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The sense of life and disability in family

According to the latest records, mental handicap affects from one to ten percent of population (2) and creates a serious life problem in families of the mentally handicapped. These families live under bigger stress in comparison with healthy children families, which is confirmed by thorough studies, both American and Swedish (1, 4). According to our own studies we think that Polish families have the same experiences. It is also known that occurrence of different behaviour disorders in mentally handicapped persons makes additional problems in these families. It is connected with higher sensitiveness to stress and incompetence of coping with it by mentally handicapped persons (5). Taking into consideration a special situation of these families, we decided to analyse their sense of life. Generally, feeling the sense of life has four components in its structure: intellectual, emotional, volitive-tending and existential-acting (7). First component refers to recognizing the human life's nature, environment and personal goals and thus implicates the person's ability to recognize his or her own nature, the history of life, surrounding and socio-cultural structures. The second one is connected with human's self-experience, with reacting to values (among them achievements and defeats). The third component refers to human's ability of choice making and the fourth one is identified as a cause of life sense consciousness and the effect of its existence.

Thus, feeling the sense of life is directly connected to subjective and individual personal experience and is determined by the structure of personality, individual aims and aspirations. The sense of life but also its loss is inseparably connected with human's fate. Loosing the sense of life is most often linked with immaturity or lack of values structure, lack of the leading ideas or impossibility of forming the personal lifestyle (6, 7). The latest experiences (3) prove the necessity of training the mentally handicapped persons in making their own decisions of everyday life. This is the motive power of forming higher self-determination, which gives grater life satisfaction to a mentally handicapped person and let him or her find the sense of life (3). A man who does not find a sense of life and has no need of reevaluation, remains in the state of existential frustration, in the state of internal disintegration. On the other hand, a person feeling the sense of life can see the usefulness of his or her activity or even suffer (6, 7).

The studies of families with mentally handicapped children show that usually parents accept the child's disability with difficulty (1, 5). The level of acceptance depends on many factors, among which emotional balance and married life accordance play a great part (4). In spite of the institution or system's manner, range and effectiveness, the families of the disabled persons create a great potential supporting and assisting the child. The meaning of this potential increases in the period of system

changes, when the efficiency of the rehabilitation systems lowers. It can be said that the effects of medical, psychological and pedagogical aid depend mainly on the proper acceptance of the child by his or her parents and other family members (grandparents, siblings, relatives) (6).

The parents of mentally disabled children cope with different problems. Their characteristic type of relation with the social surrounding is an attitude of withdrawal from different aspects of life. As a consequence, this leads to increased emotional overload of all the family members. It may also cause chronic fatigue, irritation, depression, somatic disorders or alcohol abuse. It is also worth to analyse the family problems in aspects of loneliness, helplessness, shame and feeling of guilt of their members. The latest studies of the disabled persons done in Poland (6) show that disabled persons are more seldom lonely than the average Polish, so the problems of disability are connected with the family in which the disabled person lives.

The goal of our own research was an assessment of psychological functioning of families with a child mentally handicapped to a high degree, in the existential area connected with different aspects of feeling the sense of life.

MATERIAL AND METHODS

The research was done in 120 families divided into two experimental groups. Group A was made up of families with a child mentally handicapped to a higher degree (60 families) and group B consisted of families with a healthy child (60 families) of a similar socio-demographic status. They were all whole families.

The methods used in this study were: Interview Questionnaire and Scale Sense of Life by Warner and Williams. Scale Sense of Life consists of 13 items serving to qualify the sense, aim or the meaning of life. Techniques of estimated scales are used here. Particular items refer to belief in God, taking part in different forms of religious activity, self-confidence, hobby, activity.

Mothers' education in group A was the following: 36.7% – primary, 20% – technical, 30% – secondary and 13.3% – higher. In this group 36.7% of fathers had primary education, 26.7% – technical, 6.6% – secondary and 6.6% had higher education. In the researched families of group A there were 43.3% of mothers and 60% of fathers professionally engaged.

The families with a healthy child from group B were chosen intentionally, that means the socio-demographic rates of sex, age and education were close to those describing group A.

RESULTS

The value of life and thus the sense of life are very subjective, because each human can feel these values in a very individual way (11). The results obtained by Scale Sense of Life were analysed in a quantitative and qualitative aspect.

THE GENERAL LEVEL OF FEELING THE SENSE OF LIFE IN THE RESEARCHED GROUPS (TABLE 1)

The sense of life is a very composed structure. The Scale's items represent only some dimensions of this structure. They refer to human himself, his attitude towards himself and others, his activities and interests, aspirations, relation to God, visions and prognoses of his own existence. On the basis of the above numerical values, the statistical significance was found in one of the thirteen items.

A descriptive analysis of the obtained data will be presented according to the four aspects of the general level of the sense of life: • God–human relation • human’s interpersonal relations • attitude towards oneself • attitude towards one’s life.

Table 1. The comparison of results of general feeling of the sense of life by families with a disabled child (Group A) and families with a healthy child (Group B)

Scale's items	Group				The comparison of the mean	
	A		B		t/C	p
	M	SD	M	SD		
Belief in God	3.667	0.66	4.167	0.79	-2.65	0.01
Conversation and being among people	1.833	0.79	1.633	0.76	.99	0.32
Me	1.967	0.76	2.000	0.83	-.16	0.87
Participation in different...	3.933	0.94	4.167	0.83	-1.01	0.31
Showing attachment...	4.167	0.75	4.200	0.76	-.17	0.86
I feel that...	2.200	0.76	1.900	0.80	1.48	0.14
I feel that my life is...	2.133	0.68	1.967	0.76	.89	0.38
Activity and hobby	1.733	0.64	1.800	0.71	-.38	0.70
Doing something for oneself	4.333	0.76	4.300	0.79	.17	0.87
Consolation of other persons	1.667	0.66	1.867	0.73	-1.11	0.27
Planning and achieving...	1.667	0.71	1.467	0.63	1.15	0.25
Philosophy of life or religion...	1.900	0.71	2.000	0.74	-.53	0.60
I feel that...	1.967	0.76	1.867	0.73	.52	0.61

GOD–HUMAN RELATION

In the analysis of this aspect of the sense of life in the researched group the following groups of items were taken into consideration: • belief in God • participation in different forms of religious activity • philosophy or religion as a way of life.

The God–human relation is an important value for both researched groups. The data shows that persons from group A achieved significantly lower results than persons from group B. The birth of a mentally handicapped child most often brings moments of doubt for parents. Personal disintegration which accompanies such events, displays in all dimensions, also in the spiritual one.

Turning back from God and religion is one of the few external symptoms of the human’s spiritual suffering. Participation in different forms of religious activity did not differentiate the researched groups. Both groups had a similar ratio of persons achieving high and low results. The results regarding the philosophy of life or religion as a way of life were similar and did not differentiate the researched groups.

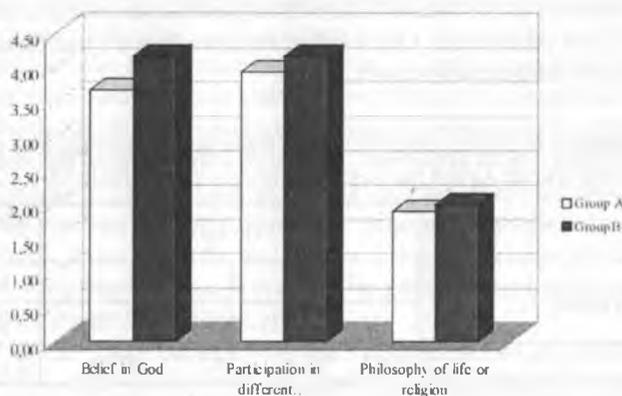


Fig. 1. Graphic presentation of the results achieved by the researched groups with regard to God-human relation

HUMAN'S INTERPERSONAL RELATIONS

The sphere of interaction with others (relations, patients, strangers) is another domain which composes the general sense of life. This domain was analysed by referring to four items: • conversation and being among people • showing attachment to the beloved person • consolation, support and the presence of another human • the feeling of being loved and needed.

The results achieved by parents of disabled and healthy children in the item *conversation and being among people* are similar and show no difference in this area between the groups. Other items depicting interpersonal interactions did not differentiate the researched groups on the significant level. Consolation, support and the presence of another human in difficult moments are important for the majority of the researched persons, both from families with a disabled and a healthy child.

The aspect of showing attachment to the beloved person has a similar trend. Persons from both researched groups like to show attachment to the beloved person. Love itself is a value as well as a need, a desire, inspiration and power for every activity. The need of love, of being loved, is one of the most important and strongest human needs. Strong feeling of being loved and needed also do not differentiate significantly the researched groups. However, the smaller dispersion of low results in the group of parents with a disabled child may prove an inadequate self-evaluation and judgement of the social interaction.

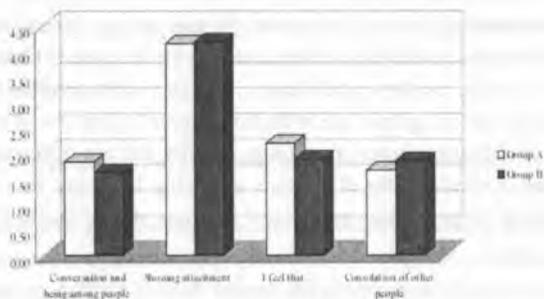


Fig. 2. Graphic presentation of the results achieved by the researched groups with regard to relations with others

ATTITUDE TOWARDS ONESELF

An attitude towards oneself is another aspect composing the general sense of life. It is included in the following items: • acceptance of oneself and one's illness • activity and hobby • doing something for oneself • planning and achieving the short-time goals.

These items are closely connected with each other, because they refer to the domain in which a human being entertains relation with himself. They show no significant differences between the compared groups. The qualitative analysis shows that families with a disabled child pay less attention to the long-term plans and fixed goals. The goals are less important for them. The self-evaluation of these parents is lower than that of parents with a healthy child.

ATTITUDE TO ONE'S OWN LIFE

The last analysed aspect is related to the attitude towards one's own life and its value. The results of items included in this area did not achieve the significant level of difference. The qualitative analysis let us conclude that a higher rate of the researched families with a healthy child agreed that their life was valuable. Many internal and external factors affected the attitude towards one's own life in the families with a disabled child. These factors also affect the general level of the sense of life. The fact of child's disability leads to disintegration of the whole reality, but later parents reorganize on many levels.

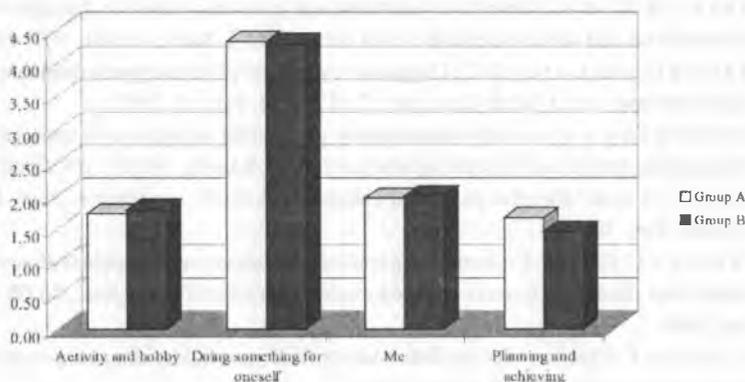


Fig. 3. Graphic presentation of the results achieved by the researched groups with regard to the attitude towards oneself

CONCLUSIONS

The results depicted in the above study were obtained by Scale Sense of Life and refer to the level of the sense of life in its different aspects in families with a disabled child. Recapitulating the obtained results, most of the enquired families with a disabled child are religious persons, engaged in religious activity, getting much joy and satisfaction from it. Such form of a spiritual and intellectual involvement has an important meaning and creates a way of living for many of them. Conversation and contact with other people having similar problems is a source of joy and support for the researched parents of a

disabled child. Hobby and the attached activity play an important role in the researched families' life. The sense of life value is precious in the analyzed families with a disabled child. Planning and achieving the short-term goals is very important for families with a disabled child and this aspect often determines lifestyle satisfaction.

Long-term goals are important for the families with a healthy child and achievements make them feel their life sensible. Generally, the researched families with a child mentally handicapped to a high degree perceived life as valuable in deeper spiritual-existential dimension.

The above research shows the importance of creating a system of social support for those families. The basis of this system would be made up of specialized institutions, associations, foundations, charity groups and support groups. Contact with people having the similar problems and experiences connected with bringing up and taking care of a mentally handicapped child, gives emotional support, safety and the possibility of exchanging professional advice.

The results of the study also show the importance of the priest's role in the general sense of life. Giving support by priests, especially social and emotional, is very important for the researched parents with a disabled child.

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SUMMARY

Questioning somebody about the sense of his own life and the aim of acting is an inherent human feature. Feeling the sense of life is directly connected with a person's individual experience and is determined by personality structure, goals and generally understood psycho-social situation. The results of our own research refer to the level of the sense of life in its different aspects in families with a disabled child. Most of the enquired families with a disabled child are religious persons, engaged in religious activity, getting much joy and satisfaction from it. Conversation and contact with other people having similar problems is a source of joy and support for the researched parents of a disabled child. Short-term goals seem to be more important for them than the long-term ones. The church also gives much support to the researched families.

Poczucie sensu życia a niepełnosprawność w rodzinie

Pytania o siebie samego, o poczucie sensu własnego życia, o celowość własnej działalności jest nieodłączną cechą człowieka. Poczucie sensu życia pozostaje bezpośrednio związane z indywidualnym doświadczeniem osoby i jest zdeterminowane strukturą osobowości, celami i dążeniami jednostki i ogólnie rozumianą sytuacją psychologiczno-społeczną. Wyniki przeprowadzonych badań dotyczą poczucia sensu życia w jego różnych aspektach przez rodziny wychowujące niepełnosprawne dziecko. Większość z badanych to osoby aktywne religijnie, co przynosi im satysfakcję oraz stanowi ważny aspekt życia. Rozmowa i pozostawanie wśród ludzi o podobnych problemach życiowych jest źródłem radości i wsparcia dla badanych rodziców z dzieckiem niepełnosprawnym. Cele krótkoterminowe wydają się ważniejsze w przypadku tych rodzin od celów długoterminowych. Ważnym źródłem wsparcia dla rodzin jest Kościół.