a child with Rubinstein-Taybi Syndrome. *Acta Neuropsychologica*, *11*(1), 53-76

- Bristol, M., Gallagher, J., Schopler, E. (1988). Mothers and fathers of young developmentally disabled and nondisabled boys: adaptation and spoufal suport. *Developmental Psychology*, 24, 441-451.
- Chinn, P. C., Winn, J., Walters, R. H. (1978). *Two-way talking with parents of special children. A process of positive communication.* Saint Louis: The C. V. Mosby Company.
- Furgał, M. (2010). Terapia rodziny z dzieckiem autystycznym. W: T. Pietras, A. Witusik, P. Gałecki (red.). *Autyzm epidemiologia, diagnoza i terapia* (s. 219-225). Wrocław: Wydawnictwo Continuo
- Furgał, M. (2012). Terapia rodziny dziecka z niepełnosprawnością intelektualną. W: K. Bobińska, T. Pietras, P. Gałecki (red.). Niepełnosprawność intelektualna etiopatogeneza, epidemiologia, diagnoza, terapia (s. 506-513). Wrocław: Wydawnictwo Continuo.
- Gray, D., Holden, W. (1992). Psychosocial well-being among the parents of children with autism. *Australia and New Zealand Journal of Developmental Disabilities*, *18*, 83-93.
- Heszen, I., Sęk, H. (2008). Psychologia zdrowia. Warszawa: Wydawnictwo Naukowe PWN.
- Hobfoll, S.E. (2006). Stres, kultura i społeczność. Psychologia i filozofia stresu. Gdański: Gdańskie Wydawnictwo Psychologiczne.
- Kazak, A. E., Marvin, R. S. (1984). Differences, difficulities, and adaptation: Stress, and social networks in families with a handiccaped child. *Family Relations*, *33*, 67-77.
- Koller, H., Richardson, S. A., Katz, M., McLaren J. (1983). Behavior disturbance since childhood among a 5-year birth cohort of all mentally retarded young adults in a city. *American Journal of Mental Deficiency*, 87(4), 386-395.
- Kościelska, M. (2010). O wolności, ograniczeniach, przymusie i odpowiedzialności osób z niepełnosprawnością intelektualną i ich opiekunów. W: J. Wyczesany (red.). Wspomaganie rozwoju dzieci z genetycznie uwarunkowanymi zespołami zaburzeń (s. 53-61). Poznań: Stowarzyszenie na Rzecz Dzieci z Zaburzeniami Genetycznymi GEN
- Kozieł, D., Naszydłowska, E., Ździebło K. (2003). Rodzina w zdrowiu i w chorobie. *Małżeństwo i Rodzina*, 2, 35-38.
- Lazarus, R. S. (1986). Paradygmat stresu i radzenia sobie. *Nowiny Psychologiczne, 40-41* (3-4), 2-40.
- Liberska, H., Matuszewska, M. (2011). Model rodziny z dzieckiem niepełnosprawnym. W: H. Liberska (red.) *Rodzina z dzieckiem niepełnoprawnym możliwości i ograniczenia rozwoju* (s. 41 66). Warszawa: Difin SA
- Malina, A. (2011). Sposoby adaptacji do choroby dziecka rodziców dzieci przewlekle chorych. W: H. Liberska (red.) *Rodzina z dzieckiem niepełnosprawnym możliwości i ograniczenia* (s. 217 234). Warszawa: Diffin SA.
- Margalit, M., Leysner, Y., Avraham, Y., Lewy-Osin, M. (1988). Social-environmental characteristics (family cli mate) and sense of coherence in kibbutz familie with disabled and nondisabled children. *European Journal of Special Needs Education*, *3*(2), 87-98.
- Margalit, M., Raviv, A., Ankonina, D. B. (1992). Coping and coherence among parents with disabled children. *Journal of Clinical Child Psychology*, 21, 202-209.
- Margasiński, A. (2010). Rodzina alkoholowa z uzależnionym w leczeniu. Kraków: Oficyna Wydawnicza "Impuls".
- Margasiński, A. (2013). Skale Oceny Rodziny. Polska adaptacja FACES IV Flexibility and Cohesion Evaluation Scales Daivida H. Olsona. Warszawa: Pracownia Testów Psychologicznych Polskiego Towarzystwa Psychologicznego.
- Olsson, M. B., Hwang, C. P. (2003). Sense of coherence in parents of children with different developmental disabilities. *Journal of Intellectual Disability Research*, 46(7), 548-559.
- Pasikowski, T. (2001). Kwestionariusz Poczucia Koherencji dla Dorosłych SOC-29. W: H. Sęk, T. Pasikowski (red.) *Zdrowie Stres Zasoby. O znaczeniu poczucia koherencji dla zdrowia* (s. 71-86). Poznań: Humaniora
- Pecyna, S. M. (1993). Wpływ psychologicznych kryzysów rodzinnych na ujawnienie sie objawów choroby Alzheimera u ludzi w wieku produkcyjnym. *Przegląd Epidemiologiczny, 47(3)*, 343–348.
- Pisula, E. (2003). Autyzm i przywiązanie. Gdański: Gdańskie wydawnictwo psychologiczne.
- Pisula, E. (1993). Autyzm fakty, wątpliwości, opinie. Warszawa: Wyższa Szkoła Pedagogiki Specjalnej im. Marii Grzegorzewskiej.

- Pisula, E. (1998). *Psychologiczne problemy rodziców dzieci z zaburzeniami rozwoju*. Warszawa: Wydawnictwo Uniwersytetu Warszawskiego
- Pisula, E. (2000). *Autyzm u dzieci. Diagnoza, klasyfikacja, etiologia*. Warszawa: Wydawnictwo Naukowe PWN.
- Pisula, E. (2007). Rodzice i rodzeństwo dzieci z zaburzeniami rozwoju. Warszawa: Wydawnictwo Uniwersytetu Warszawskiego
- Pisula, E. (2010). Pozytywne doświadczenia rodziców dzieci z zaburzeniami rozwoju. W: J. Wyczesany (red.). Wspomaganie rozwoju dzieci z genetycznie uwarunkowanymi zespołami zaburzeń (s.79-93). Poznań: Stowarzyszenie na Rzecz Dzieci z Zaburzeniami Genetycznymi GEN
- Radochoński, M. (1987). Choroba a rodzina. Rzeszów: Wydawnictwo WSP.
- Rutkowska, E. (2012). Wsparcie jako element rehabilitacji kompleksowej osób z niepełnosprawnością. *Niepełnosprawność zagadnienia, problemy, rozwiązania*. 3, 39-52.
- Schilling, R. F., Gilchrist, L. D., Schinke, S. P. (1984). Coping and social support in families of developmentally disabled children. *Family Relations*, *33*, 47-54.
- Seligman, M. E. P. (1989). Explanatory style: Predicting depression, achievement, and health. W: M. D. Yapko (red.) Brief Therapy Approaches to Treating Anxiety and Depression (5-32). New York: Brunner/Mazel.
- Sęk H., Pasikowski T. (2001). Wprowadzenie. W: H. Sęk, T. Pasikowski (red.) *Zdrowie Stres Zasoby. O znaczeniu poczucia koherencji dla zdrowia* (s. 7-9). Poznań: Humaniora
- Sharpley, C., Bitsika, V. (1997). Influence of gender, parental health, and perceived expertise of assistance upon stress, anxiety, and depression among parents of children with autism. *Journal of Intellectual and Developmental Disability*, 22, 19-29.
- Shonkoff, J. P., Hauser-Cram, P., Krauss, M. W., Upshur, C. C. (1992). *Development of infants with disabilities and their families*. Monographs of the Society for Research in Child Development, 57 (6, Serial No. 230). University of Chicago Press.
- Siemiński, M., Nitka-Siemińska, A., Nyka, W.M. (2007). Zespół wypalenia. Forum Medycyny Rodzinnej, 1(1), 45–49.
- Skórczyńska, M. (2007). Przewlekła choroba dziecka w aspekcie realizacji zadań życiowych jednostki i rodziny. W: B. Cytowska, B. Winczura (red.) *Dziecko chore. Zagadnienia bio-psychiczne i pedagogiczne* (s. 39–51). Kraków: Oficyna Wydawnicza "Impuls".
- Sloper, P. (1999). Models of service suport for parents of disabled children. What do we know? What we need to know? *Child: Care, Health and Development, 25*, 85-99.
- Stelter, Ż. (2013). *Pełnienie ról rodzicielskich wobec dziecka niepełnosprawnego intelektualnie*. Warszawa: Wydawnictwo Difin
- Szulman-Wardal, A., Mański, A. (2014). Selected elements of the psychosocial functioning of a girl with holoprosencephaly. *Acta Neuropsychologica*, 12(1), 103-113.
- Świętochowski, W. (2010). System rodzinny wobec przewlekłej choroby somatycznej: gdy rodzina ma korzyść z choroby. Łódź: Wydawnictwo Uniwersytetu Łódzkiego.
- Veisson, M. (1999). Depression symptoms and emotional states in parents of disabled and non-disabled children. *Social Behavior and Personality*, 27, 87-98.
- Walsh, F. (1998). Strengthening Family Resilience. New York London: Guilford Press.
- Wallander, J. L., Venters, T. L. (1995). Perceived role restriction and adjustment of mothers of children with chronic physical disability. *Journal of Pediatric Psychology, 20*, 619-632.
- Zubrzycka, E. (2001). Rodzinne związki z chorobą. Charaktery, 3, 14-20.
- Żmijewska, A. (2010). Zespół Aspergera w ujęciu rodzinnym przegląd badań. *Psychiatria Polska*, 44(5), 713-722

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