

Functioning of the family of a child suffering from cerebral palsy

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Abstract

Objective: The aim of the research was analysis of the problems of parents with children suffering from cerebral palsy, and evaluation of the degree of change that appeared after the birth of the disabled child.

Material and methods: 100 randomly-selected families with children suffering from cerebral palsy who lived in the Podkarpacie region of Poland. The method of diagnostic survey was used, while a questionnaire served as a research technique.

Results: In most cases, the care of the disabled children was undertaken by the mothers (77%). On the birth of the baby, the parents reacted in different ways, the most frequent being: acceptance (24%), sadness (19%), anxiety about the child's future (17%), disbelief (11%), shock (10%). The child's illness did not change family relations among the majority of the examined groups – 51%, in 31% it tightened family ties, and in 18% the family relationships deteriorated.

Conclusions: Having a baby suffering from cerebral palsy has a notable influence on one of the parents, with the mothers most often resigning from professional activity. The child's disability worsens the financial situation of family.

Key words

cerebral palsy, child health, family problems

INTRODUCTION

The term 'cerebral palsy' originates from the 19th century. The modern definition of the paralysis was formulated by, *inter alia*, Bax in 1964, as the complication of movement and carriage connected with injury or evolutionary complication in an immature brain. Medical knowledge acquired during the subsequent years, especially from the time of introduction of the picture diagnostic, not only allows assessment of the type of brain injury responsible for the appearance of the complication, but also allows determination of the time of the brain injury. Among the physicians researching cerebral palsy during last 20 years there was the discussion about the objectiveness of using a collective definition. In 1990, a group of experts from different countries finally agreed to adhere to the collective definition because of its usefulness in epidemiological researches and similar medical and social problems for patients with cerebral palsy. According to the then accepted arrangements, cerebral palsy was defined as being a collective definition, including the group of non-progressive, but with changeable clinical diagnosis and syndromes as the effect of an injury or evolutionary brain complication in the early stage of development of the illness. For the precise definition, it was regarded that for the certified complications it was important to use a division, taking into consideration the different clinical diagnosis of cerebral

palsy, dependent on the neurological kind and the degree of intensity of the symptoms, and also the time, formation and reason for the brain injury [1].

Nowadays, an increase is observed worldwide in the number of cerebral palsy patients. The development in general medicine, midwifery, neonatology and paediatrics contributes to saving the life of an endangered child, but it does not prevent the disability. The continued life of children who came through a difficult pregnancy or birth is the 'shining light' of modern medicine, but the appearance of cerebral palsy is the 'dark shadow'. For many years, the number of children suffering from cerebral palsy in countries with a high standard of living and a high standard of medical care standard has been great, and although the mortality rate among the babies and infants death has largely decreased, the number of the children with central neural system complications has increased. For about the last 20 years in Poland, the number of children with cerebral palsy has been systematically increasing. The World Health Organization claims that about 7% of children suffer from different central nervous system complications. In Poland, there are about 50,000 children with cerebral palsy, and among the 600,000 births per year around 1,200 of children are endangered by cerebral palsy or its symptoms [2, 3, 4].

The most important thing in the care of a child suffering from cerebral palsy is the proper functioning of the family. The family is the best educational environment necessary in each stage of life, especially in the initial stage, constituting the first, basic, and most valuable environment for the development, care and education of the afflicted child.

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However, the great importance of the family in the care process for the paralysed child is very difficult because of the complexity and prolixity of the syndrome, as well as the feelings of the parents caused by the acceptance of having a disabled child.

Because of the development disability of the child, the parents have a feeling of loss, after the expectation of a healthy offspring, a feeling similar to that of mourning. The disability of the child has a significant impact on the psycho-social sphere of family life. The adaptation to that situation is a long-lasting process, and one that often remains uncompleted. Psychological adaptation of the family members to the situation of disability, and the way of coping with the difficulties, influence the state of the child. A good educational environment allows the equalization of some deficiencies in the psycho-motor, intellectual and spiritual sphere, and also allows the formation of personality and positive features [5].

OBJECTIVE

The aim of the study was analysis of the problems of parents with children suffering from cerebral palsy, and evaluation of the degree of change that appeared after the birth of a disabled child.

MATERIAL AND METHOD

A group of 100 families with children suffering from cerebral palsy were randomly-chosen in the Podkarpacie region of Poland. Most of the researched families (75%) lived in an urban area, and 25% lived in the countryside. In the examined group, there were 46% of girls and 54% of boys. The largest group of the ill were aged from 11-15 (40%), followed by those aged 6-10 (30%), while in the group aged 16-18 constituted 16% of examined. The children in less numerous group were aged up to 5 years (14%). The disturbances coexisting among the children were as follow: epilepsy (37%), hearing disturbances (10%), sight disturbances (10%), mental disability (10%), autism (9%) and hydrocephalus (9%).

The method used in the research was a diagnostic opinion poll, and the technique was an anonymous survey.

RESULTS

In most cases, care of the disabled children was undertaken by the mothers (77%). The parents reacted in different ways on the birth of the baby, the most frequent reactions were: acceptance (24%), sadness (19%), anxiety about the child's future (17%), disbelief (11%), shock (10%), despair (10%), grudge against God and physician (8%), indifference (4%). Parents regarded the child's future with fear (75%), resignation (10%), helplessness (10%), and lack of possibility to guarantee proper care (7%). The largest number of children, i.e. 43%, needed help to a medium degree, 39% to a large degree, 12% of children need help to a small degree, and only 6% of parents claimed that their children did not need any help.

A very important element in the care of the child is the parent's knowledge about the illness and its nursing. Up to 58% of the examined parents assessed their knowledge as

sufficient, 30% as satisfactory, and only 12% as inadequate. The source of knowledge about the child's illness were conversations with other parents whose children also suffered from cerebral palsy (17%), associations helping children with cerebral palsy (19%), physicians (12%), rehabilitation material (6%), literature about the subject (8%) courses for families (4%), and nurses (5%).

Without doubt, the presence of a disabled child in the family influences the living conditions. Education of the ill child, undertaken by most of the mothers, influences the lowering of living standards. An additional element that worsens the financial situation of the family are expenses connected with treatment and the child's rehabilitation, expenses for equipment, help in preparing a proper place to study, development of interests and attractive ways of spending spare time. The financial position was declared as follows: average status – 57% of families, good status – 27%, bad status – 11%, very bad status – 3%, while only 2% claimed a very good financial status. Nearly a half of the examined families (44%) considered that their financial situation had worsened after the birth of the child to the medium degree, 39% considered that it was to a large degree, 13% to a small degree, while 4% of the families considered that their financial situation had not changed.

Each disability which appears in children at an early period of life is a shock for the parents, and causes a strong emotional jolt. Disability is a factor that brings disordering to the previous family order, and is the reason for the disorganization of the previous lifestyle. The child's illness, however, did not change family relations in the majority of the examined group (51%), in 31% it tightened family ties, and in 18% relations in the families deteriorated. The majority of the examined children with cerebral palsy had siblings (90%). Over a half of the siblings (57%) had a very good attitude towards the ill child. The majority of parents received support from family members – 35%, from rehabilitation material – 21%, associations helping the disabled children – 10%, physicians – 6%, while only 1% of the families declared a total lack of support. The greatest restriction for the parents was the notice (81%), but also the adaptation of working hours to the child's needs (5%), subjection of own life to care of the child (4%), physical effort and resignation from free time (3%), and charges (2%). Lack of help from the State hampered taking care after the child the most (57%), as well as a difficult financial situation (22%), job (11%), lack of preparation to care for the child (3%), unfavourable relations between family members (1%), and environmental difficulties (1%). Only 2% of the families considered that there were no difficulties influencing the care of the child.

DISCUSSION

The family is the natural surrounding for the child's development. It is a kind of system in which relations between each family member have influence on the others, and results in the appearance of a complex interactive dependency net. Positive relations between family members, full of love, kindness and understanding, give the child the feeling acceptance and safety, with the result that the child functions without fear in other conditions or surroundings.

The importance and meaning of the family grow even more when one thinks about the development of the disabled

child. Before the child is born it is very rare for parents think about their child as being disabled. If there were no specialist examinations carried out and there were no any hereditary diseases in the family, the parents would not be prepared for the birth of a disabled child. On being informed that they have a disabled child, they experience very strong negative emotions: anger, anxiety, fear, grudge, and a feeling of guilt that disturbs relations between family members [6, 7].

From own researches, it transpires that the parents reacted in different ways on the birth of such a child, the most frequent being: acceptance (24%), sadness (19%), anxiety about the child's future (17%), disbelief (11%), shock (10%), despair (10%), grudge against God and physicians (8%), and also indifference (4%). The parents then experience fear for the child's future (75%), resignation (10%), helplessness (10%), and the lack of possibility to guarantee proper care (7%).

Studies by E. Wiśniewska [5] found that there appeared in the parents an intensification of negative feelings: fear for the future, lack of life stamina, and embitterment. Positive emotions: satisfaction with life, self-realization, and happiness, appeared in only 10–15% of the examined parents. The most dominant was fear was for the child's future, especially after the death of both parents [5].

Research by Wojciechowski [8] concerning the families of disabled children show similar fears of the parents for the child's future (54%), deterioration of the child's state of health (27.87%), possibilities of security and proper care (11.48%), and exhaustion of parents' strength (6.56%). All such thoughts were connected with fear for the lot of the child (36.63%) and concern caused by lack of perspectives for an independent life (20.58%). Only 19.75% of examined parents had an optimistic attitude towards the future had [8].

In recent years, there has been increasing research on the influence of disability on the family in which the experiences of the parents and siblings of mentally disabled, autistic, handicapped or chronically ill children were collected and analysed. The impact of evolutionary disturbances of the child on every family member, including the sibling, cannot be disregarded. Every kind of disability causes disturbances to the previous family system and is the reason for the disruption of the previous lifestyle [6, 7].

In the examined group, to a great extent, the child's illness did not change relations within the family (51%), in 31% it unified the family relations, but in 18% the relations deteriorated. Over a half of the siblings (57%) had a very good attitude towards the ill child. Wiśniewska's studies (2010) showed that good relations between the siblings in families without disability appeared over 20% more often than in families with a child suffering from cerebral palsy [5].

The differences in family functioning were usually connected with the child's illness. The greatest commitment in the examined group is the notice (81%), as well as adjustment of working hours to the child's needs (5%), the adjustment of own life to care for the child (4%), physical commitment or resignation from spare time (3%), and financial charges (2%). Lack of help from the State hampered taking care of the child the most (57%), as well as a difficult financial situation (22%), job (11%), lack of preparation to care for the child (3%), unfavourable relations between family members (1%), and adverse treatment from the environment (1%).

Studies by Hornik et al. conducted among children suffering from cerebral palsy showed the existence of such problems for the parents as: the necessity of constant assurance of care (90%), the duty of systematic rehabilitation (45%), lack of professional equipment, difficulties in organizing a holiday break (42%), transport to diagnostic examinations and encounter visits (40%), and difficulties connected with self-service (50%) [9].

Assistance from the closest relatives had big impact on evaluation of the living situation of the parents of a disabled child. In Wiśniewska's research analysis, the biggest support was given by the closest relatives: spouse (65%), parents of the guardians (26%) and their healthy children (23%) [5]. Own research has also shown that the parents receive the biggest support from own families (35%), from rehabilitation material (21%), associations helping disabled children (10%), and physicians (6%). According to the studies by Hornik et al., those who provide support the most often are: the grandparents (73%), neighbours occasionally (30%), and friends (15%). 15% of the examined parents were left without any help whatsoever. With reference to institutional support, 39% of respondents replied that the help was insufficient [9].

Coping with the crisis situation depends on knowledge supplied to the parents about the illness and the problems involved. In Wiśniewska's researches, in examining the self-esteem of the parents, in the majority the knowledge about cerebral palsy was 'quite high' (44%) and 'sufficient' (39%). Most answers indicating a high level of knowledge occurred in only about 10% of cases [5]. In the examined group, as many as 58% of respondents evaluated own knowledge as adequate, 30% as sufficient, and only 12% as insufficient.

The financial situation of a family influenced the provision of needs for the family members and developmental conditions of the children, and disabled children above all. The education of a disabled child caused many mothers to resign from a job, which had an influence on the family standard of living, which deteriorated. Additional elements contributing to the deterioration of the economic status were expenses connected with treatment and rehabilitation of the child, and purchase of equipment and aids permitting the proper organization of a place for study, and the development of interests and interesting ways of spending time.

Own researches have shown that the mothers usually to care of the children (77%). An average financial status was declared by 57% of families, 27% as good, and 11% considered that their financial status was extremely bad. Up to 96% of the examined parents considered that their situation deteriorated after the birth of the afflicted child.

The education of a child with cerebral palsy is a huge challenge to the whole family. The family needs are specific and change while the child is growing up. According to studies by Peeters, the parents of small children judge the realization of diagnostic and individual therapeutic programme as being of the greatest importance, as well as assistance with the care and financial support. Parents of older children stated the need for: education, detailed preparation of teachers, some indications concerning sex education, and centres providing care in the event of an accident.

Dynamic life of family is formed by the natural evolutionary processes of its members. In the case of families with a disabled child, the life cycle of the family does not come to

the end. Some disturbances of the natural cycle occur which should end with the independence of the children and death of the parents. Disturbances in the child's development, which obstruct the natural rhythm of life, are a big burden for the relatives – parents and siblings. This situation touches all aspects of family life; it is the source of difficulties, that very often do not end [10, 11].

CONCLUSIONS

1. Having a baby suffering from cerebral palsy influences on notice of one of the parents, and the mothers most often resign from professional activity.
2. The child's disability results in a deterioration in the financial situation of the family.
3. Lack of assistance help from the State is the largest factor creating difficulties in the care of the child.

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